Physical variables to shape individual interpretations into collective knowledge. A participatory data physicalization method for women's UTI symptoms.

A Thesis Submitted for the Degree of Doctor of Philosophy

By

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2026

"[...] we need a dream-world in order to discover the features of the real world we think we inhabit (and which may actually be just another dreamworld)."

Paul K. Feyerabend. Against Method.
Outline of an Anarchistic Theory of Knowledge, 1993
(p. 25 of Third Edition).

ABSTRACT

This doctoral research investigates how data physicalization can support awareness and communication of symptoms in women affected by urinary tract infections (UTIs). Drawing on feminist theories of situated knowledge, biosemiotics, and autographic design, it reconsiders symptoms as interpretative processes that acquire meaning through the continuous interaction between body, perception, and environment, rather than as fixed biomedical evidence.

UTIs are among the most common bacterial infections, disproportionately affecting women and often recurring over time. Yet symptom communication remains limited because clinical practice privileges measurable biological indicators, while the qualities of lived experience, such as pressure, burning, discomfort, or urgency, are difficult to articulate and marginalised in clinical accounts. In response, the research identifies physical variables, understood as material properties such as texture, weight, and shape, as a way to translate embodied sensations into tangible and shareable forms. Physical variables therefore operate as participatory devices through which symptoms can be expressed, compared, and collectively interpreted.

Through participatory data physicalization, making becomes a process of knowing. Participants work with tangible materials to express, reflect on, and communicate bodily sensations that are often difficult to articulate verbally. Five workshops were conducted between 2023 and 2024 in Switzerland and the United Kingdom, involving around fifty participants. Three sessions with women affected by recurrent UTIs and clinicians form the analytical core of the research. Participants used modular Data-Probes, supported by labels and a structured protocol, to construct artefacts representing their symptoms.

The findings show that engagement with physical variables supports reflection, comparison, pattern recognition, and dialogue, transforming individual sensations into collective insights through shared material reference points.

The main methodological contribution is the Physical-Variable Apparatus, a material-discursive arrangement that connects labels, protocols, material components, and a digital interface into a system for participation, physical engagement, and interpretation. Beyond UTIs, the approach offers a transferable model for bringing embodied data into participatory enquiry, showing how data physicalization can support collective knowledge production across contexts.

DECLARATIONS

Novelty of the contribution

All materials, reflections, and design outcomes presented in this thesis are the result of my original work, unless otherwise stated through appropriate citation.

Use of artificial intelligence (AI)

In line with Brunel University's effort to promote clarity regarding the use of artificial intelligence (AI) in academic work (Brunel, n.d.), I wish to provide a detailed declaration on the use of AI tools throughout the development of this work, as I believe it is both ethically appropriate and intellectually valuable to reflect on the evolving role of AI within design research practice, particularly during this period of experimentation and transition.

The use of AI tools developed in parallel with the progression of the research. At the outset, no generative AI systems were available. During the 9-month review in January 2023, the literature review and the first substantial report were produced entirely without generative assistance. The only digital aids employed were Grammarly for translating individual words between Italian and English, and Microsoft Teams for the transcription of recordings through the institutional account.

By the time of the 20-month review in January 2024, AI tools were beginning to circulate within academic practice, yet their presence in my work remained marginal. That report focused on field activity and contained no AI-generated text. I approached these tools with caution, particularly in relation to privacy, content originality, and the risk of over-reliance. A gradual increase in use occurred around the 30-month review in November 2024. At that stage, I began using ChatGPT (version 4o) to clarify or rephrase short passages that I had written. These interventions concerned only the refinement of three or four lines at a time and were limited to linguistic improvement. By the 40-month review in September 2025, the research had entered a phase of theoretical consolidation. My use of AI became more iterative and reflective, informed by parallel writing tasks and collaborative

projects that helped me develop a critical understanding of its capacities and constraints. In this phase, AI was used occasionally to reorganise my own material or suggest alternative formulations of concepts already articulated in draft form. I also used it to rework intuitive notes inserted as prompts so that they could be shaped into coherent academic prose. Prior content always served as the basis for these interactions, and I remained attentive to preventing self-reinforcing feedback loops by starting new chats, working across different accounts or setting other environments of interaction. Towards the final stages of the thesis, I consulted other tools, such as Gemini (Google) and Claude (by Anthropic), to obtain critical feedback or to identify potential weaknesses in the text that I could address through further research.

Finally, AI-based development tools supported the implementation of the repository website that collects and shares the thesis materials. After defining the core code structure, vibe-coding techniques, primarily using Google Antigravity, were employed to refine and complete the implementation.

Overall, AI supported specific aspects of the writing process by assisting with clarity, coherence, and the organisation of material. It did not determine the conceptual development of the research, the construction of arguments, or the analytical framing that structures this thesis. These remain entirely my own intellectual contribution.

Other declarations

I made a consistent effort to follow British English conventions throughout the thesis. The terms related to “data physicalization” have been retained in their American spelling, as they are treated as established names within the field. It is possible that other cases under similar conditions were treated in the same way but not declared.

This thesis is written in the first person to acknowledge that my perspective, interests, and approach inevitably influenced the research process. Although analytical procedures were carefully applied where required and efforts were made to limit personal involvement beyond what was necessary, this choice is deliberate to make visible my role as a researcher as part of the framework through which the work was conducted and knowledge was generated. This approach reflects the stance of this work, which values situated perspectives as a source of insight rather than pursuing detached notions of “truth.”

This thesis is set using Arial in Regular, Light, and Semi-Bold, and Playfair Display in Regular and Semi-Bold. Arial is generally used for the main body text, while Playfair Display is used for selected headings and visual emphasis.

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RQ2. How can material engagement support the interpretation and communication of intimate and embodied experiences within participatory data physicalization practices? 5

RQ3. How can physical variables transform individual interpretations of embodied experience into collective knowledge? 5

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GLOSSARY

To support readers who may not be familiar with the medical domain, this thesis includes a glossary structured in three sections.

First, a list of abbreviations is provided to clarify the shortened forms of technical and clinical terms used throughout the research. Second, a collection of definitions is presented for the terms most frequently used in this study. Unless otherwise stated, these definitions are drawn from The Healthcare Ecosystem (NHS Digital, accessed 6 January 2023) and the Cambridge Advanced Learner's Dictionary & Thesaurus (Cambridge University Press, accessed 6 January 2023). Finally, a dedicated section defines key theoretical and methodological terms that are central to this research. These terms are explicitly positioned to establish their specific meanings and intended use within the thesis.

All lists are organised in alphabetical order. This structure ensures conceptual clarity and supports a consistent understanding of how each term is interpreted and applied throughout the research.

Abbreviations

- AMR: Antimicrobial Resistance
- FOPH: Federal Office of Public Health, Switzerland
- GP: General Practitioner
- HCI: Human-Computer Interaction
- HDI: Human-Data Interaction
- PAR: Participatory Action Research
- PD: Participatory Design
- PDP: Participatory Data Physicalization
- PI: Personal Informatics
- QS: Quantified-Self
- UTIs: Urinary Tract Infections

Definitions

Consultation: the interaction between a patient and a healthcare provider with the aim of discussing symptoms, concerns, diagnoses, or treatment options. It is a core component of the care pathway that enables clinical assessment, shared decision-making, and therapeutic alliance (NICE, 2022; WHO, 2016). Consultations may vary in formality, setting, and duration, but they remain fundamental to initiating and maintaining medical care. In this study, the concept of consultation is extended to include both formal medical encounters and informal advisory interactions, revealing how patients seek and interpret professional input, especially in relation to ambiguous or recurring symptoms such as those associated with urinary tract and intimate infections.

Diagnosis: the process of identifying a disease, condition, or injury from its signs and symptoms, often through a combination of clinical evaluation, patient history, physical examination, and diagnostic testing (WHO, 2022). It is a critical step in healthcare that informs treatment decisions and management strategies. In the context of this study, diagnosis is explored not only as a clinical determination made by healthcare professionals, but also through the lens of patients' own interpretations, assumptions, and self-diagnostic practices. These lay diagnostic processes are particularly relevant in intimate infections, where ambiguity of symptoms and past experiences often influence recognition and response.

Inpatient: a person who goes into a hospital to receive medical care and stays there one or more nights while they are being treated.

Outpatient: a person who goes to a hospital for treatment, but who does not stay any nights there.

Prevention: in the medical and public health context, refers to measures taken to prevent the occurrence of disease (primary prevention), to detect and treat a disease at an early stage (secondary prevention), or to reduce the impact of an ongoing illness (tertiary prevention)" (World Health Organization, n.d.). In this study, prevention refers mainly to primary prevention, which includes the individual behaviours, routines, or medical actions adopted by participants to avoid the onset of urinary tract infections or other intimate infections.

Primary care: a patient's first point of contact, including general practice, community pharmacy, dentistry, and eye care.

Secondary care: a patient's second point of contact, including planned or elective care (usually in a hospital), urgent and emergency care, ambulance services, hospital emergency departments, out-of-hours GP services, mental health care.

Tertiary care: specialist treatment, such as neurosurgery, transplants, plastic surgery, and secure forensic mental health services.

Treatment: the management and care of a patient to combat a disease, alleviate symptoms, or promote recovery. It includes any intervention aimed at curing, mitigating, or managing a health condition, and may encompass pharmacological therapies, such as antibiotics, surgical procedures, lifestyle modifications, psychological interventions, and supportive care. In the context of this study, treatment refers specifically to the actions taken by participants, either prescribed by medical professionals or self-initiated, to relieve, manage, or eliminate symptoms related to urinary tract or intimate infections (NCI, n.d.).

Key-terms

Artefacts: material configurations assembled during workshop activities using Data-Probes components to represent participants' embodied experiences. Within this thesis artefacts are physical assemblages created by individual participants based on material–meaning associations defined collectively during the activity. Each artefact is then presented and discussed with other participants, supporting reflection and collective interpretation.

Data physicalization: practice of representing data through materials whose geometry and properties are used to encode information. In this thesis data physicalization is adopted as a participatory method that foregrounds the process of mapping embodied experiences, such as symptoms, into tangible artefacts. Informed by autographic design, these artefacts are understood as material traces of bodily interpretation that emerge from workshop activities and support discussion and knowledge generation through interaction among people, data and materials.

Data-Probes: set of physical components whose material properties elicit interpretation and expression of embodied experiences. During workshop activities participants assemble these components into artefacts, associating their geometry and properties with aspects of their symptoms. Built on the practice of data physicalization and cultural probes, Data-Probes are introduced in this thesis to elicit open responses and support awareness, communication and collective interpretation of experiences.

Embodiment: perception and understanding of knowledge that is grounded in the interaction of the body with data, where meaning develops through physical

engagement with environments, technologies and materials. In this thesis the body is described as a living system that produces signs such as pain, warmth, heartbeat and chills and actively interprets these as symptoms to guide awareness, action and adaptation. Materials and physical variables, in line with autographic design principles, are adopted to extend this bodily interpretation, enabling signs emerging in the body to be expressed, shared and reflected upon and supporting the development of knowledge through a continuous movement between bodily experience and its material expression.

Participatory design: design practice in which people with relevant experience and expertise are actively involved in the investigation and generation of knowledge around a shared enquiry. In this thesis participatory design describes how women with lived experience of urinary tract infections and other diseases, clinicians and researchers collaborate in workshops to identify, collect and interpret data through manual activities that foreground often marginalised embodied conditions and contribute to contextual and inclusive forms of healthcare knowledge.

Physical variables: material properties such as texture, weight, shape, temperature or movement, intentionally associated with specific aspects of data to support representation in data physicalization. Within this thesis their role extends beyond encoding, becoming a generative method that structures how participants work with materials, articulate symptoms and relate their experiences to those of others. As an interpretative and epistemic Apparatus, physical variables connect participation, material engagement and analysis, supporting the transformation of embodied accounts into communicable and situated forms of shared knowledge.

Symptoms: bodily manifestations of internal processes sensed and described by a person, such as pain, burning, fatigue or urgency. In contrast to clinical signs, usually identified by healthcare professionals through examination or measurement, symptoms already include an initial effort by the body and the person to interpret and understand these changes. In this thesis symptoms are treated as material traces of internal states that gain meaning through bodily sense-making and function as bodily signs that invite awareness, action and adaptation. Through autographic design principles these traces are materialised with physical variables, which extend their interpretation and support communication and collective reflection on embodied conditions.

ACKNOWLEDGMENT

First of all, I would like to thank my friends at SUPSI who have accompanied me throughout this PhD journey, both within the Interaction Design unit and across the wider Institute of Design (IDe). Thanks to Antonella Autuori, who shared with me the darkness of early mornings and moments of discouragement, but also brilliant ideas that kept motivating my work. Thanks to Matteo Subet, for always having a practical solution to my mess, and to Luca Draisci, for making the mess even bigger, so that I could eventually find better solutions while trying to clean it up and make sense of it. Thank you also to Alice Mioni, for her aesthetic guidance, even when it was not always fully effective on me.

My deepest gratitude goes to my supervisors. I warmly thank Professor Arthi Manohar at Brunel, who took a chance on me back in 2019 when I first arrived in London, and who later supported me throughout this PhD, and Professor Busayawan Lam, whose precious time and extensive knowledge have supported this work to the very end. My sincere thanks also go to Dr Serena Cangiano at SUPSI, who provided me with the project and the opportunity to undertake this PhD. I would also like to acknowledge Professor Massimo Botta, whose trust enabled me to extend my research and practice beyond the boundaries of this work. I thank all the professors at Brunel whose comments during the review stages helped me clarify the contribution of this work, especially Professor Youngok Choi and Dr Gulsen Tore Yargin. I am especially thankful to the final examiners of this research, Professor Abdusselam Selami Cifter from Brunel University and Professor Uta Hinrichs from the University of Edinburgh, whose thoughtful questions and comments allowed me to discuss this work with the enthusiasm that first inspired this doctoral journey. I also wish to recognise Beatrice Gobbo, Chiara Poletti, and the entire ShapingAI team in the UK for the rich conversations and insights that inspired and informed my research. My appreciation extends to the many people I met at conferences and along the way, whose thoughtful comments and shared resources helped me move forward.

My sincere thanks go to all the participants who took part in the workshop activities. I thank them for their interest, their willingness to share personal and intimate experiences, and their openness to engaging in unconventional ways of discussing them. I also wish to acknowledge the physicians and other practitioners who contributed at different stages of the research, offering their time, reflections, and professional expertise.

Finally, I am profoundly thankful to my family, whose love is a “lifebuoy they keep throwing to me whenever I get myself caught in yet another challenge”, and to my friends Eleonora and Isabella, who never gave up trying to distract me from work.

1. INTRODUCTION. FROM UTIs TO PARTICIPATORY HEALTHCARE ENQUIRY

In this doctoral research, I examine how design can contribute to the understanding and communication of embodied experiences in the healthcare scenario. Through a design method, I explore how material, participatory, and data informed approaches support the articulation of these experiences and enable forms of knowledge and dialogue within clinical contexts.

This PhD research originated within SPEARHEAD (Swiss Pandemic AMR Health Economy Awareness Detect), a four-year project (2022–2025) funded by the Swiss Innovation Agency (Innosuisse). SPEARHEAD brought together a consortium of eight public and four private Swiss institutions with the aim of developing multidisciplinary responses to antimicrobial resistance (AMR). The project adopted a cross sectoral perspective that combines scientific, technological, and social expertise to promote responsible antibiotic use through prevention, stewardship, and public engagement (SPEARHEAD, n.d.).

Within this consortium my role was as a collaborator at the Institute of Design (IDe) of the University of Applied Sciences and Arts of Southern Switzerland (SUPSI), where Serena Cangiano led the Subproject 3, that seeks to involve citizens and raise public awareness of AMR. MAKEAWARE!, which is the name of the initiative developed for this purpose, employs design approaches to make complex health issues tangible and understandable, developing interactive and data-based activities that support reflection, dialogue, and participation (Cangiano et al., 2024). My contribution focused on the development of the engagement strategy and the design of participatory activities. This work provided the initial context for this doctoral research and introduced the interdisciplinary environment from which the research topic progressively evolved. It highlighted the crucial role patients play as holders of experiential knowledge about their condition, knowledge that is not always acknowledged or integrated into diagnostic practices. This gap underscored the importance of recognising how personal experience and clinical procedures intersect in everyday care.

Within this broader context, urinary tract infections (UTIs) provide the main empirical focus of the thesis. Their investigation across different scales of enquiry provided the basis for defining a method that is grounded in this case while remaining applicable to other diseases and embodied health conditions. This process shaped the direction of the thesis, which is outlined in the following sections and visually summarised in Figure 1.1. Developed for the PhD consortium at the Design Research Society (DRS) Conference in Boston in 2024, the mind map presents the main topics of the research and the relationships between them. The map shows how Data-Probes emerge from the intersection of cultural probes, design probes, and data physicalization. It positions physical materials as mediators between symptom experience, discussion, collective interpretation, and communication, linking women's lived experiences of UTIs with broader concerns around AMR and healthcare knowledge.

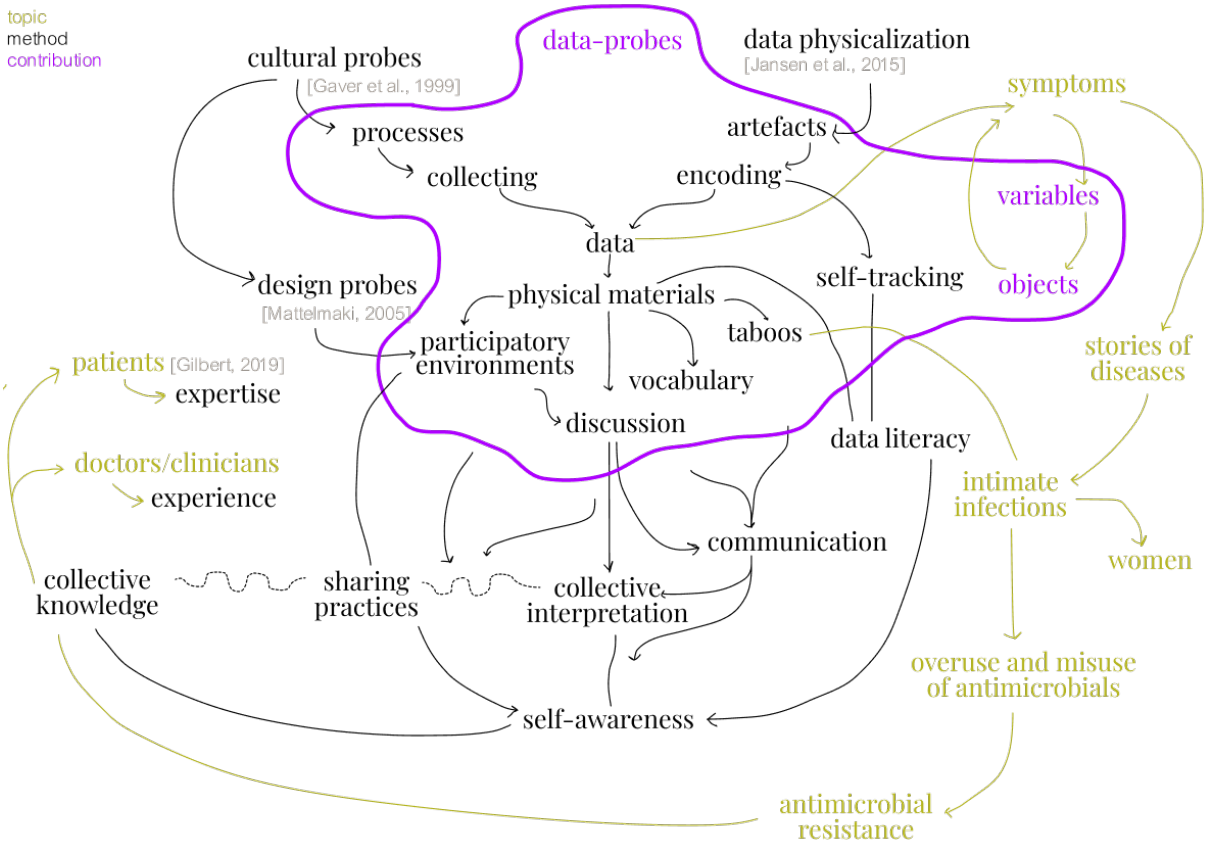


Figure 1.1: concept map developed for the PhD Consortium at the Design Research Society Conference, Boston 2024.

1.1 Research problem

Difficulties in describing and interpreting symptoms form the starting point of this research, particularly when such descriptions are expected to contribute meaningfully to diagnosis. This challenge becomes especially visible in the case of urinary tract infections (UTIs), where diagnosis and treatment often depend, at least initially, on how symptoms are perceived, expressed, and interpreted. Because UTIs are common, recurrent, and frequently treated through empirical prescribing, uncertainty in symptom communication can influence treatment decisions and, consequently patterns of antibiotic use.

For many women, UTI symptoms are intimate, changeable, and sometimes ambiguous. Their accounts are not always afforded sufficient trust within clinical encounters, particularly when symptoms are difficult to verify immediately through testing. When patients feel uncertain about how to communicate what they experience, or when their descriptions are not recognised as meaningful forms of evidence, a gap emerges between embodied experience and clinical interpretation. This gap can shape diagnosis, affect treatment decisions, and reduce opportunities for shared understanding and participation in care.

Within this wider landscape, improving how symptoms are perceived, articulated, and understood is important not only for individual care but also for the broader challenge of antimicrobial resistance (AMR). Although resistance is a natural biological process, its progression is accelerated by extensive antibiotic use across healthcare, agriculture, and everyday life. Without meaningful change, resistant infections are projected to cause up to ten million deaths annually by 2050 (O'Neill, 2016). Strengthening the communication of symptoms is therefore part of strengthening treatment pathways, supporting more appropriate clinical judgement, and reducing avoidable antibiotic use.

Within this thesis, UTIs provide the main case through which this problem is investigated because they bring into focus a particularly significant intersection of embodied experiences such as COVID-19, tonsillitis, insomnia, and lactose intolerance, which introduced different intensities, temporalities, and perceptions of symptoms. While the UTI-focused activities constitute the core of the results presented in this thesis, these additional cases are discussed separately because they offer valuable reflections on the role of materials and on the effects of applying the method beyond the condition for which it was first designed. In this sense, the UTI case grounds the research empirically while also supporting the definition of a method with broader relevance across subjective and difficult-to-communicate health experiences.

1.2 Research questions

Based on this issue, I formulated the following research questions to guide the theoretical and methodological trajectory of this thesis. The questions are expressed in order to address the broader relevance of the enquiry, while being first applied through the case of UTIs, which provides the main empirical focus of the study. Their broader formulation also allowed the research to explore other conditions and occasions of application as the methodology developed. The questions have been shaped and organised in a progressive logic. The first examines how participatory design enables women to contribute actively to the creation and interpretation of their data. The second explores how material engagement transforms personal experiences into tangible and communicable forms. The third introduces physical variables as the set of relations through which these expressions are organised, compared, and shared to support collective understanding. I present each research question with its specific objective and methodological orientation.

RQ1. How can participatory design practices expand healthcare enquiry by enabling women to articulate embodied experience and contribute to the co-creation of knowledge?

Objective: this first question examines the role of participatory design within healthcare contexts, focusing on how women's embodied experiences can be articulated and included within processes of enquiry. It is important because the communication of symptoms often relies on forms of evidence that do not fully account for subjective, intimate, and situated experiences. The question therefore addresses how design may support the inclusion of these experiences within the production and interpretation of health-related knowledge.

Approach: this question is addressed through a review of literature across design, feminist theory, healthcare studies, data physicalization, and materiality, combined with initial semi-structured interviews with experts working across antimicrobial resistance, UTIs, clinical pharmacy, infectious diseases, medical anthropology, machine learning, and women's health design. These interviews were conducted as an early exploratory phase to contextualise the literature and clarify where design could intervene. Together, the literature and expert interviews informed the development of the research approach by identifying symptom communication, patient-generated data, and embodied experience as key areas for methodological investigation. The question is then explored through the empirical activities presented in the thesis, where participants engage with Data-Probes, symptom

labels, and physical-variable labels to describe, materialise, and reflect on their experiences within a participatory setting.

RQ2. How can material engagement support the interpretation and communication of intimate and embodied experiences within participatory data physicalization practices?

Objective: this question examines the role of material engagement in the interpretation and communication of intimate and embodied experiences within participatory data physicalization practices. It is important because many bodily sensations are difficult to describe through language alone, particularly when they are subjective, sensitive, or variable. The question is concerned both with how materials support the articulation of personal experience and with how participatory practices create conditions for those experiences to be shared, compared, and interpreted with others. It therefore addresses how material engagement may contribute not only to individual expression, but also to collective reflection and communication.

Approach: the question is addressed through the use of Data-Probes, a set of material components with different textures, weights, and other material properties. In the empirical activities, participants use these components to create artefacts in response to their experiences and to present and discuss them with others. The resulting artefacts, together with participant accounts and interactions, are documented and analysed in order to examine how material engagement and participatory exchange contribute to processes of interpretation and communication.

RQ3. How can physical variables transform individual interpretations of embodied experience into collective knowledge?

Objective: this question considers how physical variables can structure and support the interpretation of embodied experience within participatory data physicalization practices. Subjective sensations are often difficult to recognise, communicate, and compare because they are felt internally and shaped by personal context. Material properties such as texture, weight, shape, flexibility, and density offer shared reference points through which participants can externalise sensations, discuss their meanings, and relate individual experiences to collective interpretation. The question therefore addresses how physical variables may contribute to connecting individual interpretations with collective forms of understanding.

Approach: the question is addressed through the analysis of artefacts and narratives produced in the empirical activities, with attention to the ways in which symptoms are associated with material properties and to the recurring combinations that emerge across cases. These associations and recurrences are examined in order to identify how physical variables can be described, organised, and used as a framework for enquiry within the research. The analysis also informs the development of the Physical-Variable Apparatus, which structures the relationship between participation, material engagement, and interpretation in a form that can be adopted in other contexts.

In this thesis, collective knowledge refers to the shared understanding that emerges when people affected by similar conditions express, interpret, and compare their embodied experiences through participatory and material practices. Through co-creation, discussion, and the use of material artefacts, individual sensations become articulated in ways that allow participants and clinicians to recognise patterns, differences, and relations across experiences. Figure 1.2 summarises the specific objectives, and approaches for each of the research questions.

	Research question	Objective	Approach
1	How can participatory design practices expand healthcare enquiry by **enabling women to articulate embodied experience** and contribute to the co-creation of knowledge?	**Explore participatory design** as a method to enhance awareness, agency, and communication of UTIs for improved diagnosis and treatment.	**Interdisciplinary review of literature and initial semi-structured interviews** of experts working across design, feminist theory, and healthcare studies.
2	How can material engagement support the **interpretation and communication of intimate and embodied experiences** within participatory data physicalization practices?	**Explore materiality** to externalise symptoms as interpretations of embodied signs.	**Data-Probes** (material components with different features) **and physical-variable labels** to support women affected by UTIs construct artefacts that embody their symptoms.
3	How can physical variables transform **individual interpretations of embodied experience into collective knowledge**?	**Formalise individual material expressions** of embodied data to enable comparison and communication, supporting the translation of personal interpretations to collective knowledge.	**Thematic and compositional analysis** of workshops supported by visual representations. Feedback on results through semi-structured interviews with medical experts.

Figure 1.2: summary of the research questions, objectives, and approaches adopted in this thesis.

1.3 Research aims

The aim of this doctoral research is to examine how embodied experiences, such as urinary tract infections (UTIs), can be expressed and communicated within clinical consultations and broader diagnostic contexts. The study addresses the gap between women's lived experiences and the standard forms of information commonly used in diagnosis and treatment. This gap points to wider limitations in how healthcare systems and clinical practices engage with subjective, intimate, and context-dependent forms of knowledge.

In response, the research develops and studies design-based approaches that support women in articulating embodied sensations to be perceptible, interpretable, and relevant to patient–clinician communication. In doing so, the thesis contributes to the study of symptom communication and to methodological discussions on how participatory and material practices can support the expression of embodied experience. More specifically, the research aims to:

- Bring lived experience into closer dialogue with clinical knowledge;
- Support women in developing awareness of their bodily sensations and expressing them through participatory and material practices;
- Examine how material engagement shapes the articulation and communication of subjective sensations;
- Explore forms of symptom expression that can sit alongside biomedical accounts in clinical communication;
- Strengthen data physicalization as an approach for generating knowledge that connects individual experiences with shared understanding in healthcare contexts.

These aims establish the conceptual purpose of the research and frame the methodological direction that follows.

1.4 Research objectives

To pursue these aims, I structured the research around the following objectives. Each objective describes a concrete step that enables the study to meet its broader purpose.

1. Develop participatory practices for expressing embodied experience: design and conduct activities that enable women affected by intimate diseases to articulate symptoms, exchange experiences, and reflect on the meanings they assign to bodily sensations.

2. Investigate material engagement as a means of interpretation: introduce material components that support participants in externalising embodied sensations and translating them into tangible and communicable forms.

3. Establish physical variables as a structure for comparison and interpretation: provide an analytical method for examining the artefacts and narratives produced during the workshops, identifying how material properties such as texture, shape, weight, and density organise individual expressions into patterns that support comparison and interpretation within collective environments.

Overall, the thesis aims to develop a methodological framework for the study of embodied symptom communication by synthesising insights from participatory and material practices in order to define a coherent method for investigating how embodied experiences can be expressed, interpreted, and discussed in healthcare contexts. These objectives translate the aims into specific actions that shape the design and execution of the research.

1.5 Outputs and outcomes

Drawing on the research questions and the methods applied, I produced a set of outputs and outcomes that together constitute the contribution of the work. Outputs refer to the practical and tangible elements generated during the enquiry. Outcomes refer to the conceptual and methodological advances that arise from the analysis of these outputs.

1.5.1 Outputs. Practical and tangible deliverables

Through this enquiry, I generated practical outputs that support both the development and examination of the research. These include:

Workshop protocol and sessions:

* the ‘Shape Your Symptoms’ protocol, developed to apply participatory data physicalization within healthcare contexts;

- a series of five workshop sessions, primarily focused on women affected by UTIs and refined across iterative applications on other conditions.

Physical artefacts:

- a kit of physical components (Data-Probes) designed to support the interpretation and communication of symptoms and embodied experiences;
- a collection of thirty-one artefacts created by participants to express embodied sensations;
- photographic documentation and analytical decomposition of artefacts used as primary research material.

Digital and visual tools:

- an online repository that organises and presents the material collected;
- an interactive interface that enables cross format exploration of symptoms, materials, and variables;
- visual maps and diagrams that show associations between symptoms and material qualities.

Dissemination and academic activities:

- publications and conference papers that present the literature review and workshop framework;
- teaching activities and workshops on data physicalization;
- ongoing collaborations exploring extensions of the method, including sound based physicalization;
- a journal article in preparation to present the methodological contribution and results.

I use these outputs as the empirical and material basis for the conceptual contributions of the research, which are following described.

1.5.2 Outcomes. Conceptual and methodological contributions

The research generated a set of conceptual and methodological insights that shape the discussion developed in the later chapters. These outcomes indicate the main

areas in which the study contributes to ongoing debates in design and healthcare. They include:

Design for healthcare:

- an exploration of how participatory design can support women's involvement in symptom communication;
- insight into how embodied and intimate experiences can be articulated within healthcare-related enquiry;
- reflections on gender-related gaps in the interpretation of women's health experiences.

Data-Probes as methodological tools:

- an account of how Data-Probes can function as artefacts for eliciting and externalising embodied sensations;
- insight into how material engagement can support the communication and comparison of subjective experience.

Materiality as a mediator:

- clarification of the role of material qualities such as texture, shape and density in supporting perception and dialogue around embodied experience;
- insight into how tactile exploration enables tacit and emotional dimensions of experience.

Data physicalization as a generative process:

- a framing of participatory data physicalization as a method for engaging with embodied experience through making and reflection;
- an examination of how engagement with materials can support shared interpretation in participatory settings.

Physical variables as a method:

- an account of how physical variables can work to structure and analyse embodied experience in participatory contexts;
- a description of how physical variables can connect individual expressions with forms of shared understanding.

Together, these outcomes provide the conceptual significance of the study and outline its methodological contribution to design and healthcare.

1.6 The structure of this thesis

I structured the thesis into ten chapters to reflect the progression of the enquiry from context and theory to methodology, empirical results, assessment, discussion, contribution, and conclusion. Figure 1.3 provides a visual overview of the thesis structure, showing word counts for each chapter, sub-chapter, and section. The dimensions of the shapes are based on the word count for each chapter and section.

Following this introduction in Chapter 1, each subsequent chapter develops the theoretical, methodological, and empirical dimensions of the research in a progressive sequence, leading to the definition of the contribution and its consolidation within the Apparatus of guidance and materials.

Chapter 2 introduces UTIs as both a clinical condition and a gendered health concern. The chapter examines how women are disproportionately affected and how systemic biases in medical research have limited the recognition of women's embodied experiences. Drawing on feminist theories, biosemiotics, and autographic design, the chapter positions symptoms as interpretative and material phenomena that acquire meaning through perception and interaction. These perspectives establish the conceptual grounding for a participatory design approach that recognises the body as both the source and interpreter of its own evidence.

Chapter 3 describes the methodological approach developed to investigate how material engagement supports the communication of embodied experiences. Building on the theoretical foundations of the previous chapter, it introduces physical variables as mediators between perception and interpretation and presents Data-Probes as participatory artefacts that enable people to externalise sensations. The Shape Your Symptoms workshop protocol is detailed as the practical application of this approach, combining reflection, co-creation, and discussion to foster awareness and patient agency in healthcare.

Chapter 4 presents the Data-Probe artefacts produced during the participatory workshops as the physical results of the research. Rather than offering the full thematic analysis at this stage, the chapter documents and organises the material outcomes generated by participants, including their forms, compositions, and associated descriptions. This chapter establishes the visual and material basis for the analyses developed in the following chapters.

Chapter 5 analyses the health-related findings that emerged from the workshops, with particular attention to women's experiences of UTIs.

It examines how participants discussed prevention, symptoms, diagnosis, consultation, and treatment, showing how embodied experience is shaped by personal histories, healthcare encounters, and recurrent uncertainty. This chapter addresses the empirical context of the research and clarifies what the workshops revealed about symptom awareness and communication.

Chapter 6 analyses the methodological findings generated through the use of Data-Probes, physical variables, and the workshop structure. It focuses on how participants engaged with materials, associated symptoms with physical qualities, constructed artefacts, and used these artefacts to present and discuss their experiences. This chapter examines how material engagement and physical variables supported interpretation, comparison, and collective meaning-making.

Chapter 7 presents the engagement with medical experts conducted after the workshop analysis. Healthcare professionals reviewed selected workshop outcomes and reflected on how participants' material and narrative expressions could contribute to clinical understanding and patient-centred communication. Their responses offered a clinical perspective on the insights generated through the method, clarifying how embodied accounts of symptoms may complement existing forms of medical knowledge while also indicating practical considerations for future use in healthcare contexts.

Chapter 8 discusses the findings across the empirical, methodological, and assessment phases. The chapter reflects on how participatory design, material engagement, and physical variables contributed to the transformation of individual embodied experiences into shared forms of knowledge. It also examines how the research reframes measurement, validity, materiality, and interpretation within participatory data physicalization.

Chapter 9 consolidates the Physical-Variable Apparatus as the central methodological contribution of the thesis. The chapter formalises the Apparatus as a system for participatory knowledge generation, integrating labels, the workshop protocol, Data-Probes, and the cross-format analysis interface. Taken together, these components support the elicitation, materialisation, comparison, and interpretation of embodied experiences, enabling individual accounts to become collectively discussable and analytically meaningful.

Chapter 10 concludes the thesis by synthesising the overall research process and outcomes. The chapter revisits the research questions, summarises the main methodological, theoretical, and empirical contributions, and reflects on the limitations of the study. It also outlines directions for future work, including the further development of the Physical-Variable Apparatus, its application to other chronic or subjective conditions, and the integration of digital, multimodal, and sensory forms of documentation.



Figure 1.3: treemap visualisation of the thesis structure, organised by chapter. The size of each rectangle corresponds to the word count of each thesis section, providing an overview of the relative weight of the different parts of the document.

The thesis concludes with the References and Appendix. The Appendix provides supporting documentation for the different stages of the research process. It first includes the question guides used for the initial expert interviews, the pilot expert interview, and the final medical expert interviews. These are followed by the corresponding transcripts from the initial expert interviews, the pilot expert interview, the workshop conversations, and the final medical expert interviews. The Appendix also includes the ethics approval letters and supplementary materials that support the transparency, traceability, and contextual understanding of the research process.

2. LITERATURE REVIEW AND THEORETICAL BACKGROUND TO CO-CREATE KNOWLEDGE FROM SYMPTOMS

In this chapter, I present the theoretical background that supports the study and outline the literature on which it is based. The literature review and the theoretical background are introduced as a single, integrated process rather than as separate stages. Insights from design, healthcare, feminist theory, and data practices, organised and shown in Figure 2.1, come together to frame the study and guide the methodological direction developed in Chapter 3.

As outlined in the introduction, urinary tract infections (UTIs) provide the main empirical case of the research. UTIs are common and often recurrent bacterial infections whose diagnosis frequently relies on patients' descriptions of symptoms within diagnostic and care processes. This makes them especially relevant to this study, as they place embodied experience, symptom communication, antibiotic use, and gendered health inequalities in close relation. Within this chapter, UTIs are considered both as the condition that grounds the research context and as a case through which the theoretical concerns of the thesis are introduced.

The subjective and embodied nature of symptoms demands methods that move beyond detached observation and externally imposed data collection. Conventional biomedical practices often extract patient accounts as impersonal data to be recognised through a process of standardisation by professionals, stripping them of context and diminishing their relevance to those experiencing illness. In contrast, this research adopts the concept of situated knowledge, emphasising that meaningful representations of health must be co-created with those who live with the condition.

Within this context, symptoms are framed as material traces that acquire meaning through interpretation. Symptoms are understood as manifestations of internal states that become significant through bodily perception and interaction. This framing builds on two key perspectives: biosemiotics considers symptoms as bodily signs within an ongoing process of signalling and meaning-making, while autographic design extends this view by treating these signs as self-inscribing

qualities that can be revealed and interpreted through material engagement. Together, these perspectives recognise the body as both the source and interpreter of its own evidence, while data physicalization offers a practice through which this evidence can be externalised, materialised, and discussed.

To enable this interpretation to emerge and to support understanding between individuals with lived experience and medical professionals, participation becomes a means of connecting scientific knowledge with everyday realities. Through participatory engagement, mutual learning is fostered and insights are produced that no single actor could generate alone. Participation is not framed as an additional step but as an integral practice through which participants actively shape how phenomena are explored, understood, and communicated. Grounded in design practices, participatory processes support people in collecting, interpreting, and communicating their own data, transforming situated personal interpretations into knowledge that holds value at a collective level.

On this basis, the literature and theoretical framing developed in this chapter identify the key elements that guide the methodology presented in Chapter 3.

2.1 The problem of UTIs within women's health	2.1.1 UTI disease concerns	Women's involvement and causes of infection
		Recurrence and chronic burden
		Resistance development
	2.1.2 Feminist perspectives on UTIs as a gender issue	Gender bias in data and practice
		Situated knowledge and feminist critique
	2.1.3 Positioning this research	
2.2 The methodological stance: challenging neutrality in healthcare	2.2.1 Considering the role of data within the healthcare scenario	
	2.2.2 Situatedness and accountability to add value	Shared subjectivity
		Data within the humanities: from capta to humanism
	2.2.3 Embodiment to generate healthcare data	Data sense, data-bodies and tacit data
		Cradling the undefined
	2.2.4 Self-Tracking and patient-generated data	Quantified Self and Persona Informatics practices
		Self-tracking limitations
	2.2.5 Data literacy through design in healthcare	From technical competences to awareness
		Making sense of persona data
		Creative and participatory approaches to literacy
2.3 Theoretical framing: symptoms as physical indicators	2.3.1 Symptoms as interpreted bodily signs	Biosemiotics perspectives
		Understanding indexes
	2.3.2 Physical indicators within autographic design	Recognising and interpreting traces
	2.3.3 Towards a material approach to symptom interpretation	
2.4 Materiality as mediator for knowledge creation	2.4.1 Materiality for data collection: cultural probes	
	2.4.2 Materiality for data representation: data physicalization	Analytical and artistic meaning
		Historical and contemporary interests
		Physical artefacts in clinical and care contexts
	2.4.3 Material agency in meaning-making	
	2.4.4 Advancing from situated bodies to material interpretation	
2.5 The approach: participation and co-creation	2.5.1 Participation in healthcare	Challenges in participation
	2.5.2 Collaboration strategies and levels	Participatory Action Research (PAR)
	2.5.3 Patient definition and role	
	2.5.4 Participation within data physicalization practices	Participatory Data Physicalization
		Participation for data collection
		Participation for representation
		Participation for interpretation
2.6 Towards structured openness in symptom collection		
2.7 Initial expert interviews to inform methodological development	2.7.1 Analytical insights from the interviews	Data is necessary but partial
		Symptom description shapes prescription decisions
		Patients hold experiential knowledge, but interpretation requires support
		Participation supports awareness but needs structure
	2.7.2 Methodological implications of the initial interviews	
2.8 Physical variables as a structure for embodied symptom collection	2.8.1 Existing classifications of physical variables	
	2.8.2 Encoding and decoding multisensoriality	
	2.8.3 Do we need a vocabulary?	
2.9 From literature and interviews to methodology		

Figure 2.1: Diagram representing the sections of the chapter that build the theoretical background of the research. Drawing on the literature review and initial interviews with experts who work with symptoms and data from different perspectives, the chapter starts by introducing the problem of UTIs. It then expands the discussion to the need to challenge assumptions of neutrality in healthcare. From this position, symptoms are recognised as situated indicators, while materiality is considered as a way to deepen their interpretation within participatory approaches. This framing grounds the research theoretically and supports the development of its methodological approach.

2.1 The problem of UTIs within women's health

This first section examines urinary tract infections (UTIs) more specifically as the condition through which the central problem of the thesis is grounded. They are introduced at the beginning because they provide the main empirical case of the research and establish the clinical and social context from which the later theoretical discussion develops. UTIs are especially relevant for this work because they are widespread, often recurrent, and frequently approached through patients' descriptions of symptoms, which makes their diagnosis closely tied to questions of interpretation and communication. Their significance within this thesis also lies in the fact that they disproportionately affect women and therefore bring into view broader issues of gender bias, credibility, and the uneven recognition of embodied experience in healthcare. For these reasons, UTIs are addressed both as a clinical issue and as a women's health concern.

2.1.1 UTI disease concerns

UTIs are among the most frequent bacterial infections worldwide, with an estimated 150 million cases each year (Mohiuddin, 2019). They represent a major public health concern due to their high incidence, impact on quality of life, and significant contribution to antibiotic consumption. Accurate diagnosis of UTIs is essential to ensure effective treatment and to avoid unnecessary use of antibiotics. However, diagnosis often depends heavily on how patients describe their symptoms during medical consultations. This reliance on patient narratives presents significant challenges. Symptoms such as pain, burning, urgency, or discomfort are personal experiences. They are variably expressed, influenced by personal perception, cultural factors, and communication styles, and they are sometimes incomplete or inconsistent (Masajtis-Zagajewska & Nowicki, 2017). However, they are fundamental in guiding critical treatment decisions, often before laboratory confirmation is available. The tension between objective signs and subjective symptoms defines the central difficulty of UTI diagnosis. Objective indicators, such as urine culture results or the presence of fever, are prioritised in medical practice because they are measurable and verifiable. However, these results are not always accessible when decisions need to be made. Laboratory tests require time, and in many primary care settings, the results are unavailable at the moment of consultation (Ribers and Ullrich, 2022). As a consequence, physicians must often make decisions based on incomplete information, relying on the patient's description of their condition.

Women's involvement and causes of infection

Women experience UTIs far more frequently than men, with about 81 percent of all UTIs reported in women (Kaur and Kaur, 2020). An estimated 40 to 50 percent of women will have at least one episode during their lifetime, compared with around 5 percent of men (Mohiuddin, 2019). This disparity stems primarily from anatomical and physiological differences. The female urethra is shorter, meaning bacteria have less distance to travel before reaching the bladder and less time to be removed by urination. The urethral opening is also positioned closer to the anus, allowing easier transfer of uropathogenic bacteria from the perineal area to the bladder. Additionally, the vaginal and periurethral environments are more susceptible to microbial colonisation, particularly during periods of hormonal change (Pigrau and Escolà-Vergé, 2020). In fact, the presence of the vaginal cavity and the close proximity of the rectum to the urethral opening create favourable conditions for bacterial colonisation. Beyond these anatomical factors, several other risks contribute to recurring UTIs in women, including behavioural factors, genetic susceptibility, age-specific factors, pregnancy-related factors, and urinary catheterisation.

Several biological and behavioural conditions further increase susceptibility. Menopause reduces levels of estrogen, which can alter the vaginal flora and diminish natural protection against pathogens. Diabetes compromise immune function and increases glucose in urine, providing a favourable environment for bacterial growth. Behavioural factors include frequent sexual activity, sexual initiation at an early age, recent changes in sexual partners, and the use of spermicides, all of which disrupt normal flora and facilitate bacterial colonisation. Previous antibiotic use is also a contributing factor, as it can disturb the protective balance of lactobacilli in the vaginal microbiota, leaving women more vulnerable to infection (Pigrau and Escolà-Vergé, 2020).

Across these cases, the primary pathogen responsible for UTIs is *Escherichia coli*, which causes more than 80 percent of infections. Other microorganisms, such as Staphylococcus saprophyticus, Klebsiella pneumoniae, Enterobacter spp., Proteus mirabilis, and Enterococcus faecalis, are also involved, particularly in recurrent or complicated cases (McLellan and Hunstad, 2016). The clinical presentation of UTIs depends on the site of infection. Lower UTIs, commonly referred to as cystitis, typically cause symptoms such as dysuria, urinary frequency, and discomfort. Upper UTIs, including pyelonephritis, present more severe manifestations such as fever, chills, nausea, and flank pain, reflecting a more systemic inflammatory response (Masajtis-Zagajewska and Nowicki, 2017).

Because laboratory confirmation requires time and is often unavailable at the point of care, treatment is frequently initiated during the first consultation based

on reported symptoms and patient history (Ribers and Ullrich, 2022). This reliance creates a diagnostic risk, as when symptoms are vague, unclear, or misinterpreted, the treatment may not target the actual cause of infection. A patient may receive an antibiotic that is ineffective against the bacteria responsible, which can reduce the likelihood of full recovery and prolong illness (Masajtis-Zagajewska and Nowicki, 2017). To minimise this risk under uncertainty, clinicians frequently prescribe broad-spectrum antibiotics designed to treat a wide range of bacteria (OECD, 2019). While this strategy can offer immediate relief, it has unintended consequences, as broad-spectrum drugs disrupt the balance of normal bacteria in the body, potentially causing side effects and leaving behind resistant strains that are harder to treat (Holmes, 2016).

Recurrence and chronic burden

Inadequate or inappropriate therapy may temporarily relieve symptoms without fully eradicating the infection, increasing the likelihood of recurrence. Between 20 and 30 percent of women experience a recurrent infection following an initial episode (McLellan and Hunstad, 2016). Recurrent UTIs are defined as two or more episodes within six months or three or more within twelve months. This leads to considering the impact extending beyond physical symptoms, as repeated pain, discomfort, and disruption to daily life, often lead to anxiety, frustration, and feelings of helplessness. Persistent infections can interfere with work, education, intimate relationships, and social participation (McLellan and Hunstad, 2016). Chronic cases are frequently associated with sleep disturbances, fatigue, and emotional distress, amplifying their personal and social burden. From a healthcare perspective, recurrent UTIs present ongoing challenges. They necessitate repeated consultations, diagnostic tests, and antibiotic prescriptions, increasing costs and resource demands (OECD, 2019).

Prophylactic or long-term antibiotic regimens are sometimes used to prevent recurrence, but these strategies remain controversial. Although they may reduce short-term episode frequency, they contribute to resistance development by selecting resistant strains that perpetuate the cycle of infection (Holmes, 2016; Pigrau and Escolà-Vergé, 2020).

Resistance development

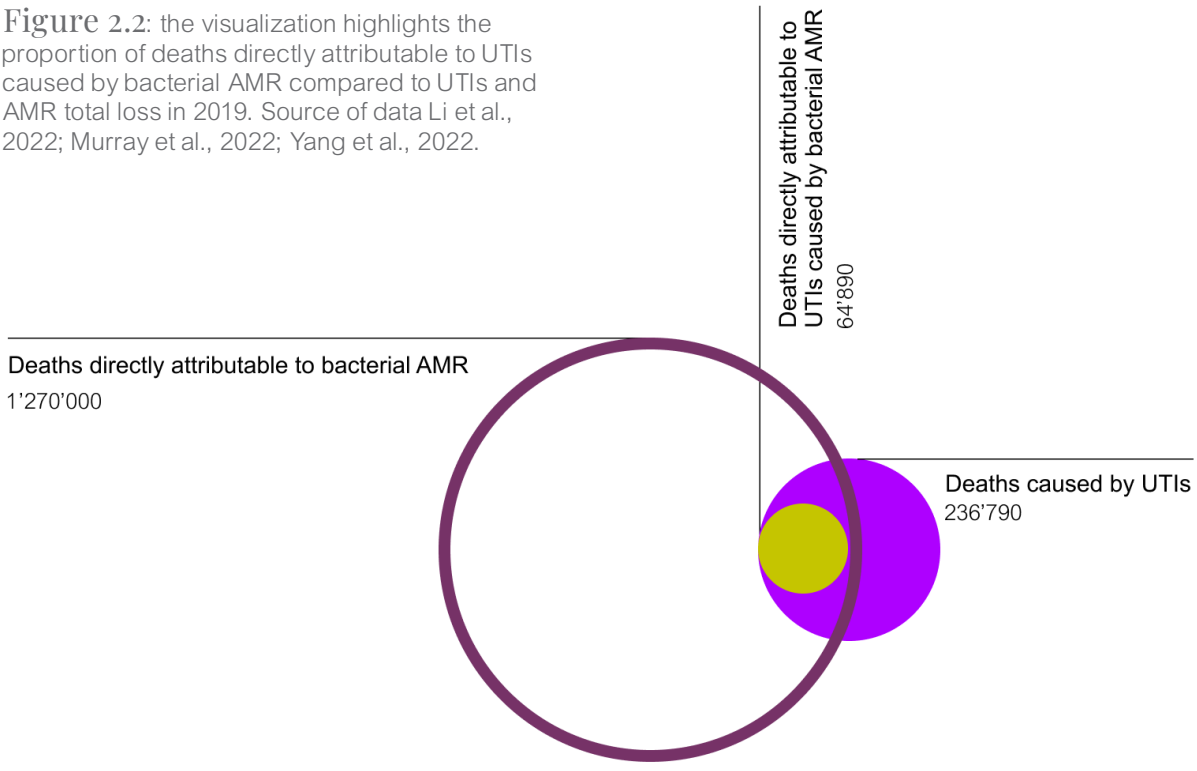
What happens in all these cases of recurrence is that unnecessary or inappropriate courses of antibiotics increase bacterial ability to withstand future treatments, making the disease progressively harder to manage. Resistant infections often demand more costly or invasive medications, longer treatment durations, and, in severe cases, hospitalisation (ECDC and WHO, 2022). For these reasons, antimicrobial resistance

(AMR) is recognised as one of the most urgent global health threats (WHO, 2023). In 2019, AMR directly caused an estimated 1.27 million deaths and contributed to nearly 5 million worldwide (Murray et al., 2022). Without effective action, projections indicate that AMR could result in 10 million deaths annually by 2050, surpassing cancer as the leading cause of mortality (O'Neill, 2016).

The intersection of AMR, UTIs, and antibiotic consumption becomes particularly visible when examining their combined contribution to health loss. Figure 2.2 highlights this correlation by showing the share of deaths directly attributed to AMR related UTIs alongside the overall impact of UTIs and of AMR in 2019.

The severity of the situation also needs to take into account that the burden of recurrent UTIs extends beyond individual suffering to substantial societal consequences. The communication gap in UTI diagnosis is not a minor clinical issue but a critical link between personal illness and a global health crisis. Diagnostic uncertainty and reliance on symptom-based treatment sustain empirical antibiotic use, driving the spread of resistant pathogens. Breaking this cycle requires improved ways of capturing, interpreting, and integrating patient-reported symptoms into clinical decision-making. This research addresses this challenge by examining how subjective experiences of UTIs can be more effectively represented and communicated. Focusing on the lack of awareness and communication between patients and clinicians, the thesis is interested in investigating how individual narratives influence diagnostic accuracy, treatment outcomes, and the broader dynamics of healthcare.

Figure 2.2: the visualization highlights the proportion of deaths directly attributable to UTIs caused by bacterial AMR compared to UTIs and AMR total loss in 2019. Source of data Li et al., 2022; Murray et al., 2022; Yang et al., 2022.



2.1.2 Feminist perspectives on UTIs as a gender issue

As discussed above, UTIs affect people of all genders but disproportionately impact female bodies, a pattern linked to anatomical, hormonal, and behavioural factors that increase both susceptibility and recurrence. However, the significance of this disparity extends beyond biology. Gender also shapes how symptoms are perceived, articulated, and evaluated within clinical practice. Women have been historically underrepresented in medical research, and their embodied accounts are often undervalued or dismissed (Almeida et al., 2020a; Perez, 2019). This contributes to a clinical culture in which women's expressions of pain, reported more readily and with greater sensitivity than men's, are frequently misinterpreted as emotional excess or exaggeration rather than recognised as valid indicators of illness (Bever, 2022). These biases are further perpetuated by female health technologies often embody normative assumptions about women's bodies and reproduce structural inequalities through their design (Billuart, 2024). Taken together, these perspectives show that UTIs are not only a biomedical condition but also a gendered issue shaped by entrenched sociocultural patterns that influence how symptoms are understood, recorded, and acted upon across healthcare systems.

Gender bias in data and practice

Systemic gender bias permeates the production, interpretation, and application of medical data. Women have been historically excluded or underrepresented in clinical trials and large-scale datasets, resulting in treatments, technologies, and guidelines that are optimised for male physiology (Almeida et al., 2020a; Perez, 2019). This underrepresentation persists despite increasing evidence of sex-specific differences in disease presentation, drug metabolism, and treatment response, limiting the ability of healthcare systems to deliver effective and equitable care to women. Bias is not confined to data gaps but extends to the processes of data collection and use (D'Ignazio and Klein, 2020). Women are frequently positioned as passive subjects in medical research rather than as active contributors to knowledge production (Thompson, 2020). This reinforces an asymmetry between those who control data and those whose bodies generate it (Fotopoulou, 2021). Such asymmetries have tangible effects on care, as demonstrated by the fact that women are prescribed less pain medication than men following equivalent procedures, are less likely to receive appropriate diagnostic testing, and are more often dismissed or under-treated when they report symptoms (Tomasello and Almeida, 2020). The problem is not unique to UTIs, but similar patterns exist across a range of conditions. Women suffering from chronic pain are more likely to have their symptoms attributed to psychological causes rather than to physiological conditions. Evidence also indicates that women's

reported experiences of pain are often perceived as exaggerated, despite studies suggesting that women may have greater pain sensitivity and a higher propensity to report pain accurately (Samulowitz et al., 2018; Bever, 2022). These disparities reflect entrenched cultural and institutional patterns that undermine the credibility of women's embodied experiences.

Situated knowledge and feminist critique

Feminist theory challenges these exclusions by highlighting the value of situated knowledge. Haraway (1988) argues that all knowledge is produced from specific, embodied standpoints, rather than from a universal, objective perspective. Within this context, women's experiences of UTIs are not peripheral to medical understanding but constitute essential evidence for improving diagnosis, treatment, and care. Recognising this knowledge challenges the hierarchy that places the need of quantifiable laboratory results above understanding personal experience.

Historical feminist health movements laid the foundation for this critique. The Boston Women's Health Book Collective's 1971 publication Women and Their Bodies (later Our Bodies, Ourselves) exposed the paternalism of mainstream medicine, highlighting how opacity, authority, and mystification kept patients subordinate to medical professionals. By encouraging women to share personal experiences and reclaim knowledge about their own bodies, the collective drove a shift toward transparency, autonomy, and accountability in healthcare (Boston Women's Health Book Collective, 1971).

Contemporary feminist scholarship builds on these foundations by advocating for participatory and women-centred approaches that integrate embodied experience into research, design, and healthcare practices (Almeida et al., 2020; Billuart, 2024). In design research, this shift has produced methods and tools that position women not as passive recipients but as co-creators of knowledge. The introduction of the Research and Feminism(s) track at the 2018 Design Research Society conference is one of the examples incentivising the growing recognition of feminist approaches as critical to rethinking how design engages with complex social issues, including health. In Human-Computer Interaction (HCI), there has been an expansion of research beyond maternal care to include topics such as menstruation, menopause, endometriosis, and chronic pelvic pain. These developments demonstrate a broader commitment to challenging exclusionary practices and to legitimising women's embodied knowledge as a foundation for innovation.

2.1.3 Positioning this research

Considering that UTIs primarily affect individuals with female anatomy due to structural and physiological factors such as shorter urethral length, hormonal fluctuations, and microbial interactions within the vaginal and urinary environments (Mohiuddin, 2019; Pigrau & Escolà-Vergé, 2020), gender becomes a critical lens through which to examine both the medical and social dimensions of this condition.

While this research focuses on women's experiences, this choice does not imply that men's experiences of UTIs or related conditions are less significant. Rather, attending to gendered differences makes visible the need for integrated approaches that address a broader spectrum of experiences. Insights generated from women's experiences can inform more inclusive strategies, provided that future work continues to account for the diversity of bodies, identities, and health trajectories. This perspective emphasises the importance of approaches grounded in difference, treating it as a valuable source of knowledge rather than as a deviation from a norm.

In this thesis, the term women is used when referring to the gendered, social, and institutional dimensions through which UTIs are experienced, communicated, and often marginalised in healthcare. This includes issues of credibility, dismissal, stigma, and the historical under-recognition of symptoms associated with women's health. When referring to anatomical or physiological susceptibility, I refer instead to bodily characteristics associated in biomedical literature with greater exposure to UTIs. This distinction recognises that gendered experience and anatomical susceptibility do not fully overlap as not all individuals with these bodily characteristics identify as women, and not all women share the same anatomy. The thesis therefore keeps feminist attention on women's situated experiences while remaining cautious about reducing susceptibility to a single gender category.

On this basis, positioning the study within feminist theory constitutes both a methodological and an ethical choice. Feminist scholarship foregrounds situated and embodied perspectives and draws attention to how dominant forms of knowledge can marginalise lived experience (Haraway, 1988; Harding, 1991). In the context of UTIs, this is especially relevant because diagnosis often depends on symptom narratives shaped by pain, urgency, discomfort, and other intimate sensations. When these accounts are reduced, overlooked, or treated as secondary, important aspects of the condition may remain outside clinical recognition. For this reason, in the next section I examine how healthcare knowledge is produced, in order to identify the limits of neutral and standardised approaches and to clarify the areas in which methodological intervention becomes necessary.

2.2 The methodological stance: challenging neutrality in healthcare

This section outlines the methodological stance adopted in this research by examining how knowledge is produced through data practices in healthcare. Building on the feminist perspectives introduced above, it considers how claims of neutrality and standardisation have often shaped healthcare in ways that under-recognise women lived and embodied experiences. Conventional biomedical systems often treat patient accounts as preliminary inputs that must be standardised before they can be considered reliable. This process supports consistency and comparability, yet it also abstracts symptoms from the relational, social, and material conditions in which they emerge. When subjective descriptions are translated into fixed categories, aspects of lived experience that carry meaning for the person may be reduced or omitted.

In the case of UTIs, diagnosis frequently depends on descriptions of pain, urgency, or discomfort. These sensations are intimate and variable, and they do not always align neatly with measurable indicators. For this reason, the transformation of these experiences into clinical data involves interpretive decisions that shape what is recognised as evidence and what remains peripheral. From a feminist perspective, this is especially important because the histories of women's health show how experiences associated with the body are often dismissed, simplified, or treated as less reliable when they do not fit dominant forms of medical evidence. Challenging neutrality therefore means recognising that data is produced through situated practices that determine relevance, credibility, and visibility. These practices influence how symptoms are recorded, how diagnoses are formed, and how treatment decisions are justified.

The analysis developed in this section is intended to recognise the value of biomedical knowledge while bringing attention to the practices through which relevance, credibility, and visibility are established. This makes it possible to examine the limits of current approaches and the areas open to intervention more clearly. The research pursues this direction through a methodological stance that recognises people with experience of the disease as contributors to knowledge. Through participatory and material approaches, subjective experiences can be articulated in ways that retain their embodied and contextual dimensions while remaining communicable within healthcare settings. The following section considers the role of data within the healthcare scenario and examines how data practices shape clinical understanding and care.

2.2.1 Considering the role of data within the healthcare scenario

Data-driven medicine has transformed the landscape of modern healthcare. The systematic collection, analysis, and sharing of large-scale data underpins many of the most significant advancements in medical research, clinical practice, and health policy. By enabling the identification of patterns across different populations, data supports predictive modelling, early detection of disease, and the development of targeted interventions. Within clinical settings, access to extensive datasets allows physicians to make more accurate diagnoses, tailor treatments to individual patients, and monitor disease progression over time. On a broader scale, public health agencies rely on aggregated data to track population health trends, allocate resources, and design evidence-based policies (Hummel & Braun, 2020).

Central to this transformation is the paradigm of precision medicine, which seeks to align healthcare interventions with the specific biological, environmental, and lifestyle characteristics of each patient. Precision medicine is presented as a move away from one-size-fits-all treatments towards individualised care, a shift made possible only through the availability of large datasets and algorithmic tools capable of integrating them. In this context, data is central to all the process as it structures how disease is understood, how treatment decisions are made, and how health outcomes are evaluated (Zhu and Zheng, 2018).

Despite these benefits, the increasing reliance on data has reinforced a persistent misconception that considers numerical information inherently neutral, objective, and complete. This belief obscures the fact that data is never simply "collected", but is actively produced through processes of selection, categorization, and interpretation. As Kitchin (2014) argues, "no data are pre-analytic, or objective and independent elements." Every dataset reflects the assumptions, priorities, and constraints of those who design the systems through which information is generated. Choices about what to measure, which variables to include, and how to present results fundamentally shape the meaning and use of data.

In healthcare, the consequences of this misconception are significant. Data-driven practices often privilege measurable, quantifiable indicators such as laboratory results, imaging outputs, and standardised metrics. These forms of evidence are undoubtedly valuable, but they are not sufficient on their own (Young et al., 2017). The biomedical focus on quantifiable signs frequently relegates subjective, affective, and contextual experiences to a secondary status, treating them as anecdotal rather than essential. Yet many conditions, particularly those involving pain, fatigue, or discomfort, manifest primarily through subjective perceptions that cannot be fully captured by quantitative tests. When these experiences are excluded

or undervalued, diagnoses may be incomplete, treatments misaligned, and patients' needs left unaddressed. This overemphasis on quantity and detachment has further implications in the era of big data and algorithmic decision-making. Large datasets, if poorly contextualised, can obscure the phenomena they aim to inform. Statistical models built on incomplete or biased inputs risk perpetuating existing inequalities, producing outputs that appear objective but in fact reflect the limitations of their sources without being recognised (Obermeyer and Emanuel, 2016). The assumption that more data automatically leads to better outcomes neglects the importance of quality, relevance, and interpretation. Without recognising situated data within the lived realities that are meant to be represented, the possibility for improving healthcare remains potential.

Addressing these challenges needs rethinking what counts as data and how it is generated. This requires approaches that move beyond the accumulation of numerical values engaging with the full spectrum of human experience. Personal meaning, contextual understanding, and subjective perspectives need to be recognised not as optional supplements to biomedical evidence but integral components of it. By embedding these dimensions into data practices, healthcare can better reflect the complexities of illness and create more inclusive, responsive, and effective systems of care.

2.2.2 Situatedness and accountability to add value

The ideal of neutrality has long shaped medical and scientific practice, where objectivity is often understood as the removal of bias and perspective, implying that knowledge can exist independently of those who produce it. However, knowledge is always generated within specific contexts by individuals and communities whose positions shape what is observed, how it is interpreted, and how it is applied. From this perspective, knowledge is recognised as partial, contextual, and embodied (Haraway, 1988). Objectivity, therefore, does not result from the absence of perspective, but from acknowledging the position from which knowledge is produced and the responsibilities attached to that position. Haraway's concept of situated knowledge makes clear that expertise is inseparable from the social, cultural, historical, and material conditions in which it is formed, and that recognising this situatedness strengthens, rather than undermines, the value of knowledge.

Shared subjectivity

In healthcare system and practice, this perspective challenges the notion that medical knowledge is universal. What is often presented as deriving from

standardised protocols, clinical trials, and diagnostic criteria is, in fact, shaped by decisions about what questions to ask, which populations to include, and how to interpret outcomes. The exclusion of women from many historical clinical trials, for instance, has led to treatments and diagnostic norms that do not adequately reflect female physiology or experience (Perez, 2019; Billuart, 2024). Such systemic omissions are not accidental but reflect broader power dynamics that determine whose experiences are valued and whose are marginalised.

Recognising situatedness highlights the role of shared subjectivity in producing more comprehensive and meaningful medical knowledge. As Malterud and colleagues (2015) argue, clinical understanding emerges not only from standardised tests but from the interactions between patients, clinicians, and researchers. These interactions create collective perspectives shaped by context, dialogue, and negotiation. Shared subjectivity is particularly important in complex, real-world settings where rigid, universalist approaches fail to capture the variability of human health. Incorporating these perspectives allows healthcare practices to become more inclusive and contextually relevant, addressing the diverse ways people experience illness and care.

Data within the humanities: from capta to humanism

Drucker's critique of data offers a parallel argument from the humanities that challenges conventional assumptions about data as objective, neutral, or naturally occurring (2011). She introduces the concept of capta to emphasise that information is not simply collected, but actively taken, selected, and shaped through human interpretation, cultural context, and epistemological perspective. Rooted in a humanistic tradition, Drucker argues that knowledge production is always situated and partial, influenced by the interpretive choices of those who create, organise, and present data. Rather than treating data as self-evident facts waiting to be visualised, she advocates for an approach that recognises both data and its visual representation as products of meaning-making. Data is therefore understood not as fixed or observer-independent, but as embedded in context, shaped by values, and interpretive in nature.

This humanistic understanding of data also resonates with Lupi's notion of data humanism (2017), which calls for data practices that remain connected to human complexity, imperfection, and context. Lupi argues against treating data as distant, neutral, or self-sufficient, proposing instead that data should engage with people's behaviours, emotions, routines, and lived experiences. In this sense, data humanism translates the critique of data neutrality into a design-oriented position, where data becomes meaningful when it preserves traces of the people and situations from which it emerges.

In healthcare, this perspective makes the positionality of those who experience a condition essential to the production of accountable knowledge. Health-related data is approached not as a neutral output extracted from the body, but as something shaped through the ways bodily conditions are perceived, interpreted, and described in everyday life. Recognising this situated character helps keep representations connected to lived experience and supports their use without reducing them to abstract accounts detached from context.

For this research, data as capta and data humanism support the move towards forms of data practice that are personal, situated, and interpretable. This is especially relevant to symptoms, which are felt, described, and negotiated through embodied experience. People with lived experience are therefore recognised as important interpreters of their own bodily conditions, bringing forms of understanding shaped by perception, memory, and context. This perspective creates the basis for approaching healthcare knowledge as grounded in experience and open to interpretation, preparing the methodological move towards participatory and material practices.

2.2.3 Embodiment to generate healthcare data

The interest in embodiment reflects a broader shift in how data is understood within design research and practice. Earlier approaches often aligned data with the empirical logic of industrialisation, where it served control, optimisation, and standardisation by quantifying properties and regulating outcomes. Mid-20th century developments in statistics and decision theory introduced probabilistic reasoning, allowing design processes to incorporate variability and uncertainty. This opened pathways for integrating behavioural and contextual insights, reorienting attention toward human users rather than purely technical parameters (Cain and Zach, 2023).

The late twentieth century deeply incorporated qualitative and interpretive methods, such as anthropology, sociology, and ethnography within design practice. Data was no longer only a means to measure or predict, as it became a way to understand lived experience. Contemporary perspectives extend this trajectory further, conceiving data as situated, relational, and processual (Kitchin, 2025). Therefore, data is not a static resource to be extracted but an active component of ongoing practices of knowing and making.

Within this context, the body itself emerges as a source and site of data (Lupton, 2017). Personal sensations, perceptions, and practices shape how individuals engage with their health and how they are represented in medical and design systems. The translation of these internal experiences into data influences not only how others understand the body but also how individuals themselves experience

and interpret the meaning. The body generates understanding through continuous engagement with its own sensations rather than through detached observation. Symptoms illustrate this process, as sensations such as pain, urgency, or discomfort are not neutral facts awaiting measurement, but interpretations formed by the body, shaped by physiological processes and influenced by personal history, context, and emotion.

Data sense, data-bodies and tacit data

In this direction, Lupton's concept of data sense (2018) captures how people engage with information through their bodies. Data is not received passively or processed purely cognitively. Individuals compare it to how they feel, reconcile information with past experiences, to which they respond physically and emotionally. Knowledge is formed not only by what is represented but by the reactions and reflections it provokes, making data personal and situated.

A complementary perspective comes from the notion of data bodies, which reframes the relationship between bodies and data as inseparable and co-constitutive (Thompson, 2020). Data bodies arise through the entanglement of digital traces with embodied experience, presenting data as something shaped by how bodies are sensed, understood, and represented within broader sociotechnical systems. Together, data sense and data bodies challenge the view of data as objective or detached from human experience and show how data engagement is shaped by emotional, contextual, and evolving human feelings.

This perspective is important to the present research because it helps frame symptoms as interpretations made by and through the body. Individuals generate meaningful insight through perception, emotion, and physical state, and embodiment becomes central to understanding health and illness. Such knowledge often includes tacit dimensions, described by van Koningsbruggen et al. (2024) as subtle, experiential, and difficult-to-verbalise aspects of experience that resist formal representation. These dimensions are important for understanding the full reality of a condition, while many conventional data practices continue to value clarity, stability, and standardisation. This view also aligns with critical data studies, which call for approaches that preserve complexity and allow space for interpretation (Kitchin, 2025).

Cradling the undefined

To engage with these dimensions, this research adopts approaches that attend to the complexity of lived experience rather than reducing it to fixed indicators. Reflection, attentiveness, and interaction become ways to bring forward elements that often remain unspoken yet emerge through embodied engagement.

Instead of requiring participants to formalise their sensations into predetermined categories, the approach supports exploratory processes in which meaning unfolds through awareness. This orientation aligns with wider efforts in healthcare design to create systems that accommodate ambiguity and allow individuals to articulate sensations that resist quantification or linear reporting formats.

Within this perspective, self-tracking offers a relevant example of technological mediation. Following Lupton's work, practices such as wearable sensors and health applications allow individuals to observe patterns in their data, build awareness, and take a more active role in their care. These practices show how personal data can support agency, while also raising questions about the limitations of relying solely on digital traces to understand what people feel and live through.

2.2.4 Self-Tracking and patient-generated data

Self-tracking has become one of the most prominent ways in which individuals engage with their bodies as sources of knowledge. Tracking encompasses a wide range of practices in which people observe, record, and interpret data about their own health, behaviours, and environments (Lupton, 2017; Fors & Pink, 2017).

These practices can be as simple as keeping a symptom diary or as technologically advanced as using wearable sensors and mobile applications for continuous monitoring. The popularity of these methods reflects a broader cultural shift towards patient participation in health management, positioning individuals not only as recipients of care but as active contributors to their own well-being (Rapp, 2015; West et al., 2017).

Quantified Self and Personal Informatics practices

The Quantified Self (QS) movement has played a key role in shaping this trend. Emerging in 2007, QS advocates "self-knowledge through numbers," encouraging people to collect data, about various aspects of daily life, from sleep patterns and exercise to mood and diet, using digital tools (Wolf in Feng, 2021; Wolf, n.d.). Parallel to this cultural movement, research in Human-Computer Interaction (HCI) introduced the concept of Personal Informatics (PI), which focuses on the iterative processes of collecting, reflecting on, and acting upon personal data (Li et al., 2010).

While QS often prioritises objective measurement and automation, PI highlights the situated and cyclical nature of engagement, acknowledging that meaningful insight emerges not simply from data points but from the ongoing interpretation of information in context.

In healthcare, self-tracking holds considerable promise. Patient-generated data can enhance diagnostic accuracy, particularly for conditions that manifest

intermittently or subjectively, such as chronic pain, fatigue, or urinary symptoms (Fors & Pink, 2017). Manual logging of symptoms allows individuals to capture nuances, such as triggers, environmental influences, emotional states, that standardised clinical assessments may miss (Choe, 2014). For chronic illnesses, self-tracking supports long-term management by helping patients monitor their conditions, adhere to treatment, and detect changes early enough to seek timely intervention (Huzooree et al., 2019). Self-tracking also has value for clinicians, who can use patient-provided data to contextualise test results, guide treatment decisions, and strengthen doctor-patient communication (West et al., 2017).

Self-tracking limitations

However, self-tracking also reveals significant limitations. The reliance on quantification risks privileging what can be measured over what is meaningful. Wearable devices and mobile applications often reduce complex embodied experiences to simple metrics, potentially obscuring context, emotion, and nuance (Lupton, 2018). While numbers may feel objective, they are mediated by design decisions, data processing algorithms, and the assumptions built into devices (Rapp, 2015). Furthermore, patient-generated data is not always trusted by clinicians, who may view it as incomplete, inconsistent, or unscientific due to its non-standardised collection methods (West et al., 2017). This can create a paradox in which patients invest significant effort in tracking their health, but their data holds limited influence in clinical encounters.

Beyond epistemological concerns, self-tracking raises ethical and political issues. Data collected for personal use can be repurposed for commercial gain, often without adequate consent (Zuboff, 2019). Digital health technologies are embedded within systems of surveillance and control, producing what Lupton (2018) describes as the datafied body, where intimate information becomes a site of economic and political value. These practices also risk reinforcing health inequities as access to tracking technologies is uneven. Lastly, the cultural emphasis on self-monitoring can stigmatise those unable or unwilling to engage in constant self-surveillance (Pangrazio, 2019; van Dijck, 2014).

Self-tracking, therefore, illustrates both the potential and the limitations of patient-generated data. It shows that individuals are capable of producing valuable insights about their health, but also that these insights cannot be fully understood or applied in isolation. Data alone does not speak, but requires interpretation, context, and collaboration. Moreover, while self-tracking can empower individuals, it often remains a solitary act constrained by predefined metrics and tools.

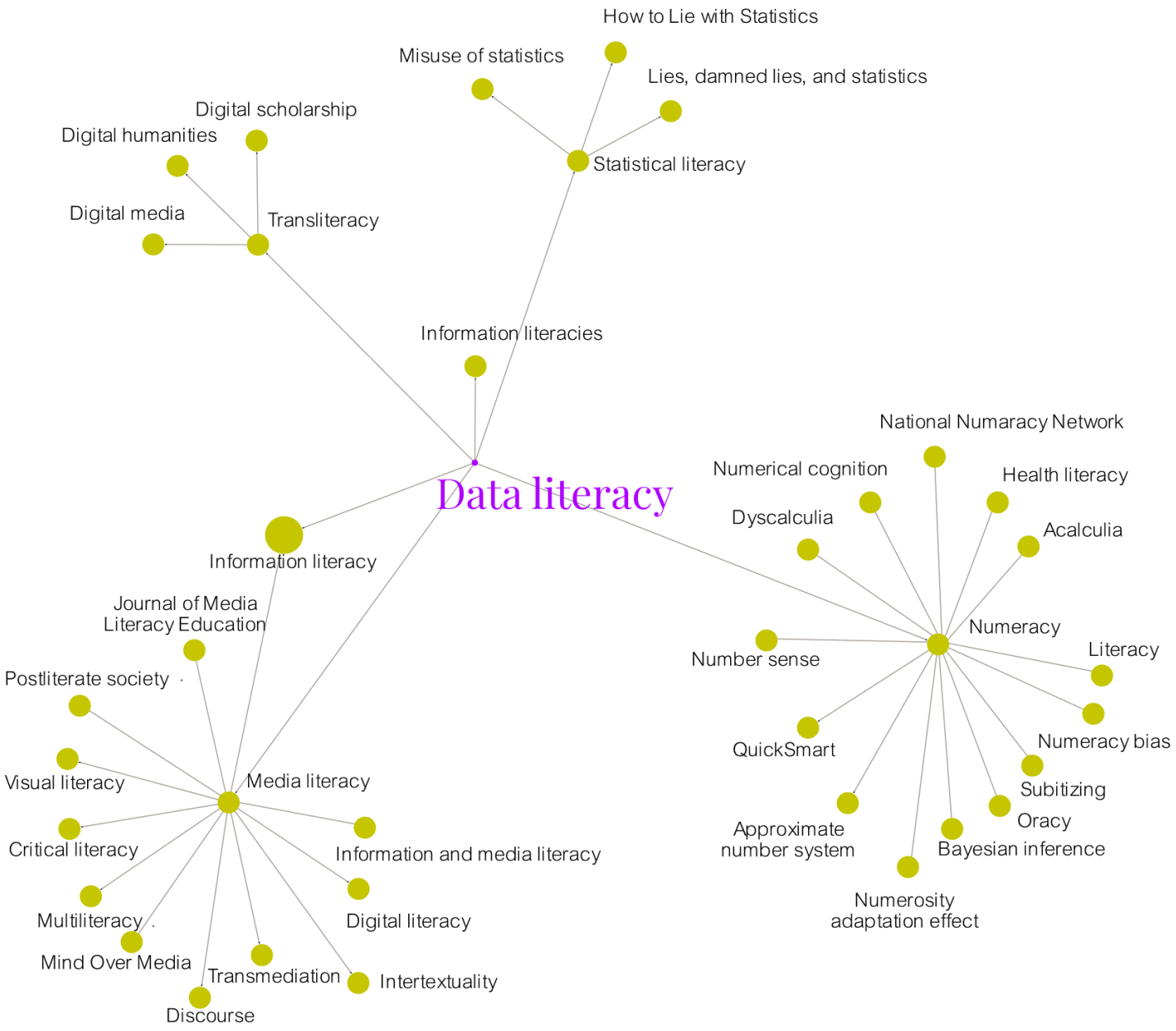
For conditions such as UTIs, these limitations are particularly pronounced. Symptoms are episodic, subjective, and often difficult to convey in terms that align with clinical expectations. While tracking can help individuals identify patterns and better understand their own experiences, it remains primarily personal and interpretive. The challenge lies in transforming these individual records into forms that carry meaning beyond the self as forms that can be understood, trusted, and acted upon by others. Addressing this challenge requires more than tools for observation, but skills to interpret, contextualise, and communicate data effectively. This is where data literacy becomes essential. Moving from self-tracking to data literacy involves developing the capacity to connect personal experience with broader frameworks of understanding, enabling individuals not only to manage their own health but also to contribute to shared, evidence-informed discussions about care. The following section examines how data literacy can serve as a bridge between embodied self-knowledge and collective, accountable practices of making sense of health data.

2.2.5 Data literacy through design in healthcare

Data literacy is the ability to read, understand, create, and communicate data as information. It involves skills to interpret data accurately, critically evaluate its sources, and use it effectively to make informed decisions. In today's data-driven world, data literacy empowers individuals and organisations to navigate vast amounts of information, discern patterns, and apply insights across various contexts, including healthcare, business, and public policy. Developing data literacy is essential not only for specialists but also for the general public to participate meaningfully in discussions and decisions influenced by data. My interest in data literacy centres on the role of data in enhancing awareness and understanding of the body and illness. By improving individuals' perception of their bodies and the data related to them, data literacy aims to empower people to engage more actively in managing their health, make informed decisions and develop a deeper connection between their subjective experiences and objective information.

As shown in Figure 2.3, the network visualisation maps the Wikipedia page on data literacy and the pages linked to it through its See also section, revealing clusters around information literacy, numeracy, media literacy, trans-literacy, and statistical literacy. The figure is not intended to provide a reliable or exhaustive description of the field. Instead, it is used as a popular and publicly accessible indication of how data literacy is connected, framed, and made visible within a broader semantic environment. Wikipedia is understood here as a collaborative, user-generated platform whose entries and internal links develop through collective

editing, editorial activity, and shifting patterns of public attention. From this perspective, the visualisation helps identify the associations most readily established around data literacy in public discourse. The absence of links to design therefore suggests that design currently holds a weaker public connection to the topic at this level of visibility, rather than indicating its absence from academic discussion. Academic approaches to data literacy extend beyond this public semantic view by emphasising critical thinking, ethical awareness, and cultural context, and by recognising that data practices are situated within wider sociotechnical systems. In this direction, concepts such as Human-Data Interaction (Mortier et al., 2014) and data empowerment (D'Ignazio, 2017; Data-Pop Alliance, 2015) shift attention away from technical skill alone and towards agency, supporting individuals in questioning data practices, participating in decision-making, and exercising greater control over their digital lives.



[In the previous page]

Figure 2.3: the network visualisation maps the Wikipedia "Data Literacy" page to its closest concepts, showing clusters around Information Literacy, Numeracy, Media Literacy, Transliteracy, and Statistical Literacy, and revealing how data literacy is semantically linked to skills across numbers, media, and information, while notably lacking connections to design, data visualization, and physicalization. The data was collected in January 2023.

From technical competences to awareness

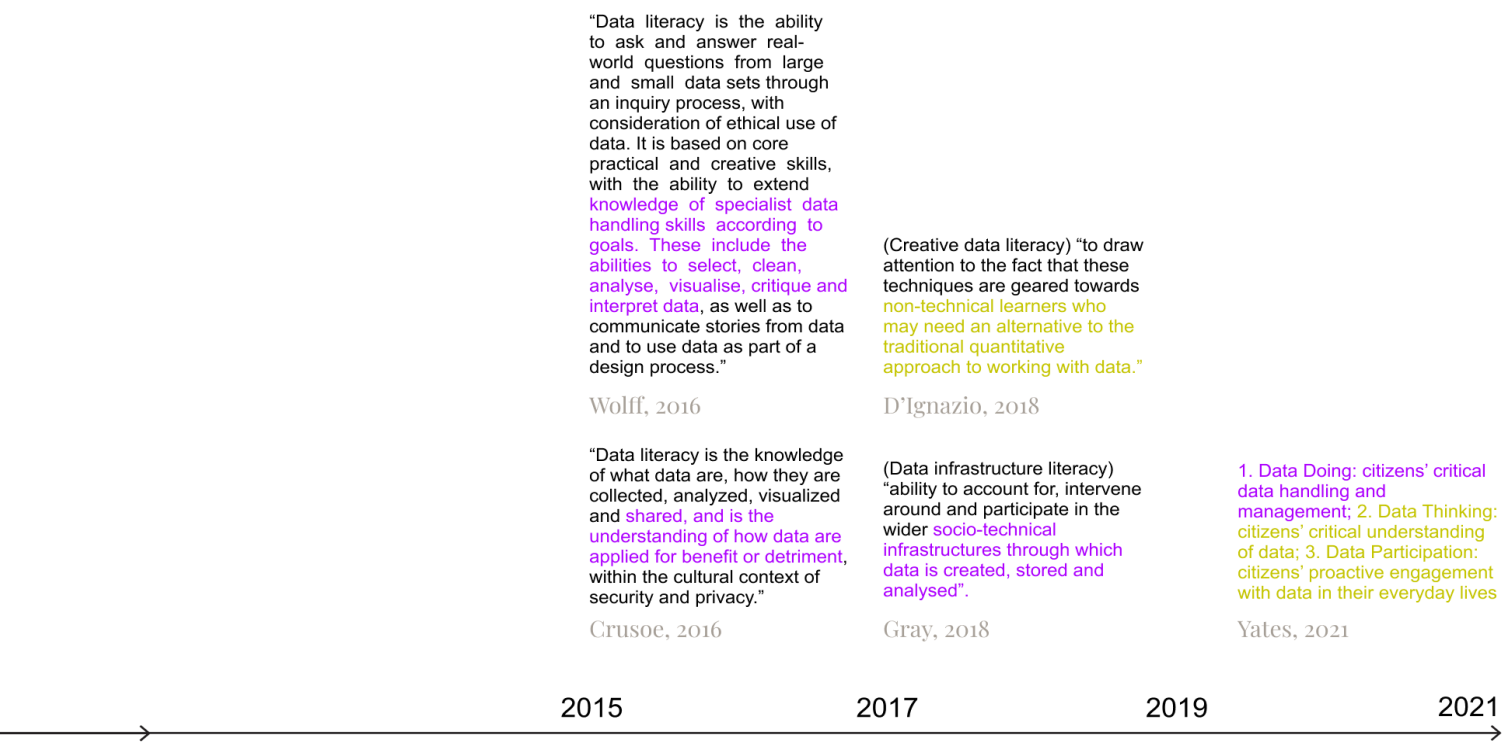
In addition to examining the semantic network around data literacy, it is helpful to consider how the definition of the term has shifted over time. As shown in Figure 2.4, the timeline traces the evolution of data literacy across the past two decades, revealing how the concept has expanded from a technically oriented skillset to a broader sociocultural competence involving critical thinking, ethics, interpretation, and agency.

Early definitions, grounded in professional environments, focused on technical skills such as accessing, manipulating, and analysing data with tools like statistical software and visualisation programs (Schield, 2004; Wolff, 2016). These views reflect a period in which data work was primarily the responsibility of experts. As digital technologies became widespread and began generating large volumes of personal and societal data, the concept broadened to include non-experts. Citizens are increasingly expected to understand how data is collected, stored, and used, and to engage with questions of privacy, consent, and bias (Yates, 2021). This shift underscores that data is never neutral but emerges from decisions, values, and power structures (Kitchin, 2014; Drucker, 2011).

Inverarity et al. (2022) at the Open Data Institute identify a dual trajectory in data literacy development. Industry and public sectors prioritise technical competence, focusing on data management, processing, and tool use to meet organisational needs, often through standardised training with limited contextual depth (Yousef et al., 2021). In contrast, academia advances a holistic approach that combines technical skills with critical thinking, ethical awareness, and contextual understanding. This academic perspective seeks to empower individuals to question how data is produced and applied, supporting reflective and responsible engagement with data.



Figure 2.4: the timeline outlines key definitions of data literacy from 2004 to 2021, highlighting the shift from early technical interpretations focused on data handling toward broader conceptions that include critical thinking, ethics, context, participation, and agency. The growing multidisciplinary nature of the term reflects the expansion beyond expert domains into everyday societal practice.


"Data literacy is the ability to ask and answer real-world questions from large and small data sets through an inquiry process, with consideration of ethical use of data. It is based on core practical and creative skills, with the ability to extend knowledge of specialist data handling skills according to goals. These include the abilities to select, clean, analyse, visualise, critique and interpret data, as well as to communicate stories from data and to use data as part of a design process."
Wolff, 2016
(Creative data literacy) "to draw attention to the fact that these techniques are geared towards non-technical learners who may need an alternative to the traditional quantitative approach to working with data."
D'Ignazio, 2018
"Data literacy is the knowledge of what data are, how they are collected, analyzed, visualized and shared, and is the understanding of how data are applied for benefit or detriment, within the cultural context of security and privacy."
Crusoe, 2016
(Data infrastructure literacy) "ability to account for, intervene around and participate in the wider socio-technical infrastructures through which data is created, stored and analysed".
Gray, 2018
1. Data Doing: citizens' critical data handling and management; 2. Data Thinking: citizens' critical understanding of data; 3. Data Participation: citizens' proactive engagement with data in their everyday lives
Yates, 2021
2015
2017
2019
2021
"The desire and ability to constructively engage in society through and about data."
Data-PopAllianz, 2015
(Data sense) "It acknowledges the use of the human senses in people's responses to data, including their personal data as well as big data sets. It also recognises the participation of technological sensors."
Lupton, 2017
(Personal data literacy) "data literacies require critical reflexivity regarding the implications of data profiling and data recirculation."
Pangrazio, 2019
(Data Walks) "interactive way for community stakeholders, including residents, researchers, program administrators, local government officials, and service providers, to engage in dialogue around research findings about their community."
Murray, 2015
"a specific skill set and knowledge base, which empowers individuals to transform data into information and into actionable knowledge by enabling them to access, interpret, critically assess, manage, and ethically use data."
Koltay, 2017
"data literacy includes the ability to read, work with, analyze and argue with data."
D'Ignazio & Bhargava, 2015

Making sense of persona data

In healthcare, the raise of agency is particularly significant. Data literacy enables patients to move beyond passive data provision toward active engagement with their health information. Literacy fosters awareness of how data relates to their bodies, supports communication with clinicians, and strengthens their capacity to challenge the dominance of objective measures that may overlook lived experience. As Fotopoulou (2021) notes, prioritising empowerment over technical instruction ensures that data literacy can address inequalities by equipping individuals and communities to use data meaningfully in their own contexts.

In this work, I adopt a broadened view of data literacy as a sociocultural process that connects embodied experience, critical reflection, and collective action. While technical skills are acknowledged as valuable, they are not the primary source of expertise for this research. Instead, expertise is rooted in lived experience, particularly in relation to illness, care, and medical practices. Data literacy is therefore understood not as technical skills alone but as the capacity to make sense of information through personal relevance, transforming individual traces into shared knowledge that supports agency and accountability.

Creative and participatory approaches to literacy

Drawing on Freire's critical pedagogy, literacy is understood as an emancipatory process grounded in engagement with one's own reality. D'Ignazio and Bhargava (2018) extend this perspective to the field, showing how connecting information practices to people's lived contexts can support understanding, agency, and reflection. Their work shows that non-expert audiences often relate more easily to narrative and contextual forms than to numerical abstraction, highlighting the need for creative and accessible ways of engaging with data.

Several methods have been developed to cultivate this ability. Data biographies invite participants to trace how datasets are produced, including the decisions, contexts, and omissions that shape them, fostering a critical awareness of data's constructed nature (D'Ignazio, 2017). Data fragments and annotations encourage participants to reflect on and critique their own data, using notes as a means to question and interpret information (Thompson, 2020). Attention to gaps and anomalies, as seen in self-tracking practices, further supports this process by showing that absences in data can be as meaningful as what is present (Lupton, 2017; West et al., 2017). Participatory approaches play a central role in developing these capacities. Learning within communities allows individuals to share experiences, question assumptions, and develop collective understanding (McCosker et al., 2022). In such contexts, personal data becomes a resource for shared reflection and action rather than a private and isolated asset (Karyda et al.,

2020). Collective engagement fosters solidarity and relevance, making data practices more meaningful and sustainable (Hummel & Braun, 2020).

In this research, data literacy is approached as a shared practice through which personal experience can contribute to broader health knowledge. Data is understood as something people interpret, question, and shape through active engagement. This allows what a person feels, notices, and describes to enter wider processes of reflection and understanding, connecting lived experience with social and clinical contexts. In this way, personal data becomes a resource for shared interpretation.

Within this process, medical experts retain an essential role. Their clinical experience supports the recognition of patterns, the interpretation of symptoms, and the relation of personal accounts to diagnosis and care. At the same time, patients contribute knowledge of how a condition is felt and lived. Health knowledge is therefore approached as something that develops through the meeting of medical expertise and lived experience.

Figure 2.5 illustrates this relation by showing how patients and clinicians work with information throughout the treatment process, from identifying what matters to interpretation and decision-making. In this view, data literacy helps patients express experience in ways that can support care, while also creating the conditions for exchange with clinical knowledge.

This perspective is important to the present research because it highlights the value of approaches that help people articulate embodied experience in forms that others can recognise and interpret. The next section develops this direction by examining design methods that engage symptoms more directly, supporting their expression and interpretation through embodied and material practices.

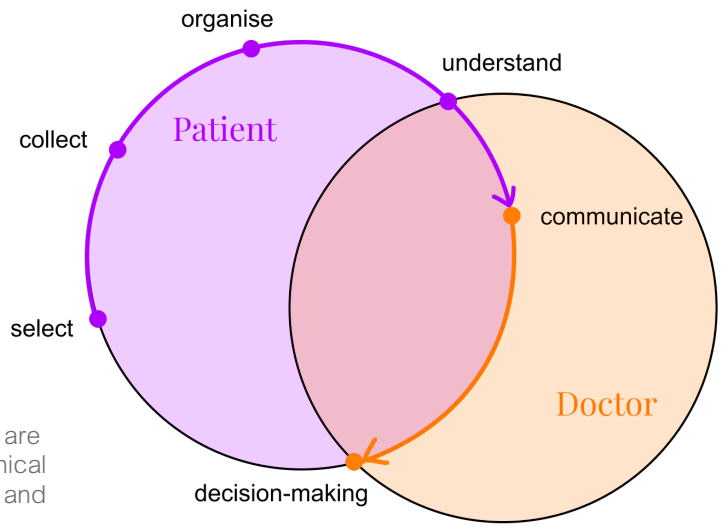


Figure 2.5: through data literacy, patients are recognised for the skills they bring to the clinical encounter, supporting shared interpretation and informed decision making.

2.3 Theoretical framing: symptoms as physical indicators

Building on the discussion above, this section introduces a theoretical framing that supports design in exploring alternative ways of approaching symptoms as data within healthcare. In this research, symptoms are considered as physical indicators of internal bodily conditions whose meaning develops through perception, interpretation, and context. This view helps foreground their value as situated expressions grounded in patient experience and opens space for design to engage them beyond standardised clinical description alone.

Two theoretical perspectives support this direction. The first is biosemiotics, which understands symptoms as bodily signs produced and interpreted within ongoing processes of meaning-making. The second is autographic design, which focuses on how bodily processes leave traces that can become perceptible and materially interpretable. Together, these perspectives provide the conceptual basis for design approaches that reconsider symptoms as embodied, contextual, and expressive forms of knowledge.

2.3.1 Symptoms as interpreted bodily signs

Medical practice traditionally distinguishes between signs, described as observable, measurable indicators identified by clinicians, and symptoms, subjective experiences communicated by patients. Signs can be externally verified through examination or testing, while symptoms depend on a person's ability to perceive and articulate internal sensations. A symptom such as pain or burning is therefore not a simple fact, as it is a mediated account of an underlying phenomenon shaped by individual experience, language, and context (Malterud et al., 2015).

Biosemiotics perspectives

Biosemiotics contextualises this symptom definition within a broader framework of semiosis, understanding living systems as continuously engaged in processes of signalling and interpretation (Hoffmeyer, 2008). Within this perspective, symptoms are not passive reflections of pathology, but active interpretations performed by the organism itself. The body generates and responds to signs internally, triggering protective actions such as withdrawal, rest, or behavioural adaptation. This ongoing exchange positions the body as active interpreter, where biological processes are perceived, and acted upon.

Peircean semiotics provides a deeper foundation for this view by classifying symptoms as indexical signs. Peirce distinguished three main types of signs: icons, which signify by resemblance; symbols, which signify by convention; and indexes, which signify through a real causal connection to what they represent (Peirce, 1967). For example, smoke is an index of fire, and a footprint an index of passage. Within this view, a burning sensation during urination results from specific physiological processes such as tissue irritation or inflammation. This connection gives symptoms an evidential quality, as they emerge from the body's response to internal disturbances and carry information about those disturbances.

In this perspective, symptoms are not mere consequences of the disease, but on-going signals generated by the organism as part of its adaptive mechanisms. For example, inflammation triggers chemical mediators that stimulate nerve endings, producing pain or discomfort. This sensation draws attention to a potential threat, prompting protective actions such as reduced activity, increased fluid intake, or seeking medical care. In this way, symptoms function as bodily traces of underlying states, linking biological processes to perception and behaviour. They are material expressions of internal events, requiring interpretation to be transformed into knowledge that can guide diagnosis and treatment.

Understanding indexes

Like all indexes, symptoms are not self-explanatory (Malterud et al., 2015). The presence of a sign indicates that something is happening, but it requires interpretation to become meaningful. Peirce's concept of the interpretant, which is the effect a sign produces in a mind, explains this process. According to Peirce, a sign exists only within a triadic relation (Peirce, 1967). The object is what the sign refers to, the representamen is the form the sign takes, and the interpretant is the understanding or response it generates. In the case of symptoms, the bodily sensation functions as the representamen, pointing to an underlying condition as the object. The interpretant emerges when the sensation is recognised, evaluated, and given significance by an individual or a clinician. This process is not static. New experiences, diagnostic tests, and changes in the condition can alter the interpretation, either confirm an initial understanding or prompting a reassessment. In this way, symptoms evolve as part of a continuous cycle of perception, interpretation, and response.

Viewing symptoms as indexical signs highlights their evidential and experiential dimensions simultaneously. In this thesis, they are considered neither purely objective nor purely subjective but occupy a hybrid space where biology and interpretation intersect. This framing challenges the biomedical tendency to dismiss

symptoms as unreliable because they lack the objectivity of measurable signs. First, indexicality shows that symptoms are grounded in physiological processes while acquiring meaning through interpretation. Second, it opens the possibility of designing methods that enhance this interpretive process. By externalising symptoms through material engagement, as proposed in this thesis, individuals can participate more actively in constructing meaning from their embodied experiences, generating interpretants that are richer, more precise, and more shareable across clinical and social contexts.

2.3.2 Physical indicators within autographic design

Autographic design extends the semiotic perspective outlined above by focusing on phenomena that reveal themselves through the traces they produce. Offenhuber (2019, 2020) introduced autographic visualisation as the practice of making processes perceptible through the marks they leave behind. The term autographic refers to the self-inscribing qualities of materials, considered as their capacity to register and reveal aspects of the phenomena through which they are formed. Such traces may arise naturally as indicators; tree rings that reveal patterns of growth (Figure 2.6), and ice layers that record past climates (Figure 2.7) are example of this; or they may be deliberately produced through practices designed to make otherwise invisible processes perceptible, such as the sundial (Figure 2.8, a-b), the litmus paper changing colour in response to pH levels (Figure 2.9), and the mercury thermometer, which measure temperature through the expansion of mercury inside a glass tube (Figure 2.10). Designing an autographic display involves setting the conditions under which information can emerge, allowing self-inscribing qualities to record aspects of phenomena as they unfold, while making the processes of data collection and their underlying causalities experiential and accountable (Offenhuber, 2019, 2023). This approach has proven particularly effective in valorising qualitative data within interface representations (Lockton et al., 2017, 2022).



Figure 2.6: an example of autographic displays. Tree rings illustrating the yearly growth of a woody plant, a record used in dendrochronology to date and interpret past events and climatic conditions.

Figure 2.7: an example of autographic displays. The image shows an ice core extracted at a depth of 1,855 metres. In the GISP2 sample, lighter summer layers and darker winter layers are visible, with the section recording eleven annual cycles.

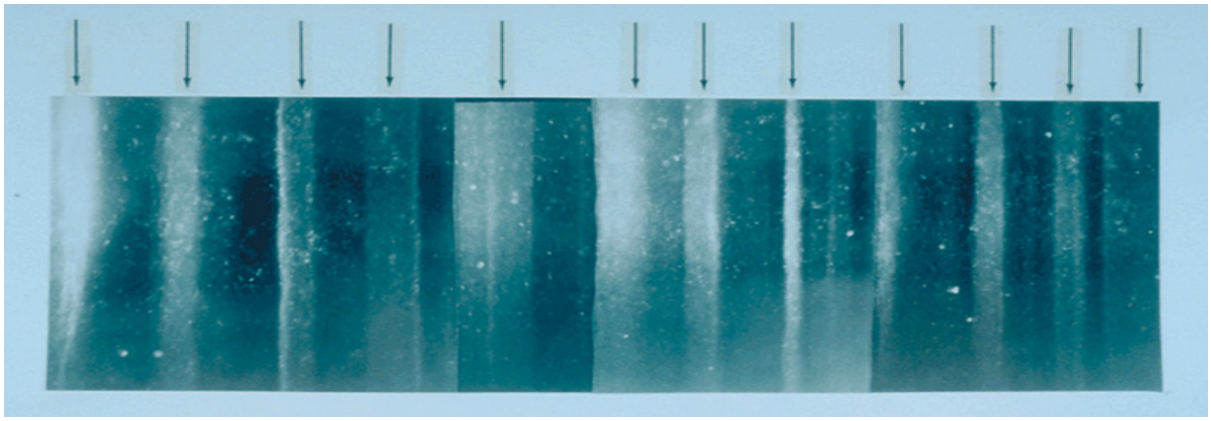


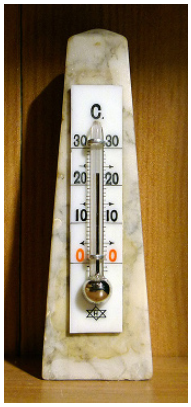
Figure 2.8 (a-b): examples of autographic tools designed to track processes and make them visible. The dolphin sundial at the Royal Observatory, Greenwich. The sundial uses the shadow cast by the meeting point of two bronze dolphin tails to indicate solar time. As the Sun moves across the sky, the shadow falls across the marked dial plate, making the passage of time visible through the interaction between sunlight, shadow, and the designed form.





Figure 2.9 and Figure 2.10: examples of autographic tools designed to track processes and make them visible. On the left, the pH-indicator paper, which changes colour according to the acidity or alkalinity of a substance; on the right, the mercury thermometer, where temperature causes the liquid to expand and rise to the point on the scale corresponding to the measured degree.





From this perspective, symptoms can be understood as autographic traces produced by the body. They arise directly from physiological processes, such as inflammation, infection, or immune responses, and contain within them information about these processes. For example, a burning sensation during urination results from chemical mediators released in irritated tissue, while fever reflects complex immune activity aimed at controlling infection. Like ice cores and tree rings, the spots that appear with tonsillitis, the red dots on the skin, or a bruise with blended colours, such as the ones in the Figure 2.11, can acquire new meanings as they register events within the body and mark changes in its condition over time.



Figure 2.11: examples of visible bodily signs that indicate underlying diseases or health conditions. From top to bottom, the images show tonsillitis, measles, and a bruise. Tonsillitis, caused by a viral or bacterial infection, appears as white patches on swollen tonsils. Measles, caused by a viral infection, produces a widespread red rash whose intensity and distribution indicate the progression of the illness. A bruise, caused by bleeding beneath the skin after impact, presents changing patterns of colouration that reveal different phases of healing.

Recognising and interpreting traces

Autographic traces acquire significance through a process that involves both perceptibility and interpretation. A process may leave marks, residues, or alterations, yet these do not automatically become available as meaningful signs. Their relevance depends first on conditions of exposure, attention, and recognition, through which material changes become accessible to the senses and begin to function as evidence of underlying events. Perceptibility, however, does not by itself secure meaning. Once recognised, traces still require interpretation in order to become informative. Their significance emerges through acts of reading, contextualising, and relating the trace to the process from which it arose. In this sense, autographic design does not simply reveal phenomena, but organises the conditions through which their traces can be noticed, explored, and interpreted. Its role is to support an active engagement with material signs, where meaning develops through attention, interaction, and enquiry rather than through the passive reception of a fixed representation (Offenhuber, 2023).

Through this perspective, autographic design provides a way of understanding how traces become perceptible and interpretable through their material expression. This emphasis on materiality demonstrates how underlying processes become recognisable through the forms they take and the traces they leave behind. For this thesis, these processes open the way to approaching symptoms as mediated signs that can be engaged through material interpretation.

2.3.3 Towards a material approach to symptom interpretation

The previous section describes symptoms as bodily signs and traces whose meaning develops through interpretation (Rosendal et al., 2013; Malterud et al., 2015). Biosemiotics explains symptoms as signs produced in the body (Hoffmeyer, 2008), while autographic design shows how these processes become perceptible through the traces they leave behind (Offenhuber, 2020). Together, these perspectives frame symptoms as experiences shaped through the body, perception, and context.

This understanding opens the way to a material approach to symptom interpretation and discussion. Symptoms such as pain, burning, pressure, or fatigue are lived through changing sensations that words express only in part. Their meaning develops through bodily feeling, memory, and situation, which gives them a form of complexity that benefits from modes of enquiry beyond verbal description or clinical measurement alone. In this direction, materials become relevant because their

qualities, such as texture, weight, shape, softness, resistance, or temperature, can support the exploration of sensations in the physical environment.

Material engagement enriches symptom interpretation by giving bodily experience a form that can be explored, expressed, compared, and shared. Through physical qualities and relations, materials can support reflection on what is felt and create conditions for discussing sensations with others. In this way, materiality is introduced here not as a means of fixing symptoms into stable representations, but as a way of investigating how embodied experience can become more perceptible and communicable.

From this perspective, symptoms can be approached as traces of the body that become tangible through material engagement. The following section develops this direction by examining the role of materiality as a mediator of knowledge creation. It considers how materials support the externalisation of experience, guide reflection through physical engagement, and create shared forms through which sensations can be interpreted and discussed with others.

2.4 Materiality as mediator for knowledge creation

Materiality plays an important role in design research because it supports how people think, reflect, and work together. In this view, materials do not simply carry meaning after it has already been defined. They take part in shaping perception and understanding through touch, movement, arrangement, and response. When people engage with materials, they often clarify ideas, notice new aspects of experience, and develop meanings through the process of making.

Schön (1984) describes this process as a “conversation with materials”. As people work with physical forms, materials answer back through their own qualities and limits, guiding reflection and further action. Wiberg (2014) extends this view by showing how material engagement also shapes the relationship between the person and the material itself. Meaning develops through this interaction, as materials influence thought while being shaped in return. Giaccardi and Karana (2015) further describe this process through the idea of material experience, where knowledge emerges through situated acts of touching, handling, and using materials over time. In this sense, materials support the generation of ideas as much as their expression.

Materiality also plays an important role when knowledge is created with others. In collaborative settings, materials can support exchange between people who bring different experiences and perspectives. Star and Griesemer’s (1989) concept of boundary objects helps explain this role. Boundary objects hold enough stability

to be shared, while remaining open enough to carry different meanings across contexts. Their value lies in supporting coordination without requiring complete agreement. In this way, materials can help people work together around a shared object while keeping space for different interpretations. A related role is described by Rheinberger's (1997) concept of epistemic objects. These are objects that support enquiry because they remain open, unfinished, and partly unknown. Rather than closing interpretation, they invite questions, discussion, and exploration. Nicolini and colleagues (2012) show how such objects help people express assumptions, compare positions, and develop understanding through interaction. This makes them especially relevant in contexts where the aim is to explore experience rather than fix it quickly into stable categories.

Together, these perspectives show that materials can mediate knowledge creation in more than one way. They can support reflection by giving experience a physical form. They can promote collaboration by creating shared points of attention, and they can also push for enquiry by keeping meaning open to development. This is especially important in healthcare contexts, where experiences are often subjective, intimate, and difficult to describe. Material engagement can help move sensations from private and personal experience towards forms that can be expressed, interpreted, and discussed with others. Within this thesis, the role of materiality is important because it helps explain how symptoms can become available for shared interpretation without being reduced to fixed descriptions from the start. Materials create a space in which bodily experience can be externalised and explored, while still remaining open to discussion, comparison, and change. This understanding prepares the ground for the next section, which examines how materiality is considered contributing to knowledge creation and helps define the methodological direction developed in this research.

Figure 2.12 situates this research within a broader landscape of material and data-related practices that use physical artefacts to support knowledge generation, interpretation, and communication. It moves from design-oriented concepts, such as material objects, cultural probes, boundary objects, epistemic objects, and physical props, towards data-oriented practices, including tokens, data objects, data physicalizations, data sculptures, data-bodies, data manifestations, and autographic visualizations. Across these examples, physical artefacts appear as mediators that collect responses, externalise experience, support negotiation, make abstract information tangible, and reveal phenomena through material traces. The figure therefore highlights a progressive shift from objects as contextual or participatory tools to objects as active means for producing, sharing, and interpreting data.

Material objects

O'Toole & Were (2008)

Corporeal and tangible objects constructed by humans within their lives (such as agricultural tools, ceramics, residences, furniture, playthings, buttons, roads, and urban centres), are considered providing important clues about human lives in the past.

Cultural probes

Gaver et al. (1999)

Probes as a collection of objects such as maps, instant cameras, or postcards to collect responses from people who the researchers were prevented to spend time with. An alternative 'designerly' mode of conducting research (research as design).

Design probes

Mattelmäki (2005)

Probes as source of inspiration, information, participation and dialogue.

Wallace & Lindley (2013)

Probes as externalization of complex aspects of identity, personality, self worth and relationships with external things.

Boundary objects

Star & Griesemer (1989)

Bounday objects are artefacts already existing but selected for the specific meaning defined by the user. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation.
[...] four types of boundary objects: repositories, ideal types, coincident boundaries and standardized forms.

Vines et al (2013) & Ehn (1989)

Boudary objects act act as shared articulations of knowledge of those participating in the design process.

Epistemic objects

Rheinberger (1997) in Nicolini et al. (2012)

Epistemic object is an attempt to foreground the power of material objects (in contrast to ideas or concepts) as driving forces in knowledge develop. Epistemic things and objects embody "what one does not yet know".

Physical props

Alexiou & Zamenopoulos (2019)

Props can be moved around by the users, redefined and repositioned promoting active, playful and engaging participation. Tangible assets are perceived as more negotiable, based on the fact that they can physically be renamed, repositioned, combined and discarded.

While probes tend to be used individually by users on their own, toolkits tend to be used as part of a facilitated collaborative process.

Figure 2.12: overview of methods based on materiality for knowledge generation, organised horizontally according to the relationships between objects and data identified in this research.

Tokens

5500 BCE, in Schmandt-Besserat (2007)

Tokens are physical representations of something they stand for, such as data, facts, quantities, etc. These artefacts were created to compute entities and expenditures of goods during the first four millennia of the Near Eastern redistribution economy. Tokens correspond to clay geometric shapes, such as cones, spheres, disks, cylinders, tetrahedrons, ovoids, triangles, and quadrangles, of the dimension of 1-2 cm.

Data objects

Gwilt et al. (2012)

Objects pecifically built to communicate and generate interest to a wide range of people and communities. Digital fabrication and physical making approaches are considered separated and combined to investigate different ways of translating and representing data.

DataGlyphs

Johnson et al. (2019)

Data glyphs are produced as physical artefacts which extend the digital exploration of the dataset.

Dataphys

Jansen et al. (2015)

Physical artifact whose geometry or material properties encode data.

Data sculptures

Zhao & Vande Moere (2008)

Data-based physical artefact, possessing both artistic and functional qualities, that aims to augment a nearby audience's understanding of data insights and any socially relevant issues that underlie it.

Data-bodies

Thompson (2020)

Data-bodies draw attention to both data and bodies while recognizing that data and bodies are utterly implicated in one another.

Data manifestation

Lane and Roussos (2022)

Tangible information to understand and interpret complex and tangible information, emphasing a comprehensive and immersive approach to processing information using various senses.

Autographic visualizations

Offenhuber (2019)

Phenomena that reveal themselves as visible traces. Physicalization does not just represent data but becomes data itself: qualities and features of the material identify the dataset.

2.4.1 Materiality for data collection: cultural probes

The previous discussion on self-tracking highlighted both the value of personal data and the need for approaches that involve people more directly in how data is collected, interpreted, and communicated. In this thesis, materiality is therefore considered as a way of working with experience through physical means. In this direction, cultural probes, introduced by Gaver and colleagues in 1999, provide an important reference for understanding how materials can support data collection through personal, situated, and reflective forms of engagement. Their relevance lies in the way they use artefacts to invite response, guide attention, and open space for interpretation. Materiality therefore contributes not only to recording experience, but also to shaping the conditions through which it can be expressed.
Cultural probes were designed to help researchers learn about people's lives, contexts, and perspectives through indirect and open-ended forms of participation. Participants received packages containing items such as maps, postcards, and other artefacts, together with prompts that encouraged reflection on everyday life, places, and technologies. Through this format, materials supported communication while leaving room for imagination, interpretation, and personalisation (Gaver et al., 1999).

A central quality of cultural probes is the kind of response they support. They encourage open contributions shaped by experience, context, and individual meaning. Their tangible form helps participants focus on the task, engage in a self-directed way, and respond through different modes of expression. Cultural probes were also framed as a way to make issues emerge and to open possibilities for design, rather than as tools for collecting standardised or controlled data (Gaver et al., 1999). Later developments expanded this approach by showing how probes can support dialogue, empathy, and participation more broadly. Mattelmäki (2006) described design probes as sources of inspiration, information, and dialogue. Wallace et al. (2013) used probes to support conversations around dementia, while Alexiou and Zamenopoulos (2019) highlighted how probe-like toolkits and tangible assets can help people collaborate by moving, renaming, combining, and repositioning physical elements. Across these developments, materials support collection, reflection, exchange, and participation among people with different experiences and perspectives.

This research considers cultural probes because they approach data collection through action, attention, and the interpretation of physical materials. Tangible assignments can help people externalise aspects of experience that are difficult to express in direct conversation, including personal feelings, memories, and relations. Slegers et al. (2013) further suggest that probe objects and actions can reveal something new to participants about their own experiences.

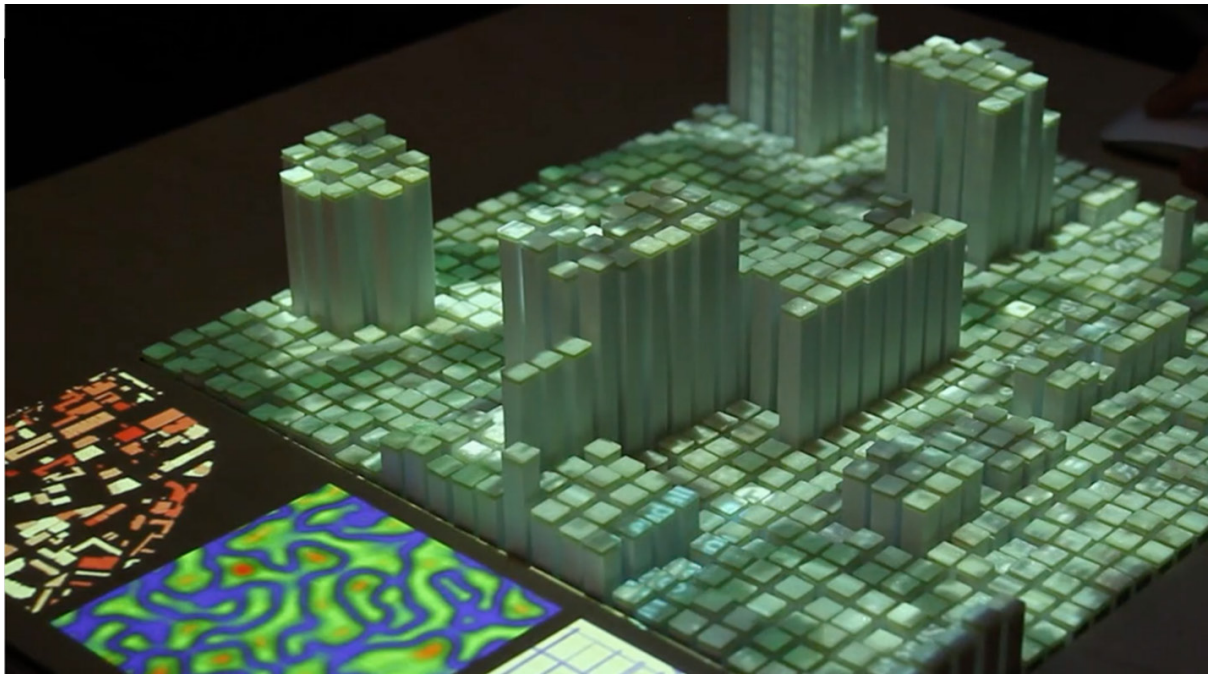
In this way, cultural probes support self-awareness as well as collection, and they show how material engagement can connect private reflection with shared understanding. The relevance of this perspective lies in the way it frames materiality as part of the process through which experience becomes expressible. In this thesis, cultural probes are therefore considered as a reference for data collection. To extend this direction towards the representation of experience within the same process of enquiry, the next section introduces data physicalization and examines how its practices of making and sense-making can support the material articulation of experience. Together, these two perspectives point towards a more integrated approach in which collecting and representing are closely connected, allowing material engagement to support awareness and interpretation of symptoms as embodied conditions.

2.4.2 Materiality for data representation: data physicalization

This research considers data physicalization as a key reference for understanding how materials can support the representation of information through physical form. While cultural probes demonstrate the value of materials in inviting responses and supporting data collection, data physicalization focuses more directly on how information can take shape through tangible artefacts. In this sense, it provides an important complement to the previous section, extending the role of materiality from eliciting experience to giving form to it.

Analytical and artistic meaning

The term “data physicalization” was formally defined at the 2015 Conference on Human Factors in Computing Systems as a physical artefact whose geometry or material properties encode data (Jansen et al., 2015). This definition helped bring together a growing field of diverse projects under shared language. This concept builds on earlier research in physical visualizations, which examined whether moving data from screens into tangible forms could improve how people perceive, understand, and reason with information, including by making comparisons and estimates more intuitive (Jansen and Dragicevic, 2013). An example is Tangible Cityscape (Figure 2.13), where physical elements support urban massing by translating abstract planning data into forms that can be manipulated by users. At the same time, engineering-focused studies explored “data objects” as accessible carriers of statistics, using digital fabrication to create forms that people can handle directly to support comprehension (Gwilt et al., 2012).



[Top]

Figure 2.13: Tangible Cityscape (2013) is a physical interface that supports urban massing by translating abstract planning data into manipulable physical forms. MIT Media Lab (Tang, S. K., Sekikawa, Y., Leithinger, D., Follmer, S., and Ishii, H.)

[Bottom]

Figure 2.14: two works by Adrien Segal. The first is the Molalla River Meander, which translates elevation data from the shifting course of the Molalla River into a sculptural form that reveals geomorphological change. Below, Unidale, a three-dimensional mapping of a year of temperature data, whose curves reflect daily fluctuations and longer-term climatic patterns.





Alongside these analytical approaches, artists began creating data sculptures that combine expressive and functional purposes. These works invite broader audiences to reflect on information through embodied perception and spatial experience (Zhao and Vande Moere, 2008). This artistic strand expanded the field beyond efficiency to include emotion, interpretation, and context. Touch, movement, and atmosphere became central to how meaning is made, particularly in public settings. Artist Adrien Segal exemplifies this approach by drawing on history, culture, and landscape to translate environmental change into physical forms (Figure 2.14). Her sculptures give presence to natural phenomena while connecting personal meaning with sensory experience, creating encounters that link people across time and place.
Alternative approaches have pushed physicalization beyond visual and tactile properties to engage additional sensory channels. Data Edibilization encodes information using edible materials, leveraging taste, smell, and consumption as ways to convey data stories (Want et al., 2016). Similarly, Data Manifestation communicates quantitative information through objects, installations, and sensory experiences specifically designed to address the boundaries that separate people from global issues like climate change (von Ompteda, 2019). These approaches demonstrate how physicalization can create more immersive and emotionally resonant encounters by engaging the full spectrum of sensory experience.

Historical and contemporary interests

The recent expansion of digital data and infrastructure has amplified the interest in physicalization however, this practice is not new. Long before researchers named it, communities have transformed information into physical form to serve social purposes that matter to them. The Wiki List of Physical Visualization documents this history by collecting cases where materials carry data (Dragicevic and Jansen, n.d.). The earliest documented example dates from 7500 BCE and was found in the Near East, where accountants used small clay tokens in geometric shapes, such as the ones in Figure 2.15, to represent goods and quantities in redistribution economies (Schmandt-Besserat, 2007). By 3500 BCE, the system had expanded to include dedicated shapes, such as miniature vessels and tools marked with lines and dots, to improve how administrative and trade information could be represented.
Physical objects have also served as forms of personal and communal memory. As shown in Figure 2.16, quipus from ancient Andean cultures illustrate a tactile form of record-keeping in which cords, colours, and knot patterns encoded numerical and narrative information. Similarly, Itiatamat time balls (Figure 2.17), created by women of the Yakama Nation around 920 CE, used hemp cord wound with pendant strings, knots, beads, and shells to mark significant life events.

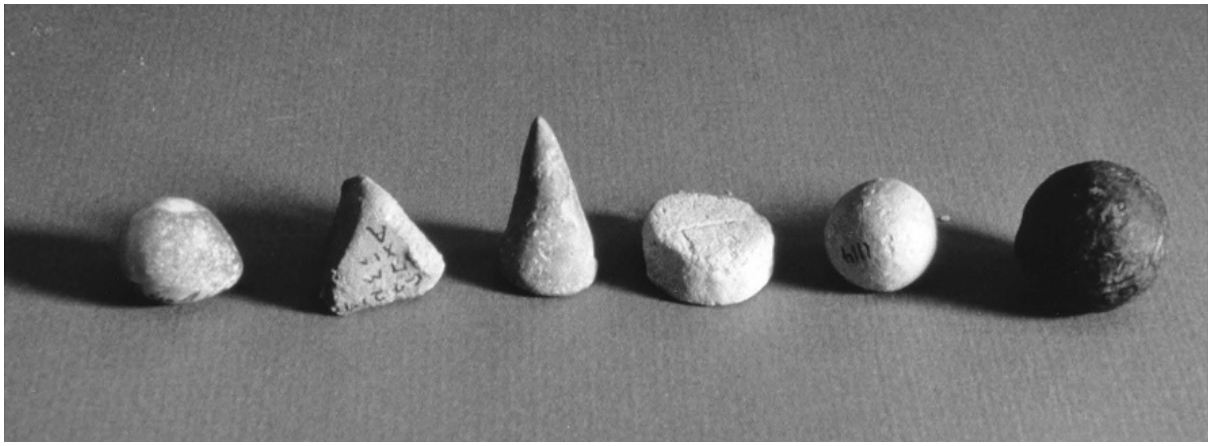
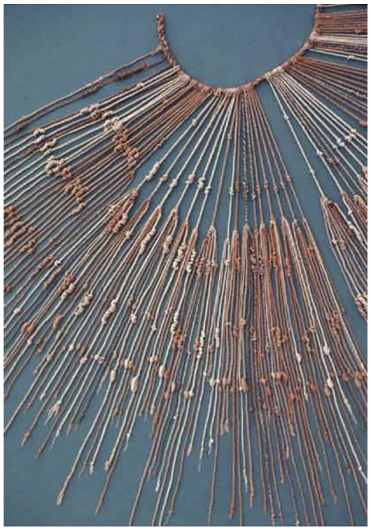
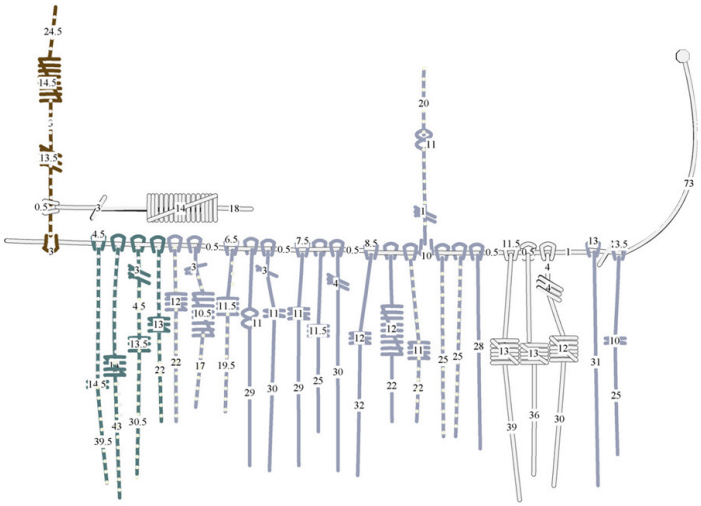


Figure 2.15: different clay tokens. Image from Antonino Crisà, Mairi Gkikaki and Clare Rowan, eds., TOKENS, CULTURE, CONNECTIONS, COMMUNITIES, Royal Numismatic Society, Special Publication No 51, 2019.



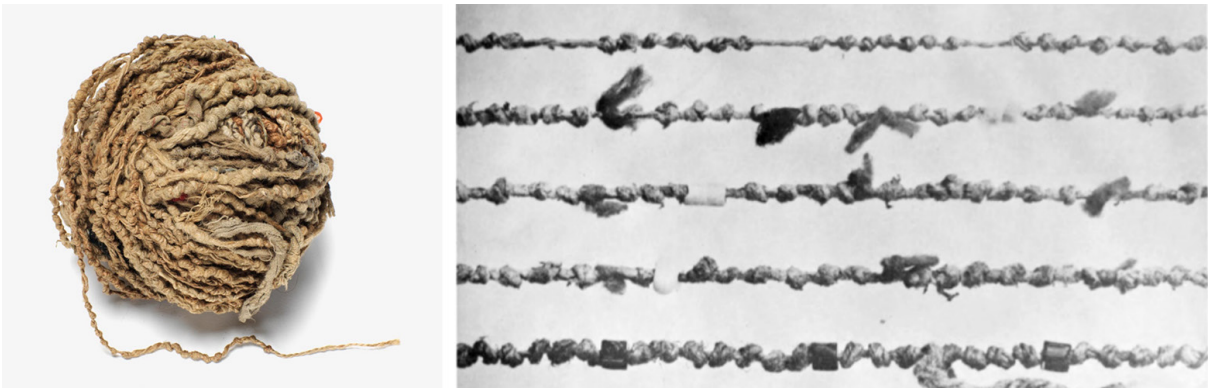
[Top]

Figure 2.16: Andean Quipus dating back to around 2600 BC, where cords, colours and knot patterns encoded administrative and narrative information, enabling storage and interpretation without written script.



[Bottom]

Figure 2.17: Itamat time balls created by women of the Yakaa Nation around 920 CE, made from hemp cord wound with pendant strings whose knots, beads and shells marked significant life events.



These objects functioned as tactile diaries that could be read through touch and shared within the community.
Created around 2600 BC, these knot-based devices use variations in cords, colours, and knot patterns to encode numerical and narrative information, materialising administrative and social data in structures that can be stored, carried, and interpreted without written script.

Across diverse contexts, physicalization functions as a means of transforming information that is otherwise ephemeral, private, or abstract into forms that are durable, shareable, and open to interpretation. This continuity highlights how physicalization responds to enduring human needs to make information tangible, portable, and available for collective sense making, including the interpretation of personal experience. These needs have become more pronounced in contemporary life, as much of the information shaping everyday practices remains embedded within device interfaces or remote infrastructures, constraining access and interpretability (van Dijck, 2014; Sinnreich and Gilbert, 2024). When data is treated as self-explanatory and detached from its contexts of production and use, opportunities for reflection, discussion, and meaning making are diminished (van Dijck, 2014). Contemporary data physicalization addresses this distance by rendering intangible information into tangible, interactive objects that people can handle, arrange, and discuss together. In doing so, it supports both individual reflection and shared learning among expert and non-expert publics (Karyda et al., 2020; Thompson, 2020). The breadth of applications, ranging from personal data tracking and research to art, education, participation, activism, and assistive technologies, demonstrates that contemporary physicalization, like its historical antecedents, responds to situated needs for making information accessible and interpretable within specific social contexts.

Physical artefacts in clinical and care contexts

In clinical and care contexts, tangible representations offer a bridge between clinical knowledge and people's understanding, helping abstract concepts connect to individual sensations and histories. Studies in this direction show that physical artefacts can foster reflection, promote self-awareness, and support more meaningful conversations (Van Koningsbruggen et al., 2024; Bae et al., 2022), which is particularly relevant in settings where patients and clinicians interact directly, such as consultations or follow-up discussions.

Many applications of data physicalization in clinical practice translate physiological parameters and disease processes into tangible artefacts, making abstract or invisible information accessible. Such representations can facilitate comparison, evoke emotional engagement, and promote sustained interaction. The

Lifestreams project (Lane and Roussos, 2012) illustrated in Figure 2.18, transforms biosensor data, such as heart rate, temperature, blood pressure, and sleep patterns, into 3D-printed artefacts that encourage ongoing reflection and a lasting relationship with personal health information. Figure 2.19, Print My Pain (Wilkinson et al., 2020) similarly externalises deeply personal and often inexpressible experiences by enabling people with chronic pain to translate sensations, intensity, and qualities of their condition into 3D-printed forms, supporting expression beyond words and fostering empathetic dialogue between patients and clinicians. Lane and Roussos (2012) advance this direction with the concept of data manifestation, advocating multisensory, embodied experiences that engage touch, spatial awareness, and movement. Their Lifecharms project for people with Parkinson's disease creates tangible souvenirs of personal health data, enabling private, direct communication between patients and clinicians while protecting data through physical encoding.



Figure 2.18: Visualise: Lifestreams (Proboscis, 2011–2012) turns medical data into tangible artefacts that express patterns of personal health.

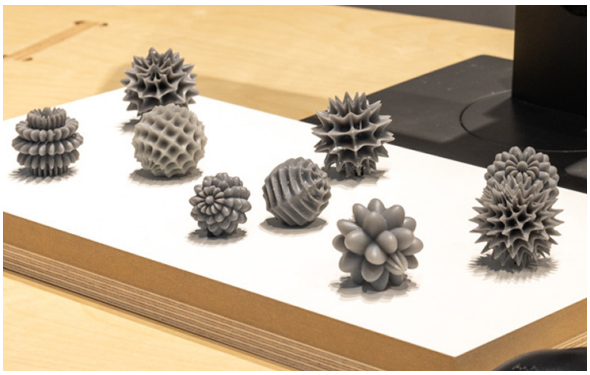


Figure 2.19: Print My Pain (Lab4Living) translates chronic pain experiences into three-dimensional forms to support communication and reflection between patients and clinicians.

The Hypertension Singing Bowl (Barrass, 2016) offers another example, transforming blood pressure data into ceramic forms that produce sound when struck, turning an invisible, often overlooked condition into a sensory and affective experience (Fig. 2.20).

Visualising the Resistance is a workshop that explores antibiotic resistance through the inhibition zones created by antibiotic pills inoculated onto bacteria (Terenghi et al., 2024). Based on principles of autographic visualisation, participants place different antibiotic pills inside Petri dishes in response to questions about their habits and beliefs around antibiotic use (Figure 2.21). The size of the inhibition zone calculated for each pill and bacteria combination is used as an answer, while also providing insights and opening reflection on how antibiotics are understood and used. This process enables worries, intuitions, and personal experiences to be externalised through material traces that are open to discussion.

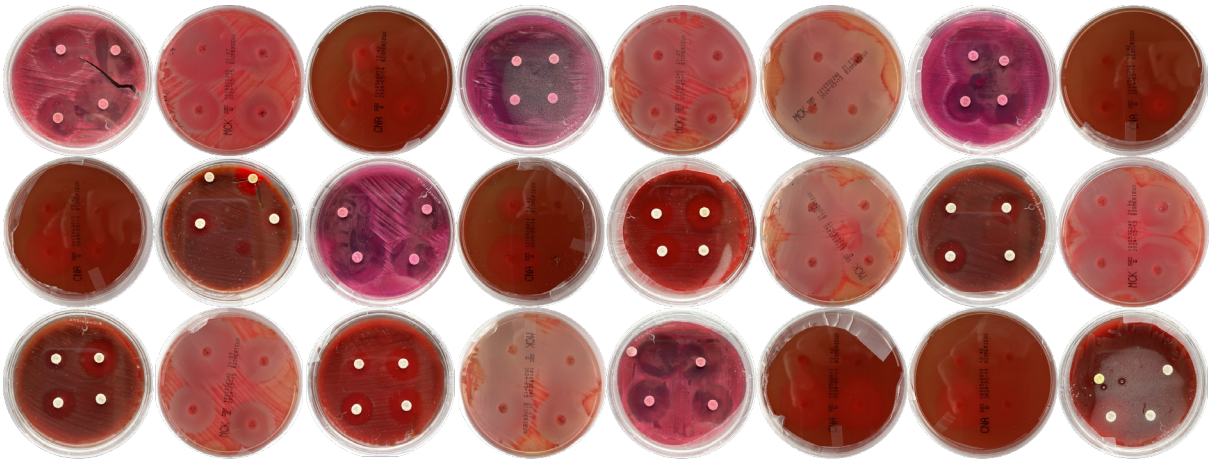
[On the right]

Figure 2.20: Hypertension (Barrass, 2016) sonifies blood-pressure data by converting systolic and diastolic measurements into an audio composition and a corresponding visual score.



[Below]

Figure 2.21: a selection of Petri dishes created by participants during the Visualising the Resistance workshop. Participants used antibiotic pills to answer questions about their patterns of antibiotic use (MAKEAWARE!, 2024).



2.4.3 Material agency in meaning-making

Beyond the healthcare context specifically, a key development in data physicalization concerns the role of material agency in shaping meaning. Early definitions focused on the encoding of information into physical form. From this perspective, meaning develops through both the artefact and the process that produces it, rather than existing as a predefined content to be represented.

This shift is reflected in constructive visualization, which is described as a practice in which people build representations step by step by assembling simple physical units (Huron et al., 2014). Rather than starting from a complete graphic form, participants create the representation through acts of selecting, placing, grouping, aligning, and rearranging. These actions support reflection while the representation is taking shape. Understanding grows through manipulation, and the structure of the representation emerges together with the thought process that guides it. Materials therefore shape meaning both during construction and

during interaction. They guide choices, invite certain gestures, and open specific possibilities for comparison and interpretation. This gives physicalization a process-based quality in which meaning develops through the relation between data, maker, material, and context.

This process-oriented view has also been explored in projects that combine personal data, making, and storytelling. Friske et al. (2020), for example, show how interpersonal data narratives can emerge through practices that entangle craft, sound, and material manipulation. In these cases, representation supports the emergence of understanding through action, exchange, and sensory engagement. Similarly, Freeman et al. (2023) show that gestures such as cutting, folding, arranging, or discarding can play an important role in how meaning is formed. These actions help people test relations, adjust interpretations, and reflect on what they are trying to express.

From this perspective, the artefact records more than information alone. It also carries traces of the process through which meaning is formed. The final object can therefore be understood as the temporary outcome of an ongoing dialogue between material choices, bodily action, and interpretative decisions. This is especially relevant to this thesis, which purpose is not only to represent predefined data, but to support the emergence and articulation of experiences that take shape in perception and language.

2.4.4 Advancing from situated bodies to material interpretation

This part of the theoretical foundation develops a material approach to knowledge creation by examining how materials support the expression, interpretation, and communication of experience. Cultural probes are considered for the role they play in supporting reflection and expression during data collection. Data physicalization extends this direction by showing how meaning can develop through making, handling, and interpreting physical forms. In this direction, material agency further highlights the active contribution of materials through their qualities and the actions they invite.

Together, these perspectives show the value of material engagement for healthcare contexts, where bodily experience, material expression, and multiple forms of understanding need to be considered in relation to one another. Materials can help translate experience into forms that are perceptible, discussable, and open to interpretation. To examine how these processes can include perspectives grounded in lived experience, the next section introduces participation as the context through which material engagement can be developed further.

2.5 The approach: participation and co-creation

The previous sections showed how materiality can support the expression and interpretation of experience. At this point, participation becomes important for considering how these processes can develop in shared settings and bring different forms of knowledge into relation. Within design research, participatory practices have become increasingly important for supporting inclusive knowledge production through structured forms of collaboration and co-creation.

This research adopts a participatory approach to bring together individuals with lived experience of illness and medical experts. Participation creates conditions for dialogue between scientific knowledge and everyday experience, supporting mutual learning and deeper understanding. In this way, knowledge is developed through collective engagement across different roles and perspectives.

This section examines how participatory processes can be designed to support inclusive and contextually grounded enquiry. It also considers how design-led participation can strengthen data literacy by enabling people to collect, interpret, and communicate their own data.

2.5.1 Participation in healthcare

Participation in clinical and care contexts emerges within a landscape where design and medical practice meet and respond to complex and interdependent challenges. Design helps reveal issues that remain unnoticed, supports the interpretation of experience, and facilitates communication among groups that work with different forms of knowledge. Clinical and organisational settings require careful attention to problems, practices, and relationships, making them fertile ground for design engagement. Within these settings, participatory design enables the creation of knowledge that arises from situated perspectives and brings attention to voices that are often absent from standard clinical procedures and care pathways.

Chauhan (2021) describes how design integrates experience, intent, and expertise to improve conditions and address emerging needs. This view understands participation as a shared activity among clinicians, patients, caregivers, and others whose lived experiences contribute to knowledge that is distributed, contextual, and shaped through practice. Mishra and Sandhu (2021) identify three ways in which design can support healthcare processes and clinical practice: framing problems from a user-centred perspective, creating space for learning and solution generation, and engaging communities and organisations from the earliest stages of defining issues.

Consistent with this, the Stanford d.school design process (Hasso Plattner Institute of Design, 2019) highlights the importance of understanding those involved by including them in shaping problems and questions. Co-design practices build on this principle by activating the knowledge, skills, and resources of individuals and groups to create solutions that reflect shared concerns (Alexiou et al., 2019).

Challenges in participation

Creating the conditions for meaningful participation requires careful attention to the sensitivities that shape discussions about UTIs and similar conditions. The intimate nature of the symptoms and the social taboos associated with bodily functions and sexual health often make people hesitant to share their experiences. Feelings of stigma, fear of judgment, and limited confidence in describing bodily sensations can silence important aspects of their condition, especially for those who live with recurrent infections. These constraints highlight the need for alternative ways of engaging with experience. Visual and material modes of expression, such as drawing, mapping, or working with physical objects, offer accessible and less exposing pathways for communication (Prochner, 2022). These practices redirect attention toward external artefacts that participants can shape in ways that match their comfort and abilities, creating an environment that supports trust and openness. Following these considerations, this research adopts participatory methods that emphasise confidentiality, empathetic engagement, and participant control. Physical artefacts and materials act as mediators through which personal experiences can be expressed safely, enabling them to move from private and often stigmatised realities to shared evidence that can inform both design enquiry and clinical understanding.

2.5.2 Collaboration strategies and levels

Participatory activities are most effective when they build on the assets and forms of knowledge that participants already hold. Encouraging collaboration between patients and clinicians to identify what information matters and how to interpret it can lead to more grounded and inclusive outcomes (Choe, 2014). Meaningful involvement begins when individuals can express their own experiences and needs, contributing to healthcare solutions that respond to lived realities rather than assumptions. To support this, Fiske et al. (2019) emphasise the importance of ethical frameworks that define goals and procedures clearly, ensuring that participants contribute to shaping research questions and design decisions. These frameworks recognise that all contributors deserve transparency, acknowledged relevance, and fair distribution of benefits, which in turn requires trust in institutions and in

the relationships formed during the process. Building such trust involves inviting participants to co-create the principles that will guide collaboration. Shared goals established from the outset help create a sense of ownership, particularly when personal data and narratives are involved.

Building this sense of ownership requires involving participants in co-creating the principles guiding collaborative work. Establishing shared goals and conditions at the outset fosters trust and engagement, particularly when projects involve personal data and narratives (Shadlyn, 2022). Structured methods can also help initiate dialogue among participants who may not know each other. Techniques such as vignettes with prompting questions (Shadlyn et al., 2022), peer-interview guides to support memory, context mapping, and event sequencing (Groeneveld, 2018), or short ethnographic stories to trigger collaborative reflection (Slegers et al., 2013) have proven effective. These approaches align with narrative enquiry, which organises shared stories to reveal clusters of meaning and validate findings (Groeneveld, 2018).

Further recommendations aim to strengthen participation by reducing jargon, clarifying expected outcomes, sharing results with contributors before public release, and acknowledging the limits of protocols and tools (Price et al., 2017). However, increased access to data alone does not guarantee democratisation, especially when participatory initiatives disproportionately engage highly educated groups (Fiske et al., 2019). Participation that invites people to share experiences yet limits their influence on consultation can lead to frustration and reinforce existing hierarchies. As De Moya (2020) notes, such conditions risk transforming participation into symbolic compliance rather than fostering meaningful collaboration.

Participatory Action Research (PAR)

Participatory Action Research (PAR) offers an approach that addresses these challenges by integrating research and action within a single, continuous process. Rather than separating investigation from intervention, PAR brings participants and researchers together to identify problems, experiment with approaches, and design responses collaboratively. In this framework, knowledge is produced and applied simultaneously (Tygel and Kirsch, 2016). PAR positions participants as active contributors rather than objects of study, supporting more balanced relationships between researchers and participants (Price et al., 2017).

Within PAR, researchers take on the role of facilitators who collaborate to refine methods, generate knowledge, overcome barriers, and open new possibilities. They act as co-investigators alongside participants, particularly those from oppressed or marginalised groups, supporting the examination of specific conditions and lived challenges (Louie, 2022). In this context, promoting data literacy extends beyond

developing technical methods or data structures, and instead involves designing participatory and engagement focused activities that enable experimentation and collective learning (Lury and Wakeford, 2014).

Meaningful collaboration emerges from ethically grounded practices developed together with participants, where lived experience is recognised as central to the enquiry. This orientation underpins the present research, which seeks both to generate knowledge on UTIs and to advance participatory design methodology.

2.5.3 Patient definition and role

Healthcare contexts often acknowledge individuals as experts only in relation to the diseases they experience, yet the broader skills and knowledge they hold frequently remain unrecognised. Professional competencies, lived experience, and practical problem-solving abilities can play an important role in identifying needs and informing more appropriate responses to health challenges (Gilbert, 2020). Constructivist pedagogical approaches strengthen this view by treating people as active contributors in the creation of understanding that helps improve their circumstances (D'Ignazio and Bhargava, 2018). In line with this perspective, the research refers to women with experience of UTIs or other medical conditions as people experienced with the disease. This terminology conveys the diversity of capacities they bring, rather than framing them solely as patients defined by a diagnosis. Clinical settings continue to rely on the term patient because of its convenience, although it does not capture the full extent of lived expertise that shapes how individuals interpret and manage their condition.

Attention to this broader understanding of expertise also highlights the importance of the social environments that surround individuals. Families, caregiver organisations, and advocacy groups often contribute knowledge, coordination, and emotional support that exceed what anyone person can provide. An initial ecosystem map of patients and related stakeholders in the field of antibiotic consumption and prescription was developed at the outset of the MAKEAWARE! project to identify the range of actors involved and the forms of knowledge they contribute (Cangiano, 2024). These collectives act as significant agents in healthcare, influencing biopolitical and ethical decisions through shared commitments and organised action (Beier et al., 2016). Collective agency becomes especially relevant in cases of under recognised illnesses, where joint efforts can raise awareness, shape research agendas, and provide mutual support for those affected. Recognising both personal and collective forms of expertise underpins the participatory orientation of this research, which seeks to create conditions where these contributions actively inform knowledge production and support more inclusive healthcare practices.

2.5.4 Participation within data physicalization practices

Considering the central role of data physicalization in this research, this section focuses on participation and participatory practices in the physical shaping of data and information. In this context, the emphasis on participation reflects a broader shift in recent work on data physicalization, which has moved from viewing artefacts as static outputs to understanding them as part of dynamic processes of creation and engagement. This perspective acknowledges that meaning is not contained in the final object alone but develops through the interactions, decisions, and reflections that occur during its making and use. Participation provides the setting for this process-oriented approach. When individuals actively contribute to shaping the data that represents their experiences, physicalization becomes a medium for dialogue, exploration, and collective interpretation.

This approach positions data physicalization as an active and situated practice shaped through continuous participant involvement. Engagement begins during data collection, where participants decide what is meaningful to capture and how their experiences should be represented. Collaborative creation of artefacts then supports the translation of these insights into tangible form, integrating personal perspectives and values into the material expression of data. The process continues in participatory presentation settings, where the artefacts are discussed, handled, or reconfigured. These encounters turn the physical objects into activators of conversation, enabling shared interpretation and further reflection.

By examining projects that embrace the participatory approach of this research, the following sections explore how data physicalization can support collective sense making, enabling diverse voices to contribute to the construction of knowledge.

Participatory Data Physicalization

Participatory Data Physicalization (PDP) is described in the literature as a dynamic, socially embedded process where data representation becomes a shared, physical act of meaning-making. Rather than positioning audiences as passive recipients, PDP involves them as active contributors. Participants bring their own data and interpretations, influencing both the form and content of the physicalization. This creates a recursive process in which individuals act as subjects, authors, and audience of the data they engage with (Moretti & Mattozzi, 2017).

PDP is framed not only as a method of representing information but as a means of fostering engagement, dialogue, and reflection. By turning abstract or digital information into tangible forms, PDP enables collective awareness around issues that are often difficult to communicate otherwise. The physical nature of the medium supports real-time, situated interactions, allowing local publics or co-located groups

to collaboratively construct meaning through guided and open-ended participation (Sauvé, 2023; Panagiotidou & Vande Moere, 2022).

Whether structured through defined rules or facilitated more fluently, PDP positions data as a mediator of social interaction and shared understanding. As Cazacu et al. (2025) note, PDP functions as a participatory approach where stakeholders co-create physical artefacts that embody negotiated meanings. Through this process, participants externalise perspectives, negotiate interpretations, and contribute to the creation of collective knowledge. PDP thus emerges as a participatory and interpretive practice grounded in embodiment, collaboration, and the empowerment of those whose experiences shape the data.

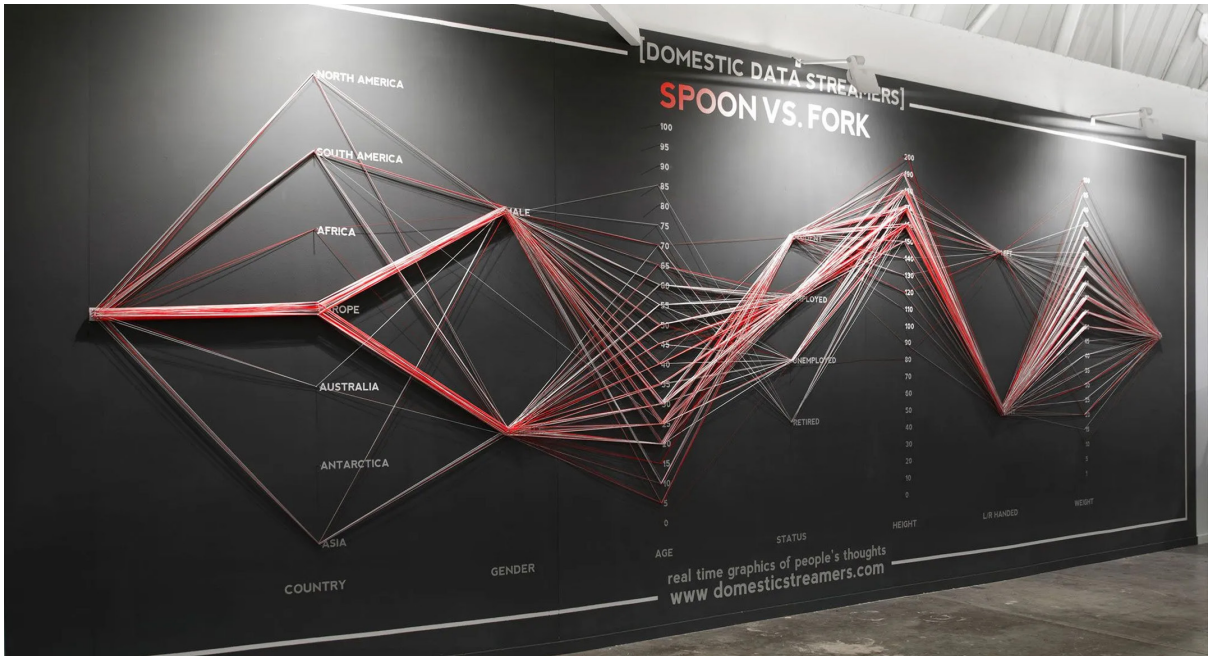
Participation in data physicalization can occur at multiple moments along the process. Early stages of data collection often introduce the first opportunities for involvement, as participants decide what should be captured and how these choices connect to their lived experience. Later phases of discussion provide another occasion for engagement, where groups collaboratively encode, interpret, and make sense of the resulting artefacts. The following sections examine these stages in detail, tracing how participation develops and becomes embedded within physicalization practices.

Participation for data collection

Participation in data collection can turn the act of gathering information into a shared, performative process. Using simple materials, participants physically record their responses through gestures such as placing a string or removing a token. In this direction, each action contributes to a collective visual narrative that is shaped by the traces of individual decisions.

Projects like Data Strings (Domestic Data Streamers, 2013), Figure 2.22, and Participatory Data Physicalization (Moretti & Mattozzi, 2020) employ strings to represent participants' positions across categories and producing tangible records of group input. Other works, including The Happy Show (Sagmeister, 2015) and Physical Bar Charts (Kimbell & Barry, 2017), in Figure 2.23, rely on the removal of gumballs or badges to create inverse bar charts that accumulate meaning over time. Contributions may occur simultaneously or sequentially, with participants adding to a shared outcome at different moments. These projects prioritise engagement and collective expression, using open ended gestures that foreground self-expression and social interaction rather than detailed analytical interpretation.

When participation shifts towards systems in which materials carry predefined meanings, the nature of engagement also changes. Participants no longer simply add to a shared display, but work within an established representational vocabulary.



[Top]

Figure 2.22: Spoon vs. Fork from Data Strings (Domestic Data Streamers, 2013) visualises personal information by turning participants' answers into hanging physical threads.

[Bottom]

Figure 2.23: Physical Bar Charts (Kimbell and Barry, 2017) rely on removing gumballs or badges to create inverse bar charts that accumulate meaning over time.



This shift is illustrated in Figure 2.24 and Figure 2.25. In Data Badges (Panagiotidou et al., 2020), participants select tokens representing academic interests and assemble them into personalised patches that support interaction and mutual recognition. In Edo (Sauvé et al., 2023), predefined tokens are used to track the carbon emissions of food choices within a cafeteria setting, linking data to everyday practices. Similarly, Cairn (Gourlet and Dassé, 2017) engages FabLab users in constructing totems from assigned tokens, merging individual contributions into a collective structure that supports reflection and discussion.

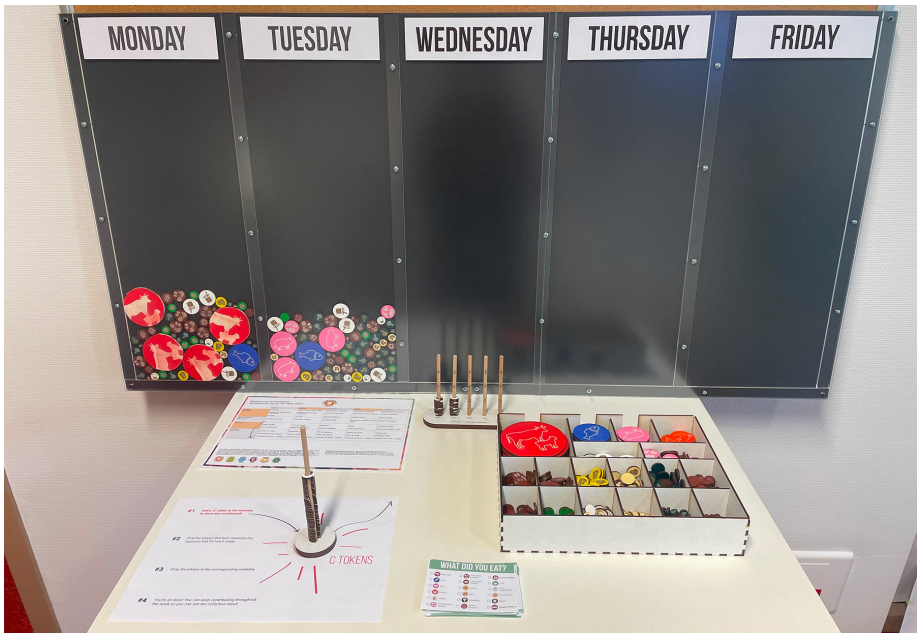


[Top]

Figure 2.24: tokens offered to conference participants for assembling their Data Badges, each element representing an aspect of their academic interests (Panagiotidou et al., 2020).

[Below]

Figure 2.25: the Edo table prepared with tokens used to track the carbon emissions of different food choices Sauvé et al., 2023).



Participation for representation

This mode of interaction, described as “participatory data translation” by Nissen and Bowers (2015), demonstrates how physical artefacts become focal points for shared reflection and dialogue. Contemporary perspectives on data physicalization recognise that meaning does not reside solely in finished objects but arises through the interactions, gestures, and conversations that accompany their use. Encoding therefore shifts from a technical act defined by designers to a collaborative and embodied activity in which meaning is co-constructed through material engagement and social participation. As shown in Figure 2.26, where participants wear 3D printed clips representing their Twitter data, these artefacts function as prompts for engagement, making personal data visible and discussable within a shared setting. The variety of clips displayed by attendees illustrates how physical forms can surface individual differences while simultaneously supporting collective interpretation.



Figure 2.26: 3D-printed clips representing participants' Twitter data (now X), produced by the authors and worn by some of the attendees during the conference (Nissen and Bowers, 2015).

Participation for interpretation

Participation for interpretation builds on approaches that balance predefined structure with opportunities for participant to set the rules. Co-Gnito (Panagiotidou et al., 2022) exemplifies this model by guiding participants through game-like activities to co-create an urban mental map. Figure 2.27 shows participants collaborating by placing physical tokens, where some encodings remain stable while others can be personalised. This flexibility allows individuals to articulate symbolic choices and to contribute as co-designers of meaning rather than simply as data providers. Interpretation can also emerge through the use of open-ended materials that prompt reflection and reconfiguration.

In Mental Landscapes (Lockton et al., 2020), modular laser-cut cards representing features such as hills or bridges encourage participants to “think with things.” (Figure 2.28). Through annotating, rearranging, and combining these elements, participants externalise internal states, express relationships, and explore personal and shared experiences. The adaptability of the materials turns them into mediators of knowledge construction, supporting tactile engagement and creating common ground for negotiation and imagination. The resulting configurations remain temporary, with meaning developing through continuous material and social interaction.



[Top]

Figure 2.27: participants collaborate by placing physical tokens that together form a shared urban mapping story (Panagiotidou et al., 2022).

[Below]

Figure 2.28: Mental Landscapes created by participants using a set of provided materials, from Lockton et al. (2020).



Healthcare contexts offer further examples of participatory interpretation grounded in slow, reflective engagement. Freeman et al. (2023) frames data physicalization as a means for slow, embodied engagement. Using duoethnography, a dialogical research method in which two or more researchers critically juxtapose their perspectives through structured dialogue, they pair reflective conversation with the creation of physical data artefacts. This combination emphasises mutual self-examination and situates data as a driver for dialogue rather than a static endpoint. Their co-design work with older adults exemplifies this approach, supporting calm, reflective interactions that contrast with the speed and abstraction of typical healthcare data processes. Acting as design probes (Mattelmäki, 2005) and boundary objects (Star and Griesemer, 1989), these physicalizations reveal tensions between clinical efficiency and the nuanced, personal meanings embedded in health data, underscoring the potential of participatory interpretation to create more inclusive, contextually rich understandings.

Taken together, these examples show that participatory data physicalization can involve people at different moments of the data process. Participation may begin with the selection or production of data, continue through the material shaping of information, and extend into the discussion and interpretation of the resulting artefacts. In this way, data physicalization becomes a participatory process through which people can externalise experience, negotiate meaning, and contribute to the formation of shared understanding.

2.6 Towards structured openness in symptom collection

The literature reviewed established the need for approaches that can account for symptoms as embodied, situated, and interpretative forms of knowledge. In the case of UTIs, symptom communication is central to diagnosis and treatment, particularly when laboratory confirmation is delayed or unavailable. Symptoms such as burning, urgency, pressure, pain, and discomfort are clinically relevant, yet they are also shaped by bodily perception, personal history, language, and context. Their articulation therefore depends on how people recognise, describe, and communicate what they experience.

Feminist perspectives on healthcare further show why this articulation matters. Women's embodied accounts have often been undervalued within clinical practice, especially when symptoms are intimate, recurrent, ambiguous, or difficult to verify through immediate testing. In this context, symptom collection is not only a matter of gathering information, but also a question of how lived experience becomes

recognised as knowledge. Haraway's account of situated knowledge supports this position by showing that knowledge is always produced from specific embodied and contextual standpoints, rather than from a detached or neutral view.

The theoretical framing of symptoms as bodily signs and material traces reinforces this need. Biosemiotics positions symptoms as signs that gain meaning through processes of interpretation, while autographic design shows how traces can become perceptible through material forms and conditions of attention. These perspectives suggest that symptom cannot be understood only as information extracted from the body. It also involves processes of perception, articulation, and interpretation through which bodily changes become meaningful to the person experiencing them and to others involved in care.

The review of self-tracking and patient-generated data shows both the value and the limits of existing approaches to personal health data. These practices can support awareness, encourage observation over time, and help people identify patterns in their bodies and behaviours. However, the literature also highlights that self-tracking often relies on predefined metrics, individual records, and digital forms of capture that may struggle to account for ambiguity, context, emotion, and tacit bodily knowledge. Patient-generated data can therefore support health communication, but it requires interpretation and contextualisation to become meaningful within shared or clinical settings.

Participatory design and participatory data physicalization offer a way to respond to these limitations by involving people directly in the production and interpretation of their own data. In these approaches, participants are not only sources of information, but contributors to how experience is explored, shaped, and discussed. Participatory data physicalization is particularly relevant because it extends data work into material engagement, where information can be handled, arranged, externalised, and discussed through tangible forms. This supports a process-oriented understanding of data, where meaning emerges through interaction between people, materials, and context.

Across these bodies of literature, a shared methodological tension emerges. On one side, symptom collection needs openness because embodied experience is situated, interpretative, and often difficult to fully anticipate through predefined descriptors. On the other side, symptom communication also requires structure, because accounts need to become communicable, comparable, and available for interpretation with others. The challenge is therefore to support experiential articulation without reducing it to fixed categories, while also avoiding forms of openness that remain too individualised to support shared understanding.

This tension calls for a structured method capable of collecting open-ended and interpretative symptom data. Such an approach should draw on participatory and

material practices to support situated forms of expression, while also providing a structure through which these expressions can be discussed and interpreted. To further contextualise this need in relation to healthcare practice, the next section introduces the initial expert interviews. These interviews examined how experts working across AMR, UTIs, clinical practice, data, and design understood patient-generated experiential data, symptom communication, and the role of structure within this process.

2.7 Initial expert interviews to inform methodological development

To move from the literature review towards the methodological design of the study, I conducted an initial set of semi-structured interviews with experts working across UTIs, AMR, clinical pharmacy, infectious diseases, medical anthropology, machine learning (ML), and women's health design. These interviews took place in Autumn 2023, in parallel with the literature review, and formed a contextual and exploratory phase of the research. Their purpose was to deepen understanding of the broader UTI and AMR context and to identify possible areas where design could contribute to symptom communication and patient participation.

Participants were recruited through the early network of the SPEARHEAD project and through snowball sampling. At this stage, recruitment prioritised diversity of expertise rather than representativeness, bringing together perspectives on antibiotic use, patient-generated data, clinical decision-making, healthcare communication, and intimate-care experiences. The interviews were conducted under ethics approval granted by Brunel University, with the approval letter included in the Appendix.

The initial expert group included seven participants with complementary perspectives on patient-generated data and women's health. They included a medical doctor and MD-PhD researcher in microbiology [IME1], an infectious-disease physician with experience in inpatient and outpatient UTI care [IME2], a clinical pharmacist working in a university hospital [IME3], a medical anthropologist working with Digital Narrative Medicine [IME4], an ML researcher developing AMR-related clinical decision-support tools [IME5], a medical doctor and professor with expertise in infectious diseases, microbiology, internal medicine, communication, and public health [IME6], and an interaction designer and educator specialising in women's health, wearable technology, biotechnology, and intimate-care taboos [IME7]. Together, these profiles framed the research problem from clinical, pharmaceutical, technological, anthropological, and design perspectives.

In the Appendix, these participants are identified as Initial Medical Experts [IME] to distinguish them from the medical experts [ME] later involved in discussing the workshop findings. The interviews are not treated as a primary findings section, but as an analytical bridge between the theoretical concerns identified through the literature and the methodology developed in Chapter 3. They contextualised the literature on UTI care, AMR, healthcare data, symptom description, and participatory communication, while supporting the transition from a broad literature-based need for open-ended but organised symptom collection towards the development of a participatory and material method.

2.7.1 Analytical insights from the interviews

The interviews were analysed thematically as an exploratory step in the early development of the research. The analysis identified recurring concerns, tensions, and opportunities emerging from the experts' accounts, which helped contextualise and extend the insights identified in the literature. For this reason, the findings are organised around four analytical insights that clarify the research problem and shape the subsequent design of the methodology.

The first insight concerns the role and limits of data related to UTI care, particularly the distinction between biomedical, epidemiological, clinical, and experiential forms of data. The second focuses on symptom description as a clinically meaningful form of communication that can influence diagnosis and prescription decisions. The third examines the value of patients' experiential knowledge, especially in recurrent UTIs, while also recognising the need to support interpretation and avoid premature self-diagnosis. The fourth considers patient participation and patient-generated data as opportunities for awareness and communication, while also addressing concerns around reliability, privacy, misinformation, and clinical usability.

Together, these insights helped contextualise the research problem and clarify the methodological requirements of the study. They highlighted the value of patient-generated experiential data while also pointing to the need for an organised process through which symptom accounts could be interpreted, communicated, and discussed within healthcare-oriented enquiry.

Data is necessary but partial

The first analytical insight concerns the role and limits of data in UTI care and eventual AMR cases. Experts repeatedly described data as essential for understanding AMR, monitoring antibiotic use, supporting clinical decisions, and

developing future interventions. At the same time, they indicated that available data captures only part of the problem. Existing systems tend to privilege biomedical, laboratory, epidemiological, prescription, and hospital-based information, while patient behaviour, awareness, experience, and symptom interpretation remain harder to collect and integrate.

IME1 made this distinction explicit by separating “scientific” data, such as “percentages, incidence, prevalence”, from forms of data that are “much more difficult to obtain and much more personal”, including “personal experience”, “awareness”, and health literacy (IME1). For this expert, both forms of data were necessary to understand antibiotic use, yet experiential and population-level forms of data were harder to access. As they stated, “we need both of them”, because the behaviour of patients is “very important” for understanding whether antibiotic treatment is taken appropriately (IME1). This distinction shows that the problem is not only the absence of data, but also the uneven status of different kinds of data within healthcare.

Other experts pointed to the limits of institutional data. IME6 explained that resistance data is important for doctors because it informs which antibiotics can be used as first-line treatment. However, they also noted that “the problem we have with the data today is that we mainly have the data from laboratories”, particularly laboratories based in university hospitals. For this reason, available data can carry “a bias towards patients that are at the hospital” and may “not really reflect the ecology that is present in the Community” (IME6). This observation was particularly relevant to UTIs, where many cases are managed outside hospitals and where everyday practices, self-management, delayed consultation, or informal antibiotic use may remain outside formal datasets.

IME3 added a further limitation by stressing the lack of real-time data. From a clinical pharmacy perspective, information on antibiotic consumption is described as mainly retrospective: “I am gathering data on antibiotic consumption, but it’s always not real time, it’s always retrospective” (IME3). This expert argued that real-time information would make it possible “to intervene in time”, for example through alerts generated when a physician prescribes an antibiotic, allowing pharmacists to check whether the indication and dosage are appropriate (IME3). This perspective positioned data not only as a resource for later analysis, but as something that could actively support decision-making if available at the moment of care.

The interviews also demonstrate that healthcare data is shaped by processes of standardisation and translation. IME5 described working mainly with data from electronic health records, laboratory exams, or genetic data, which are “selected or produced by professionals” (IME5). They also explained that free text in healthcare is often analysed through automatic methods to “extract some quantitative

variables" for use in MLmodels (IME5). While this supports computational analysis and comparability, it also demonstrates how qualitative or narrative material often becomes usable only when converted into more standardised formats. This reinforced a central concern of the thesis, as patient experience can enter healthcare systems, but often only after being transformed to fit existing analytical infrastructures.

Taken together, this theme clarified that data is central to UTI care and AMR, but unevenly distributed and differently valued. Biomedical and clinical data remain necessary, yet they capture only part of how people experience symptoms, interpret bodily changes, seek care, consume antibiotics, or follow prescriptions. This supported the need for a method able to generate data that remains close to embodied experience while becoming communicable and interpretable.

Symptom description shapes prescription decisions

The second analytical insight concerns the clinical role of symptom description in UTI-related care. Experts described symptoms as central to diagnosis and prescription, especially in outpatient contexts where laboratory confirmation is not immediately available. This reinforced the relevance of symptom communication as a site of design intervention, as the way symptoms are described can influence how clinicians interpret the condition and decide whether antibiotics are appropriate.

IME2 described this relation directly, explaining that "the symptom, the history that the patient gives" should guide clinical decision-making and "the decision to write a prescription" (IME2). This was particularly important in UTI care because clinicians "don't have culture results at the time" of the consultation, as these results usually take approximately two days. As a consequence, clinicians often prescribe "based on what they [patients] are telling you" (IME2). This account positioned patient descriptions as part of the evidence through which treatment decisions are made.

IME6 similarly described symptom description as influential in prescription decisions. They explained that descriptions such as "I have a lot of pain", "it's frequent", "I have a dysuria", or "I cannot sleep with this urinary tract infection" can "help the doctor decide to prescribe" (IME6). These examples show that symptom communication involves more than naming a condition. Intensity, frequency, disruption, and everyday impact all contribute to how the condition is interpreted in the clinical encounter.

The interviews also indicated that symptom description has different weight depending on the care setting. IME3 distinguished between hospital and outpatient contexts, explaining that inside hospitals prescription is less dependent on patient descriptions because laboratory tests are more readily available. Outside hospitals,

however, prescription is “a lot influenced by the symptoms that the patient tells you” (IME3). In this direction, a patient reporting mild pain while urinating produces a different clinical situation from one who also reports fever or blood in the urine. This distinction clarify that the relevance of patient-reported symptoms becomes particularly strong in primary care and community settings, where many UTI cases are first addressed.

At the same time, experts emphasised that symptom descriptions need careful interpretation. IME6 warned that patients may sometimes move quickly from bodily sensation to self-diagnosis, particularly when they have prior experience or medical knowledge. As they put it, patients “make their own diagnosis” and “don’t say what they feel”, but “what they think they have” (IME6). For this reason, the clinician often needs to step back from the diagnostic label and return to the symptoms themselves by asking questions such as whether the person has pain when urinating, urinary frequency, back pain, or fever (IME6). This observation highlighted the need to support the articulation of sensation before it becomes fixed as diagnosis.

Symptom communication emerges as both clinically consequential and interpretatively complex. Patient accounts guide prescription decisions, particularly when test results are delayed or unavailable, but they also require structures that distinguish bodily sensation, perceived severity, previous experience, and diagnostic interpretation.

Patients hold experiential knowledge, but interpretation requires support

The third analytical insight concerns the value and complexity of patients’ experiential knowledge. Experts recognised that people who experience recurrent UTIs often develop awareness of their symptoms over time. Repetition allows patients to recognise patterns, anticipate the development of an episode, and distinguish familiar bodily sensations. At the same time, this knowledge requires support, as patients may move quickly from describing what they feel to interpreting what they think they have.

IME2 strongly emphasised the value of patients’ knowledge in recurrent UTI cases. Speaking about people with recurrent UTIs, they stated that “they really know their own symptoms” and “they know exactly” what is happening (IME2). The expert connected this knowledge to the recognition of classic symptoms, including “burning with urination”, urinary frequency, urgency, and “suprapubic tenderness or pressure” (IME2). From this perspective, repeated experience provides a form of embodied expertise that clinicians can meaningfully consider.

IME6 made a similar point, explaining that “most of the patients are well aware if it’s

a female with a recurrent infection", because "this type of patients, they know well and they recognise well" (IME6). This recognition was also connected to self-management, as the expert suggested that some recurrent patients "can self-treat themselves" when symptoms remain within the pattern of an uncomplicated lower UTI (IME6). This account supported the idea that embodied experience can generate practical knowledge, especially when people have repeatedly encountered the same condition.

However, the interviews also showed that experiential knowledge can become clinically ambiguous when patients interpret sensations too quickly as diagnosis. IME6 described this as a difficulty that can emerge especially with patients who have medical knowledge or prior experience. For this reason, the expert argued that clinicians need to "go back to signs and symptoms and not to diagnostic level", asking patients to describe pain, urinary frequency, back pain, fever, or other concrete symptoms before accepting the diagnostic interpretation (IME6).

This theme clarified a central methodological tension in which patients' embodied knowledge is valuable, especially in recurrent conditions, while also benefiting from forms of articulation that keep sensations open to interpretation before they become fixed as diagnoses. The methodology therefore needed to support attention to the qualities, intensities, temporalities, and contexts of symptoms.

Participation supports awareness but needs structure

The fourth and last analytical insight concerns the opportunities and risks of patient participation and patient-generated data. Experts suggested that involving people more actively in the collection, interpretation, and sharing of health-related information can support awareness, communication, and more responsible antibiotic use. At the same time, they emphasised that participation requires structure. Data produced by patients becomes useful when it is meaningful, understandable, and clinically manageable, while it can also create problems when it is inaccurate, excessive, poorly interpreted, or shaped by misinformation.

IME2 described patient awareness as central to shared decision-making. They argued that when patients are informed about AMR, they become "less demanding of antibiotic therapy" and can become "partners in the decision making" (IME2). This account positioned data not only as clinical information, but also as a resource for patient empowerment. For this expert, access to information about AMR, repeated antibiotic use, microbiota, and the possibility that some lower UTIs may resolve without antibiotics could help patients feel more comfortable with management strategies that do not rely immediately on prescription. A similar point emerged from IME3, who connected data collection with patient empowerment. They stated that collecting and analysing data could make patients "aware of their symptoms" and

help them feel that they have “a certain responsibility also for their health and their bodies” (IME3). This perspective framed participation as a way to support informed engagement rather than as a transfer of medical responsibility from clinicians to patients. Patients remain supported by clinicians, while also becoming more able to notice, describe, and discuss what happens in their bodies.

Several experts identified information that patients could usefully collect. IME1 suggested recording “every time they consume an antibiotic”, including “how much per day”, whether they followed the prescription, why they did not follow it, and “how they obtained this antibiotic” (IME1). IME6 similarly suggested that patients could report previous UTIs, the number of episodes in the last year, the last antibiotic taken, and what they think about antibiotics (IME6). These examples show that patient-generated data could include measurable aspects, such as frequency, fever, medication, and recurrence, as well as interpretative aspects, such as attitudes, reasons for behaviour, and perceived barriers to adherence.

However, experts also raised concerns about reliability and interpretation. IME1 questioned whether patients would be “completely honest” about antibiotic use, especially when they had not followed prescriptions or had obtained antibiotics informally. IME3 warned that if people collect data without understanding how to do so, they may produce “wrong data” that can “mislead the physician” or interpret results in ways that pressure clinicians towards unnecessary antibiotic prescriptions. These concerns showed that the issue is not only whether patients can generate data, but how that data is framed, collected, interpreted, and brought into conversation with clinical knowledge.

The risks of participation also extended to sharing and community contexts. Experts recognised that sharing experiences can support mutual learning, reassurance, and solidarity, especially around conditions that are recurrent, intimate, or difficult to discuss. IME3 suggested that sharing data with others may help people receive words that reinforce their behaviour (IME3). At the same time, several experts warned that communities can also circulate harmful or inaccurate information. IME2 described online recurrent UTI forums where testimonials could be selectively used to promote long-term antibiotic use, while IME6 argued that patient groups require moderators because “wrong information can be dangerous” (IME6). Participation therefore needs forms of facilitation, governance, and critical interpretation.

IME4’s account of Digital Narrative Medicine offered a relevant example of a structured participatory format. In this approach, patients write diary entries in response to narrative “stimuli”, and healthcare providers read these narratives before the consultation. The diary creates a protected space in which patients can discuss topics they might avoid during the visit because of embarrassment or lack of time

(IME4). This example shows that personal narratives can enrich clinical encounters when they are organised through a clear process. It also highlighted a limitation relevant to this research as narrative medicine remains mainly verbal and qualitative, while the present study explores how embodied experience can also be articulated through material and physical forms.

2.7.2 Methodological implications of the initial interviews

The initial expert interviews helped clarify the methodological direction emerging from the literature. Across the interviews, patient experience was recognised as a relevant source of knowledge, particularly in relation to recurrent, ambiguous, and difficult-to-verify symptoms. At the same time, the experts pointed to the importance of making these accounts interpretable and communicable within healthcare-oriented discussions. Experiential data therefore emerged as valuable, but also as contents that requires careful organisation if they are supposed to support reflection, comparison, and shared understanding.

This reinforced the need for a method that can keep symptom expression open, situated, and participant-led, while also providing a structure through which personal accounts can be discussed and interpreted with others. The following section addresses this need by identifying the physical variables within data physicalization practices as material and spatial qualities that can offer a structure for collecting and interpreting embodied symptom experience.

2.8 Physical variables as a structure for embodied symptom collection

Building on this need, and the previous review of the literature, this section identifies physical variables as a contribution emerging from the existing panorama of data physicalization. While physical variables are already recognised in the field as material and spatial properties used to encode data, this thesis extends their role by considering how they can structure the collection and interpretation of embodied symptom experience. This move responds to the need, established through the literature and contextualised through the initial expert interviews, for a method that can support open-ended symptom expression while also providing shared points for discussion.

Their relevance to this thesis lies in their capacity to connect material qualities with interpretation. Symptoms such as burning, pressure, heaviness, urgency, or discomfort are often difficult to express through words or numbers alone. Physical

variables offer qualities that can be touched, arranged, compared, and discussed. They therefore provide possible shared reference points through which embodied sensations can be explored without immediately reducing them to fixed clinical categories or numerical scales.

This role is supported by research in data physicalization that recognises material agency in meaning-making. Physical artefacts can support reasoning through the assembly and manipulation of units (Huron et al., 2014), encourage reflection and storytelling around personal data (Thudt et al., 2018), and act as prompts through which people think, negotiate, and interpret experience (Lockton et al., 2020). Meaning is shaped not only by intentional encodings, but also by implicit material properties and by the interactions that emerge through use (Hornecker et al., 2023). Material properties therefore participate in how data becomes perceptible, interpretable, and communicable.

However, the structuring role of these properties often remains implicit. Physicalization practices frequently rely on qualities such as shape, texture, weight, flexibility, temperature, position, or movement to support interpretation, yet these qualities are not always described as methodological components in their own right. Their contribution usually remains distributed across the artefact, the making process, and the interaction with participants, making it difficult to identify how specific material properties support particular forms of meaning-making.

In this direction, the thesis extends the role of physical variables beyond representation, positioning them as structuring elements for embodied symptom collection. They are not treated as fixed encodings of symptoms. Rather, they are approached as flexible resources that can guide participants in noticing, selecting, associating, and discussing material qualities in relation to bodily experience. In this sense, physical variables provide a bridge between open symptom articulation and shared interpretation.

The following sections examine how physical variables are currently understood within data physicalization literature. They first review existing classifications and vocabularies, then discuss the multisensory relation between encoding and decoding, and finally consider the need for a flexible vocabulary that can support interpretation while preserving openness. This discussion prepares the methodological development in Chapter 3, where physical variables are operationalised within the Shape Your Symptoms workshop as components for collecting, structuring, and interpreting embodied symptom experience.

2.8.1 Existing classifications of physical variables

The literature approaches physical variables through different forms of classification,

each highlighting how material properties contribute to representation and interpretation. This diversity confirms their importance within data physicalization practices, while also showing that their role is distributed across multiple frameworks. Physical variables can be understood in relation to how they behave through interaction, as they may remain stable or change over time depending on whether the representation is fixed or responsive. This distinction shows how meaning can be shaped through permanence, variation, and transformation (Dragicevic et al., 2021).

Physical variables are also discussed in relation to sensory composition. Some operate through a single sensory feature, while others combine several qualities, such as texture, shape, arrangement, or spatial relation. This perspective is important because physical meaning can emerge from one property or from the relation among several properties working together (MacEachren, 1995). Their role is therefore not limited to encoding, but extends to how material qualities are perceived, compared, remembered, and experienced. In this sense, physical variables contribute both through sensory clarity and through the design choices that organise them (Stusak et al., 2016; Dumičić et al., 2022).

This broader understanding also raises the question of how directly physical variables are tied to data. Some variables directly encode information, some shape perception without encoding values directly, and others emerge through the making process itself. This perspective is particularly relevant for this thesis because it shows that data physicalization depends not only on formal encoding, but also on the wider material and sensory conditions through which artefacts are created and interpreted (Hornecker et al., 2023). A further perspective understands physical variables as shared interpretative resources across contexts. From this view, they can operate across disciplinary settings while supporting different interpretations and uses. This highlights their flexibility and their capacity to support expressive and accessible forms of representation across fields such as Information Visualization, Cartography, HCI, Sonification, Immersive Analytics, and Neuroscience (Ranasinghe and Degbelo, 2023).

Together, these classifications show that physical variables already play an important role in data physicalization, while their contribution remains described through several partial frameworks. These frameworks are valuable for mapping the field, but they provide more limited insight into how material properties shape meaning within a specific experiential context. This research builds on them by examining physical variables through the case of UTIs, where embodied experience, material engagement, and interpretation are brought together within a defined condition. In this way, the thesis moves from broad classification towards a situated understanding of how material properties can support symptom communication and participatory knowledge generation.

2.8.2 Encoding and decoding multisensoriality

The classifications discussed above show that physical variables cannot be understood through representation alone. Unlike visual variables, physical variables are encountered through overlapping sensory qualities that are difficult to separate. Their meaning depends on what is intentionally encoded, but also on how material properties are touched, handled, moved, heard, and interpreted in context.

Data physicalization translates information through the material properties of objects, using qualities such as texture, weight, temperature, movement, deformation, or spatial arrangement as meaningful variations. These properties draw on the affordances of materials and shape how data is created, encountered, and interpreted (Ranasinghe and Degbelo, 2023; Gwilt and Davis, in Gwilt, 2022).

Engagement with physical variables therefore involves visual, tactile, auditory, and kinaesthetic perception. Meaning develops through embodied interaction, where different sensory dimensions reinforce, modify, or complicate one another. For example, a textured surface may be perceived visually, felt through touch, and heard through the sound it produces when handled. In this sense, physicalizations can support intermodal perception, where sound, touch, movement, and visual form operate together within the same material encounter (Barrass, 2014).

This multisensory condition makes encoding and decoding closely connected. Encoding refers to the deliberate use of material variations to organise information. Decoding refers to how people perceive, interpret, and make sense of those variations through their own bodies, memories, and contexts. In physicalization, these processes overlap because physical variables are not only seen, but also encountered through handling, pressure, movement, posture, and spatial orientation.

Physical variables operate as multisensory qualities rather than isolated visual or haptic cues. Texture may be experienced with resistance, weight with size, sound with touch, and form with movement. Meaning therefore emerges through combined material perception, where different sensory qualities interact and reveal relations that may remain unnoticed when each property is considered separately.

This is relevant to symptom communication because bodily sensations are also experienced through overlapping qualities. Pain, burning, pressure, urgency, heaviness, or discomfort combine intensity, location, duration, rhythm, and affect. Physical variables therefore offer a way to explore symptoms beyond singular descriptors, supporting the discovery of additional qualities, associations, and relations within embodied experience while keeping interpretation open to participants' own meanings.

2.8.3 Do we need a vocabulary?

Efforts to define physical variables show the difficulty of creating direct correspondences between material properties and meanings. A texture, shape, weight, or movement does not carry a stable meaning in itself, because its interpretation depends on cultural background, personal experience, prior knowledge, and the situation in which a physical artefact is produced and encountered. Physical variables therefore need to be understood in relation to the social, cultural, and embodied contexts in which they are used.

In this direction, a shared vocabulary could help researchers and practitioners describe encoding mechanisms, analyse physicalizations systematically, compare projects across contexts, and communicate across disciplines (Hornecker et al., 2023). It can also be used to support theory-building and pedagogy by making distinctions between physical qualities easier to discuss and adopt. However, when vocabulary becomes too standardised, it can turn material qualities into stable codes, reducing the openness that enables experimentation, creative exploration, and situated interpretation (Offenhuber, 2023). The value of a vocabulary therefore lies in supporting clarity while leaving room for contextual meaning-making.
At this point in the research, this tension suggests the potential of positioning physical variables as a flexible structure rather than as a fixed language. Physical variables are considered for providing enough organisation to support reflection, comparison, and discussion, while remaining open to personal association and situated meaning. In relation to symptom collection, this means that material properties are not assumed to correspond universally to bodily sensations. Rather, they are considered as a way to provide a possible vocabulary through which participants can explore, articulate, and compare embodied experiences while preserving their own interpretations. The aim is therefore not to define fixed correspondences between material properties and symptoms, but to investigate whether and how physical variables can support the articulation of embodied experience within a specific health context.

2.9 From literature and interviews to methodology

This chapter has established the conceptual and methodological foundations for the study. The literature positioned UTIs as a clinical and gendered health concern in which symptom communication plays a central role. Feminist perspectives highlighted the need to recognise women's embodied accounts as situated forms of

knowledge, while biosemiotics and autographic design supported an understanding of symptoms as bodily signs that require interpretation. Within this framing, symptoms are not treated as fixed data points, but as embodied experiences that gain meaning through perception, context, and communication.

The review of patient-generated data, self-tracking, participatory design, and data physicalization further clarified the need for methods that can support people in articulating their own experiences. These approaches show the value of involving patients in the production and interpretation of health-related data, while also revealing the limits of predefined metrics, individual records, and detached forms of data collection. Symptom collection therefore requires openness, because embodied experience cannot be fully anticipated through fixed categories, and structure, because these accounts need to become communicable, comparable, and interpretable with others.

The initial expert interviews helped contextualise this need in relation to healthcare practice. They reinforced the value of patient experience, especially in recurrent and ambiguous conditions, and highlighted the importance of symptom description in UTI care. At the same time, they show that experiential accounts need forms of organisation that support interpretation and communication within healthcare-oriented discussions. This move the research towards the development of a method that can preserve the situated character of symptom experience while making it available for shared reflection.

Physical variables have been identified as a bridge between this theoretical background and the methodological development of the study. Existing data physicalization literature provides a vocabulary of material and spatial qualities through which information can become tangible, perceptible, and discussable. Within this thesis, this vocabulary is repositioned as a flexible structure for embodied symptom collection rather than as a fixed language of representation. Physical variables therefore support the movement from open-ended symptom expression towards shared interpretation, without prescribing stable correspondences between material properties and bodily experience.

Chapter 3 builds on this direction by explaining how physical variables are operationalised within the Shape Your Symptoms workshop. It describes how they are translated into workshop components, used in relation to Data-Probes, and integrated into a participatory process for collecting, structuring, and interpreting embodied symptom experience.

3. METHODOLOGY. PHYSICAL VARIABLES AND DATA-PROBES IN THE 'SHAPE YOUR SYMPTOMS WORKSHOP'

This chapter develops the methodological approach of the research by building on the literature review and the initial interviews presented in Chapter 2. The previous chapter showed how women's experiences of UTIs are shaped by broader conditions related to gender, diagnosis, and the production of healthcare knowledge. For this reason, it established the need for approaches that recognise symptoms as embodied and situated experiences, whose meaning develops through perception, context, and interpretation. This perspective creates the basis for methods that can work more closely with lived experience and support its articulation in forms that remain meaningful within healthcare contexts. Within this direction, materiality emerges as central to the expression, exploration, and interpretation of experience. Cultural probes and data physicalization show how materials can support both the collection and representation of personal accounts.

Together, these theoretical strands construct a research approach in which materiality, participation, and situated interpretation operate as interdependent components. These foundations translate into a set of methodological commitments that guide the definition of the method developed in this chapter, which are:

* revaluing subjectivity as data. This approach foregrounds the subjective, contextual, and personal dimensions of illness as meaningful sources of knowledge. These dimensions are essential for understanding UTIs, particularly because symptoms vary across people, situations, and episodes. In this research, subjectivity is treated as an epistemically meaningful source of insight that can enrich how symptoms are understood, communicated, and interpreted.

* using material engagement as a method of interpretation. Because symptoms are embodied and often difficult to verbalise, this approach prioritises methods that enable participants to interpret and express sensations through material interaction. Material engagement offers a way

to articulate experiences in forms that preserve nuance while still enabling comparison and shared understanding.

* embedding participation as a process of co-creating knowledge. Participation is framed as the mechanism through which experiential knowledge, clinical perspectives, and material exploration converge. It enables mutual learning and supports the dialogue and negotiation through which new forms of health knowledge can emerge, forms that neither patients nor clinicians could produce alone.

Physical variables have already been introduced in Chapter 2 as a flexible structure for embodied symptom collection. In this chapter, they become methodological components through which the commitments outlined above are translated into practice. The focus therefore moves to how physical variables are selected, adapted, and enacted within the research activity.

Within this methodological orientation, physical variables guide how material qualities such as shape, texture, weight, size, movement, flexibility, or resistance are made available for participants to explore, associate, compare, and discuss in relation to symptoms. They connect bodily sensation with material expression and provide a shared structure through which participants can articulate and interpret embodied experience.

This structure is enacted through Data-Probes, which provide the material components for working with physical variables during the workshop. The Shape Your Symptoms workshop brings these elements together as a participatory activity designed to support self-awareness and data literacy among women affected by UTIs, broaden the expressive resources available for describing the condition, and enable more informed participation in diagnosis and treatment discussions, including those related to antibiotic use.

On this basis, the chapter explains how physical variables are specified within this research, how Data-Probes are developed as material components for enacting them, and how these elements are organised within the Shape Your Symptoms workshop. In this way, the chapter translates the conceptual direction established in Chapter 2 into a concrete method for working with embodied symptoms through material engagement, interpretation, and participation.

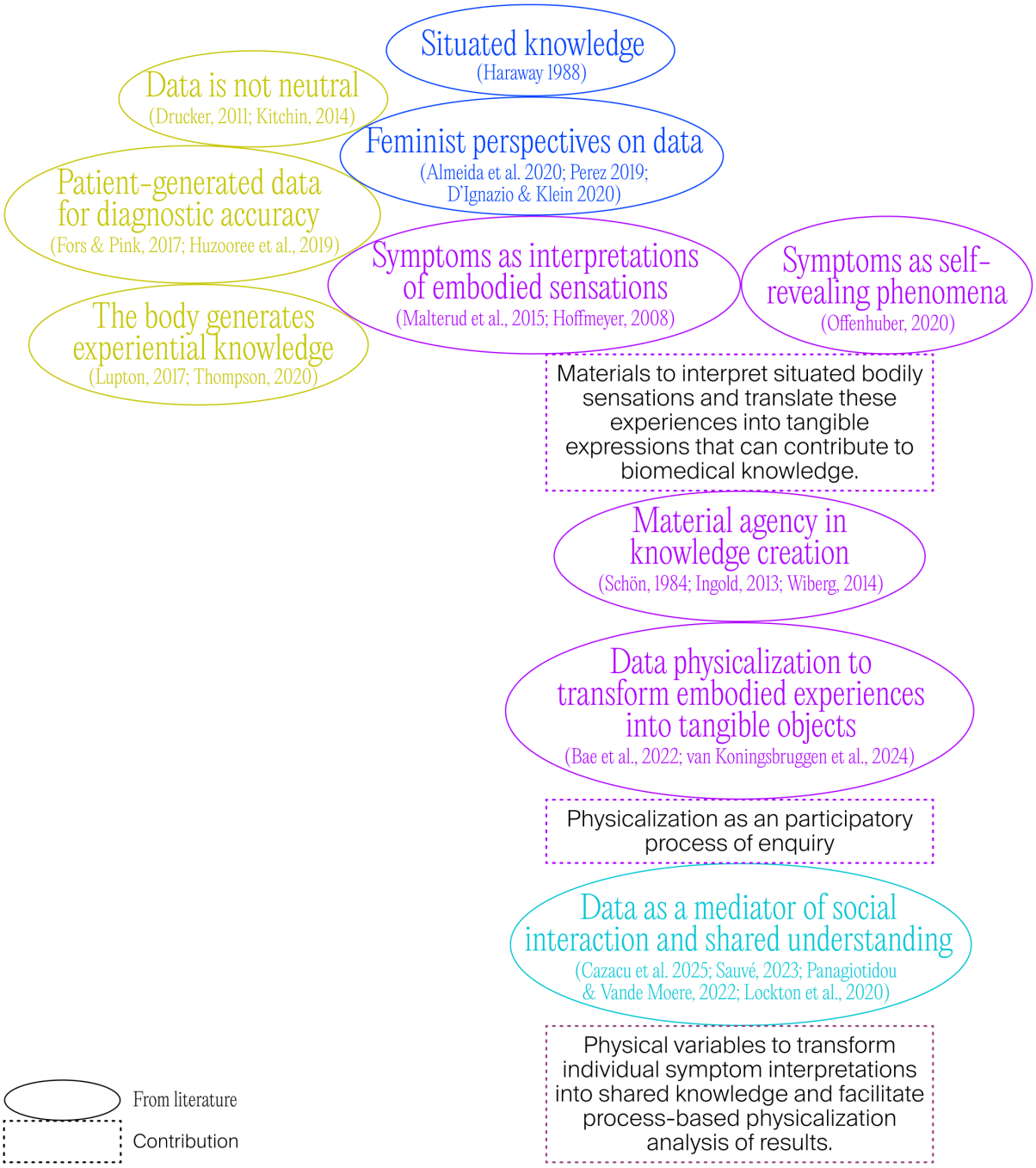


Figure 3.1: highlights from the literature review and relative contribution considered to guide the development of the method introduced in this chapter.

3.1 Physical variables as a methodological component for knowledge generation

As discussed in Chapter 2, the literature on data physicalization identifies a wide range of material properties that support representation, interaction, and interpretation. These include qualities such as texture, weight, shape, temperature, flexibility, and movement. Across the field, these properties are commonly understood as variables that connect data to physical form. Existing classifications provide an important basis for this research by clarifying the range of qualities through which data can become physically perceptible.

Building on this foundation, this study introduces physical variables as central methodological components of the Shape Your Symptoms workshop. In this thesis, physical variables refer to material qualities used to guide participants in relating embodied sensations to physical form. They are introduced to support the elicitation, expression, interpretation, and communication of UTI symptoms through material engagement and group discussion.

The methodology relies on physical variables to investigate how symptoms such as burning, pressure, pain, urgency, and discomfort can be explored through qualities such as texture, weight, shape, density, sharpness, resistance, and softness. These symptoms are intimate, variable, and often difficult to describe through words alone. Physical variables therefore provide a practical structure through which participants can begin to recognise, discuss, and materially articulate their experiences.

Within the methodology, physical variables operate on two connected levels. First, they provide tangible references that help participants approach and describe embodied sensations. Second, they structure discussion and comparison within the participatory setting, creating a shared basis for associating symptoms with material qualities. Their contribution is examined through the workshop analysis and discussed in Chapter 8.

This role is made practical through two sets of puzzle-shaped labels, which provide a tangible way to associate symptoms with physical variables during the workshop. These labels prepare participants to connect symptoms with material qualities before enacting these associations through the Data-Probes.

3.1.1 Puzzle-shaped labels for mapping and discussion

The label activity introduces a structured moment of mapping before participants begin working with the Data-Probes. During this phase, participants engage with

symptom labels and physical-variable labels as movable components, arranging them on the table and discussing how particular sensations might relate to specific material qualities.

The puzzle shape gives this association process a concrete form. Connecting two labels requires participants to make a choice, explain it, and negotiate it with the group. The labels therefore function as prompts for discussion as much as organisational tools. They slow down the movement from symptom description to material construction, allowing participants to consider how embodied sensations might be expressed before selecting and assembling the physical components. This design choice draws inspiration from the Mix and Match Machine Learning toolkit by Jansen and Colombo (2023), which uses interlocking pieces to support the intuitive and collaborative exploration of conceptual relations. In the present workshop, the puzzle shape serves a similar function. It acts as a material cue that encourages experimentation, prompts dialogue, and lays the groundwork for the interpretative connections developed in the following steps.

This step also creates a shared reference for the workshop. The associations produced through the labels remain available during the Data-Probes activity, where participants translate the agreed symptom–variable relations into material artefacts. In this way, the labels support the transition from discussion to making while preserving the interpretative openness of the activity.

The physical variable labels

The physical-variable labels are developed by drawing on the classification proposed by Hornecker et al. (2023) and are visible in Figure 3.2. Their taxonomy constitutes one of the most comprehensive mappings of data physicalization practices available and offers a robust conceptual foundation for identifying material properties that can meaningfully mediate embodied experiences. Importantly, this work was published at the time this study was being designed, offering a timely and up-to-date conceptual resource. Unlike the other classifications reviewed to define the role of physical variables in this research (Chapter 2), which present taxonomies as secondary outcomes of broader investigations, Hornecker et al.'s research explicitly focuses on a vocabulary for physicalization. This clarity of intention makes their classification particularly suitable for adaptation within a workshop setting where participants rely on a coherent and accessible set of expressive tools.

A further advantage of drawing on this taxonomy is that the examples and projects used to construct it arise directly from design practice. Many of these precedents overlap with, or closely resemble, the types of projects already examined in this research to understand how physical forms support experiential

representation. As such, the vocabulary proposed by Hornecker and her colleagues is grounded in a design context that aligns with the methodological aims of this study and reflects practices similar in intention to the Data-Probe approach developed here. Additionally, their framework distinguishes between explicit variables, implicit properties, and consequential aspects, capturing not only the tangible qualities of materials but also the perceptual and experiential dimensions that emerge through interaction. This approach reflects the aims of this research, which seeks to support participants in externalising sensations through touch, manipulation, and spatial arrangement rather than assigning symptoms to predetermined categories.

For the purposes of this workshop, however, only a curated subset of these variables is presented to participants. This selection responds to two considerations. First, participants cannot be assumed to be familiar with specialised material terminology, and introducing overly abstract categories, such as implicit or consequential aspects, could impose unnecessary cognitive load. Second, the workshop operates within practical constraints of material availability, meaning that some variables identified by the researchers cannot be meaningfully expressed through the components included in the Data-Probe kit. The list used in the session therefore represents a simplified and accessible adaptation of the broader taxonomy, offering participants a focused set of physical variables that supports embodied interpretation without requiring prior expertise or technical knowledge:

* position;
* shape;
* size;
* colour;
* orientation;
* pattern / texture;
* fuzziness / blurriness;
* roughness;
* viscosity;
* weight;
* timing;
* movement / motion;

* opacity;

* 3S-form / contour;

* brightness.

Most of these variables are self-explanatory in the workshop setting, while some require a short introduction before the activity begins. For example, 3D form/contour refers to the felt form or contact contour of an object, such as curvature, concavity, or convexity. Discussing the meaning of these variables with participants before they begin to work with materials supports a more conscious use of the vocabulary and contributes to one of the wider aims of the workshop, correspondingly to the strengthening of data literacy through material and participatory engagement.



Figure 3.2: laser-cut plywood labels representing the physical variables used during the workshop. These variables were defined based on the classification by Hornecker and colleagues (2023).

The symptom labels

Alongside the physical-variable labels, the workshop also uses a set of symptom labels. These labels provide an initial shared basis for identifying and discussing sensations associated with UTIs before participants begin to shape them materially. Their role is to support recall, facilitate dialogue, and create a common starting point for later associations with physical variables. In this sense, the two sets of labels work together as symptom labels name what is felt, while physical-variable labels support how it can be materially interpreted and expressed.

The introduction of symptom labels responds to a practical and methodological need. Participants are not expected to be experiencing symptoms at the exact moment of the workshop, and discussing intimate bodily conditions in a shared setting can be challenging without a clear point of departure. For this reason, the labels act as prompts that activate memory and reflection. They are presented as open references rather than fixed categories, encouraging participants to recognise, adapt, question, or expand them in relation to their own experience.

To define this set, I consulted the clinical and experiential literature on UTIs, particularly the overview provided by Kaur and Kaur (2021), in order to assemble a list of symptoms commonly associated with the condition across different stages and intensities. This list provides participants with a grounded yet flexible vocabulary that remains open to personal interpretation and addition. In this way, the symptom labels support the workshop not by prescribing experience, but by helping participants approach it, recall it, and begin to discuss it in a situated and meaningful way.

At the beginning of the activity, participants are presented with a set of nineteen symptoms printed on individual wooden labels, such as the ones in Figure 3.3. The UTI symptoms considered at this stage of the workshop are the following:

* swollen stomach;
* cloudy urine;
* bloody urine;
* need to pee;
* pain when peeing;
* discomfort when peeing;
* low temperature below 36;
* pressure in the groin;
* lower abdomen cramping;
* lower back pain;
* side pain;
* shivering;
* unable to empty the bladder fully;

* incontinence;
* vomiting;
* nausea;
* tiredness;
* aching;
* foul-smelling urine.



Figure 3.3: some of the laser-cut plywood labels representing the symptoms used during the workshop.

Together, the sets of symptom and physical variable labels create an initial bridge between experience, vocabulary, and material engagement. They help structure the early stages of the activity, support discussion among participants, and prepare the conditions through which physical variables can be enacted more directly through Data-Probes.

Empty labels were also made available so that participants could add symptoms or material qualities that were absent from the prepared sets. This kept the activity open to experiences that might not be captured by existing clinical symptom lists or by the selected vocabulary of physical variables. The empty labels therefore supported participant agency within the structured format of the workshop, allowing the shared vocabulary to expand in response to the group's own interpretations.

3.2 Data-Probes as material components for eliciting embodied experience

This research introduces Data-Probes as the material components through which embodied symptoms and physical variables are brought into relation within the workshop activity. Their role is to make physical variables tangible and usable, while giving participants material means to recognise, express, interpret, and discuss embodied symptoms. In line with the autographic framing developed in Chapter 2, Data-Probes support the externalisation of bodily sensations as material traces that can be handled, reflected on, and shared.

The term Data-Probes brings together two methodological references: cultural probes and data physicalization. From cultural probes, Data-Probes take the use of artefacts to elicit personal, situated, and reflective responses. From data physicalization, they adopt the use of material form to support interpretation, comparison, and communication. The name reflects this combination, as materials are used to probe experience as data and to give that experience a tangible form for interpretation.

This integration responds to the healthcare context addressed in this research. Experiences of UTIs are shaped by personal histories, cultural expectations, social dynamics, and the settings in which care is sought. Symptoms are interpreted through previous episodes, everyday routines, intimate relationships, and expectations around what can be shared in clinical encounters. For this reason, the emphasis on location in Gaver's original probes is reinterpreted through the lens of situatedness. Traditional probes foregrounded physical localisation, using artefacts such as maps or postcards to capture contextual insights in situations where researchers could not be present (Gaver et al., 1999). In this study, context is understood more broadly, drawing on Haraway's view that knowledge is produced within specific social, cultural, and historical conditions (1988). Data-Probes are therefore developed to generate data within the lived conditions through which symptoms are perceived, expressed, and interpreted.

The design of Data-Probes also draws on data physicalization as a process, rather than only as the production of a final artefact. As discussed in Chapter 2, data physicalization shows how materials can be configured, manipulated, and reconfigured to embody and communicate experience. Tangible artefacts invite interaction, negotiation, and dialogue, while meaning develops through actions such as selecting, handling, combining, adjusting, and explaining materials. Building on this understanding, Data-Probes use physical materials as active elements in the generation and interpretation of embodied data.

In practice, Data-Probes consist of modular material components available in different shapes, dimensions, and materials. Participants work with pieces such as cubes, spheres, prisms, and connectors, whose physical qualities vary in texture, weight, softness, resistance, and flexibility. Through touch, manipulation, selection, and arrangement, they combine these components into physical artefacts that reflect how symptoms and disease experiences are felt. This process supports the articulation of sensations that are often intimate, changeable, and only partly expressible in words, making them available for reflection and discussion.

3.2.1 Defining the aspect of the Data-Probes

The aspect of the Data-Probes kit is defined through a set of material, methodological, and participatory possibilities. The kit needs to support the expression of embodied experience while also enabling comparison across participants and sessions. For this reason, its design balances expressive richness with methodological clarity. It offers a range of physical qualities, remains accessible to participants with no design or making expertise, supports simple forms of handling and assembly, and relies on components that can be reproduced and used consistently across workshops.

The diagram in Figure 3.4 functions as a design map that gathers visual references, material examples, workshop reflections, and practical questions informing the development of the Data-Probes. The references are organised around a set of recurring concerns, including modularity, participation, reproducibility, assembly, customisation, and levels of intervention. Read in this way, the figure makes visible the main questions that shaped the kit: what kinds of materials can support self-awareness, what kinds of actions they invite, how participation unfolds through modification, and how resulting artefacts can remain both expressive and comparable.

[In the next page]

Figure 3.4: map showing the initial research of materials and identification of parameters for developing the Data-Probe kit.



Loro Piana, Salone del Mobile Milano 2023 (IG story by adaydreamer)



Balancing rocks, kit Flying Tiger



Unknown (IG story by andre_beli)



Building hopes Accurat Studio

How do components can be organised so to make the activity reproducible (from others as well)?

What kind of action/ gesture is supposed to best elicit self-awareness?

What material does best represent symptoms?

How does the final results affect the design of the artefacts process?

Research question:
What material can better foster the activity*?

*participatory workshop involving women to promote self-awareness and data collection of UTI symptoms

What is the role of materiality within the workshop activity?
→ engage participants
→ promote self-reflection
→ facilitate communication

3D printing



Thoughtforms: 3D-Printed Thoughts, 2016 - Kellyann & Dae Hwang



Computer Glitches as 3D Objects, 2010 - Tracy Cornish

"Where do I start from?"-from the workshop pilot



Workshop pilot SUPSI, 24/11/2023

Is there any size restriction? Do materials need to be transported?

KIT
components to make the activity reproducible



Cuboro kit - murble run system



Chloé Hamel-ECAL-2023



Wanimokko



ONO-25 BEECH - Tonouchi Tetsuo

How much the material should be polished? (attractive-make participants confortable in hacking → prototype?)

"I was scared to write on the labels because so well polished"
-from the workshop pilot





Bigodini flessibili - Ebay

MODULARITY
different shapes, colours, dimensions
different materials?



Pixio: magnet blocks + app to recreate and share shapes

How to provide participants with a starting-point?



Lego bricks



Colour number rules

What does the participatory environment bring to the process of assemblage? How does participation affect the creation of the artefact?

PARTICIPATION

individual activity to be shared collectively once completed

CUSTOMISATION
personalise materials based on personal experience



Pinterest



Tubo kids space



Silicon rods - pic from cobetter.com

Tokens - as objects to represent information



Tokens - as surface to inscribe information



How to avoid the "stationary shop" modality and mood?



How much the material should be pre-defined?
How much should participants' intervention be allowed? /incentivised by the material?
How much unites should be modifiable?

What material can provide defined unites that participants can modified?

How do participants assemble unites?
What kind of gesture/ intervention is needed to assemble materials?

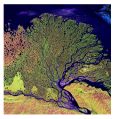
CONDITIONAL DESIGN
→ "Conditional physicalization"?



stiker kit per conditional design studio Moniker



Organic blob Polymer clay cutters set - Etsy



Biochemical flows (plates) physicalization.xyz

ASSEMBLY
interaction among unites to create the artefact

"units need to stick instantanly, you can not wait for the glue to dry"
-from the workshop pilot





Rodgriguez, Lockton 2018 research steps

LEVELS OF INTERVENTION

- clay

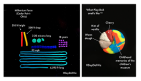


5500 BC – Mesopotamian Clay Tokens



Life in Clay: Sharing Memories through Data Pottery, 2015 - Alice Thudt

- plasticine /playdoh



DayDohViz, 2018 - Amy Cesal

- beads to thread



Touching air, 2025. Stefanie Posavec

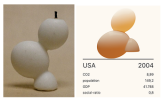
Given order to



→ timeline
→ cause-effect

Self Knitted Scarf of Train Delays, 2019. Mother [of] Sara Weber

- wax



Candle for Climate Change - physicalization.xyz

- totem to build upon



Learning to DIY Pinterest

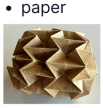


Lotte De Jong - Pinterest *Calder, Mirò



Pinterest

- paper



Origami - Dario Zenuto (folding paper strategies)



v-pleat data origami by Sarah Hayes



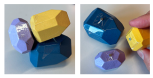
Mandorla Palace - Pinterest

- base to start from/ to draw on



Cork - Pinterest

- magnet to stick



Balancing rocks + external magnets Flying Tiger

What does has a shape but is mallable?



Marko -artist

What if, instead of working on the material, participants intervene on the tool that gives the shape to the material?

What role does the consumption of the artefact has in creating the meaning? /to read-interpret-understand data?



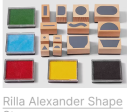
Doodle Crayons



Farvekridt Crayons - Flying Tiger



Areaware Moon Chalk



Rilla Alexander Shape Stamps

The map in Figure 3.4 brings together the initial material references explored for the definition of the Data-Probe kit, showing how different materials, forms, and gestures were considered for their capacity to support embodied expression. Within this exploration, one possibility concerned the use of soft and highly modifiable materials. Clay, yarn, felt, foam, wax, paper, plasticine, Play-Doh, chalk, and pastels offer direct bodily engagement and invite participants to shape, press, stretch, mark, fold, or transform matter through intuitive gestures. These materials foreground immediacy, tactility, and personal expression. They are particularly relevant when the aim is to support self-awareness through open-ended manipulation and to allow embodied sensations to leave visible material traces. Historical clay tokens, origami structures, v-pleat paper forms, and Life in Clay: Sharing Memories through Data Pottery by Thudt (2015) show how direct manipulation and material traces can communicate experience in ways that remain situated, personal, and sensory. Another possibility concerns the use of more rigid, predefined, or recognisable elements. Wooden blocks, folded paper structures, ceramic forms, cardboard units, cork bases, magnetic pieces, and shaped components offer clearer starting points for participants. These elements reduce the need to invent a form from scratch and make the activity more accessible to people without making expertise. They also support methodological comparison, because participants work from a shared material vocabulary. In this sense, predefined units provide a common framework through which different interpretations can emerge.

Modularity is central to this design space. Repeated components allow participants to build individual configurations from shared elements. They support variation through combination, while also making it possible to compare how similar forms are assigned different meanings across participants and sessions. Toy construction systems, and modular precedents such as LEGO bricks, Pixio magnetic blocks, Cuboro, Wanimokko, and ONO-25 demonstrate how simple units can generate complex arrangements through stacking, joining, balancing, and sequencing. Similar principles appear in data physicalization projects such as Cairn by Gourlet and Dassé (2016), where collective forms are built through stacked modular pieces, and Data Badges by Panagiotidou et al. (2020), where tokens are assembled into personalised wearable patches. These examples show how modular systems can sustain expression while maintaining a basis for comparison.

Gesture is another defining criterion. The kit is not only shaped by what materials look like, but also by what they allow participants to do. Rolling, stacking, pressing, bending, stretching, linking, threading, balancing, and arranging are all possible actions through which participants can articulate sensations. These gestures can express relations such as intensity, spread, layering, recurrence, accumulation, fragmentation, or progression over time. Rods, beads, strings, magnetic elements,

silicone components, and stackable shapes are therefore relevant because they support immediate and understandable forms of interaction. References such as Tubo kids space, magnetic balancing toys, beads to thread, and flexible rods clarify the importance of simple gestures that allow participants to externalise relations among sensations rather than represent isolated qualities only.

Connectors occupy an important position within this material vocabulary. They allow components to be joined, extended, separated, or placed in relation to one another. This makes them useful for expressing connections between symptoms, temporal sequences, causal relations, bodily locations, or changes in intensity. Connectors therefore expand the kit from a collection of discrete elements into a system capable of representing relations, transitions, and dependencies.

The participatory dimension of the kit also informs its aspect. Some references are relevant because they suggest ways of structuring shared action, rule-based interaction, and collaborative arrangement. The kit needs to support meaning-making not only through individual making, but also through discussion, interpretation, and comparison within the workshop setting. Conditional Design by Maurer and Puckey (2013), for example, foregrounds the role of rules, collective action, and shared interpretation. This perspective positions the Data-Probes not simply as objects to be made, but as prompts for dialogue and reflection.

A further possibility concerns different levels of intervention. Highly open materials invite direct shaping and invention, while predefined units offer clearer affordances and faster interpretation. Open materials support personal expression and bodily engagement, but they can also require more time, confidence, or skill. Predefined components support ease of use, reproducibility, and analytical coherence, but they need to remain flexible enough to avoid overdetermining participants' meanings. The aspect of the Data-Probes is therefore situated between these two poles. It gives participants enough freedom to interpret sensations in personal ways, while also providing enough structure to make the workshop manageable and the outcomes comparable.

Other references extend the expressive vocabulary of the kit without necessarily defining its final material basis. Parametric and biomorphic 3D-printed forms, including Computer Glitches by Cornish (2010) and Thoughtforms by Kellyann and Dae Hwang (2016), suggest how computationally generated forms can express invisible, affective, or unstable states. Organic morphologies, coral-like structures, polymer clay cutters, biochemical-flow plates, and generative natural forms point to fluidity, variation, and bodily complexity. Trace-making approaches such as chalk, wax pastels, crayons, and stamps highlight gesture, inscription, pressure, and bodily movement. These directions expand the possible language of the kit, even when they introduce additional preparation, technical skill, or a further step between

imagining and producing form.

Practical requirements also shape the range of possibilities. The components need to be affordable, portable, robust, reproducible, and suitable for repeated use. They need to be prepared consistently across workshops and handled easily by participants. These requirements favour a limited set of modular units that can support varied interpretations without making the activity too complex. The material logic of the kit therefore combines openness and structure as it supports intuitive gesture, personal expression, collaborative discussion, and analytical comparison within a coherent system.

The aspect of the Data-Probes is therefore defined by a balance between reproducibility, gesture, modularity, and interpretative potential. The kit is not characterised only by its shapes or materials, but by the range of actions, relations, and meanings it makes possible. In this way, it supports the embodied articulation of symptoms while also allowing the research process to trace how meanings are assigned, discussed, compared, and transformed during the workshop. The following section presents the final kit and describes how its components are organised for use in the activity.

3.2.2 The Data-Probes material kit

Building on the exploratory process described above and on insights gained from the initial pilot workshop, the final Data-Probes kit is developed as a structured set of material components to support the shaping activity. The aim of the kit is not to provide an exhaustive range of material possibilities, but to offer a curated system of elements that can support physical engagement, stimulate interpretation, and help participants communicate embodied symptoms through making. In this direction, the components act as interpretative prompts, supporting the externalisation of sensations through tactile and spatial exploration.

The design of the kit reflects the balance identified in the previous section between expressive openness and methodological consistency. For this reason, the final selection favours modular and repeatable units that remain simple to recognise and combine, while still providing enough variation to support different interpretations. The focus is placed on physicality rather than on visual appearance. While colour is a central variable in many traditions of data representation and visualisation (Bertin, 1967; Morrison, 1974, in Roth, 2016; MacEachren, 1995), this activity prioritises material qualities such as weight, texture, hardness, and resistance. All components are therefore kept in a neutral palette and used in their natural material state. This choice directs attention towards physical engagement and reduces the influence of visual coding on interpretation.

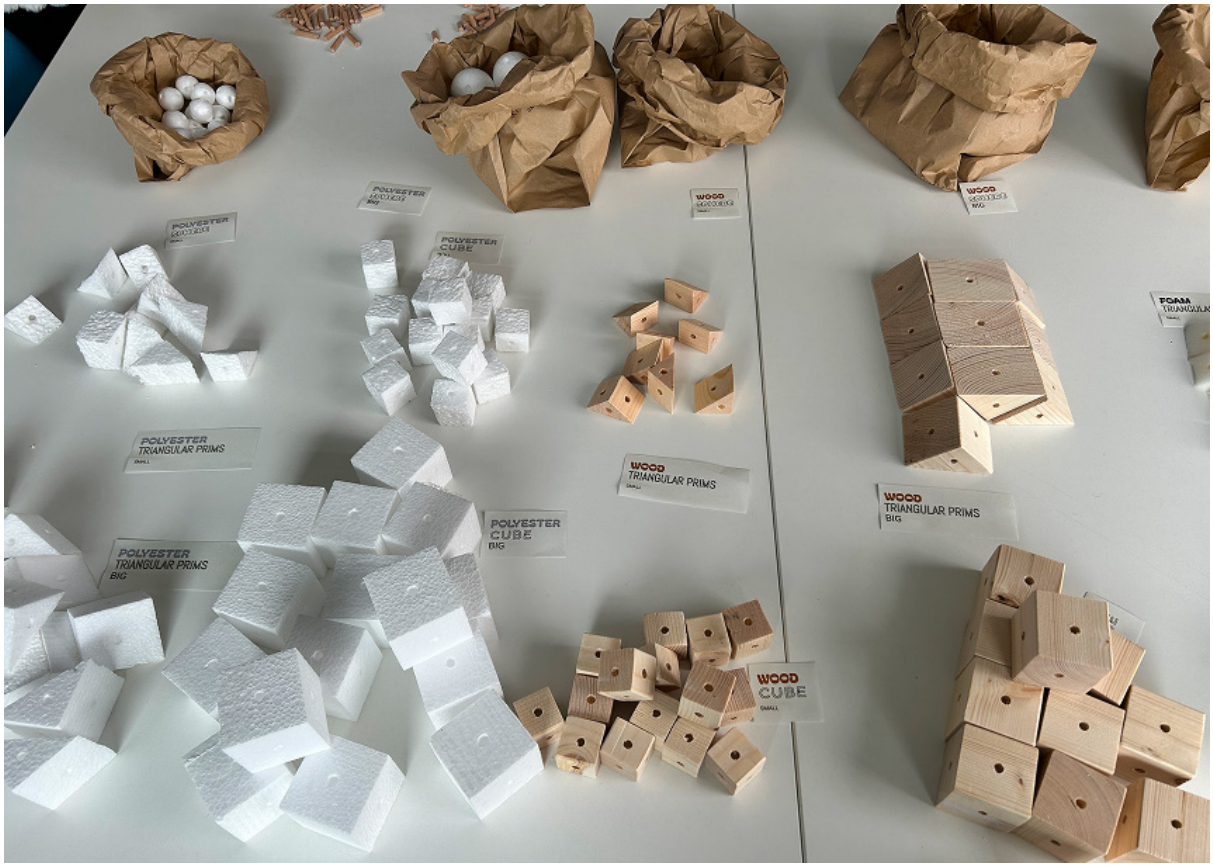
The kit consists of three basic geometric forms: the cube, the sphere, and the triangular prism. These shapes were selected because they are familiar and easily recognisable across design and craft contexts, allowing participants to engage with them quickly and intuitively. Each form is available in two sizes, small and large. The absence of an intermediate size is intentional, as it encourages participants to make more deliberate choices when relating form to sensation, rather than defaulting to a middle option.

Each geometric form is produced in three different materials: wood, polystyrene, and foam. This combination creates a clear range of contrasts in weight, hardness, texture, and tactile response. Together, the system results in eighteen main components, offering a broad yet manageable set of sensory possibilities. The kit therefore maintains simplicity while still allowing participants to explore a meaningful variety of physical variables through direct handling.

To support the construction of more complex artefacts, the kit also includes short and long wooden pegs together with flexible transparent connectors. Small holes on each face of the geometric units allow components to be joined, stacked, extended, or linked together. These joining mechanisms enable participants to create configurations that express not only isolated sensations, but also relations between symptoms, such as layering, progression, connection, spread, or intensity. In this way, the kit supports both the representation of single qualities and the articulation of more composite embodied experiences.

The final organisation of the kit is visible in Figure 3.5 and finds a useful correspondence with the Emotional Modelling project by Rodriguez, Herzog, LeFevre, Kahle, and Wolf (2018), discussed in Lockton et al. (2020b). Although developed in relation to emotional states rather than healthcare, that project shows how a limited but versatile vocabulary of modular components can support the externalisation of subjective experience. It provides a relevant precedent for the organisation and expressive potential of component-based kits, reinforcing the value of constrained yet flexible material choices for meaning-making.

Taken together, the selected shapes, materials, and joining mechanisms create a structured yet open-ended system. The kit supports the aims of the workshop by encouraging participants to interpret their embodied experiences through hands-on exploration and to articulate those interpretations through the construction of personalised artefacts. In this way, the Data-Probes material kit translates the design choices outlined in the previous section into a practical set of components ready to be used within the participatory activity.



[Top]

Figure 3.5: the Data-Probe components available for the shaping activity. The arrangement of the components is itself part of the workshop process: participants are asked to lay out the materials on the table and pair them with their corresponding paper descriptions, allowing time to familiarise themselves with the elements before starting the activity.

[Below]

Figure 3.6-3.7: organisation of the Data-Probe components across workshop iterations. After the first session (on the left), revealed confusion caused by pre-arranged materials on a paper grid, from the second workshop session onwards participants are involved in sorting the components to familiarise themselves with the kit (on the right).





3.3 Shape Your Symptoms workshop

Building on the methodological direction established in the previous sections, the Shape Your Symptoms workshop is introduced as the setting in which physical variables, labels, and Data-Probes are brought together within a participatory activity. The workshop format is developed to reflect the central commitments of this research by approaching symptoms as embodied and situated experiences, using material engagement as a means of interpretation, and supporting the emergence of knowledge through participation and discussion.

The next section explains the rationale behind the workshop format, while the following one grounds this rationale in the specific design choices that define the setting. The workshop protocol is then introduced by outlining the structure of the activity and the sequence materials through which the methodology is enacted in practice. The methodology developed through an iterative process of refinement, which affected each of the five workshop sessions in different ways. For this reason, and to provide a clearer account of how the methodological framework was defined and progressively adjusted, the settings of all sessions are described in detail, together with the changes introduced from one iteration to the next. Particular attention is given to the initial pilot workshop, whose role was central in guiding the later implementations of the activity. Feedback from this session is therefore discussed separately before moving to the analysis of results, as it informs the definition of the final protocol and several of the practical choices adopted in the subsequent workshops.

Based on the topics and aims addressed across the sessions, the analysis is organised across Chapters 4, 5, and 6. Chapter 4 presents the visual results of the Data-Probes artefacts and contextualises the material outcomes produced during the workshops. Chapter 5 focuses on the health-related findings, examining participants' experiences of UTIs as the core topic of the research, while also considering how later workshop sessions extended the discussion to other intimate and embodied conditions. Chapter 6 analyses the methodological findings, focusing on how physical variables, Data-Probes, material engagement, gestures, and workshop structure supported the interpretation and communication of embodied experience.

3.3.1 Rationale for the workshop format

To generate embodied and collective knowledge, this research required a methodological setting in which participants could move beyond individual accounts of symptoms and develop interpretations with others. Within this study, symptoms are approached as embodied and situated experiences whose meaning develops

through reflection, association, comparison, and discussion. The workshop format provides these conditions by enabling participants to engage with symptoms as embodied data, relate them to physical variables, and externalise them through material construction.

A first reason for adopting the workshop format lies in the role assigned to materiality within the research. Data physicalization is understood as a process that supports reflection, comparison, and shared interpretation. Materials therefore do not function only as supports for representing symptoms after they have been described. They actively contribute to how sensations are recognised, explored, and communicated. The workshop creates the conditions for this process by allowing participants to work with materials, labels, physical variables, and Data-Probes within a shared interpretative setting. A second reason concerns the nature of symptom experience. Sensations such as burning, pressure, urgency, or discomfort are intimate, variable, and shaped by context. Their meaning develops through memory, association, and relation to other experiences. The workshop format supports this process by allowing participants to recognise points of resonance and difference across accounts, articulate embodied perceptions through materials, and progressively develop shared interpretations. In this sense, the workshop is suited to the relational and interpretative dimensions of the study. A third reason concerns participation as a mode of knowledge generation. As discussed in Chapter 2, participatory design in healthcare supports the creation of knowledge from situated perspectives and brings attention to voices often absent from standard clinical procedures. Participation is therefore understood here as a shared activity through which people with lived experience and people with clinical expertise contribute to knowledge that is distributed, contextual, and shaped through practice (Chauhan, 2021). Participatory data physicalization strengthens this choice by treating representation as a shared physical act of meaning-making in which participants influence both the form and the content of what is produced (Moretti and Mattozzi, 2017). By turning experience into tangible forms, this format supports engagement, dialogue, and reflection, enabling participants to externalise perspectives, negotiate interpretations, and contribute to collective knowledge through guided interaction (Sauvé, 2023; Panagiotidou and Vande Moere, 2022; Cazacu et al., 2025).

The workshop also enables different forms of knowledge to meet within the same interpretative process. Participants' lived and embodied experiences can be brought into dialogue with contextual and clinical perspectives without positioning one as the standard against which the other is assessed. This is especially relevant in relation to intimate and gendered conditions such as UTIs, where personal accounts are often difficult to express and may be shaped by discomfort, stigma, or uncertainty. Material and visual practices help mediate this dialogue by directing attention towards

external artefacts that participants can shape, discuss, and interpret according to their own comfort and abilities (Prochner, 2022).

For these reasons, the workshop format is defined as the methodological setting most able to support the process investigated in this research. Through shared engagement, material exploration, comparison, and discussion, it enables knowledge to develop relationally. Patterns, nuances, and new interpretations emerge through the interaction between participants, materials, and structured prompts, in line with collaborative approaches to data physicalization where meaning develops through the making process as much as through the final artefact.

3.3.2 The workshop format

The workshop setting translates the methodological rationale outlined above into a practical and manageable format. Its definition responds to interconnected design choices concerning duration, scale, co-presence, participant composition, gendered sensitivity, modes of participation, and iterative implementation. Together, these elements create an environment in which embodied experiences can be explored materially and discussed with confidence.

The workshop is planned to last approximately two and a half to three hours. This duration supports the different phases of the process, from introduction and reflection to material exploration, collective discussion, individual artefact construction, and final presentation. The activity requires time for participants to recall symptoms, become familiar with the labels and components, test associations between symptoms and physical variables, and gradually develop confidence in shaping and explaining their artefacts. A shorter format would constrain this progression, while a longer one could reduce attention and comfort, especially given the sensitive and affective nature of the topic.

The workshop is conceived as an in-person activity involving a small group of approximately five to ten participants working together in the same physical space. This scale creates a balance between diversity of perspectives and the intimacy required for discussing sensitive experiences. In healthcare contexts, small participatory groups can support trust, enable more balanced exchanges, and recognise people with lived experience as active contributors whose perspectives shape the relevance and quality of care (Chauhan, 2021; Mishra and Sandhu, 2021). For a topic such as UTIs, where experiences may be intimate, affective, or stigmatised, a restricted group also helps create an atmosphere in which participants can feel supported by shared experience and progressively enter the discussion. Co-presence is central to this methodology because the activity depends on shared engagement with materials, direct observation of artefacts, and ongoing discussion

around what is being made. Working in the same space allows participants to handle the same labels and components, observe each other's choices and gestures, and respond directly to the associations and constructions that emerge. The workshop therefore supports not only verbal interaction, but also collective interpretation through material comparison, visual attention, and embodied dialogue.

The participant composition is defined to foster dialogue across experiential and clinical perspectives. The workshop is intended to include individuals with lived experience of UTIs together with professionals holding relevant expertise, such as doctors, nurses, or pharmacists. Caregivers and family members are also considered relevant because of the role they may play in supporting the management and understanding of recurrent or chronic conditions. Within this setting, people with lived experience contribute embodied and situated understanding of symptoms, while experts contribute contextual and clinical perspectives that widen interpretation and connect the discussion to diagnosis, treatment, and antibiotic use as part of the broader experience of the disease.

The inclusion of medical experts is therefore a deliberate methodological choice. Their role within the workshop is not to lead the activity or to position participants' accounts against a fixed clinical standard, but to take part in the same space of enquiry. Through listening, responding, and reflecting on the artefacts and associations produced, they contribute perspectives that enrich discussion and relate symptom expression to broader healthcare processes. This setting supports dialogue between forms of knowledge that are often separated in healthcare encounters and allows participants' embodied accounts to enter discussion in relation to clinical understanding.

At the same time, the workshop maintains a specific focus on women, who are the primary target of this study because UTIs disproportionately affect them. As discussed in Chapter 2, this disproportion is biological and is also shaped by broader structural conditions, including the limited attention historically given to women's health in research, design, and healthcare practice. For this reason, the workshop is designed to create a setting in which women can discuss symptoms in relation to others with shared embodied experience and with healthcare professionals able to engage with these accounts from a clinical perspective. To support openness around intimate symptoms, the sessions are structured so that participants with lived experience and experts share the same gender identity. This arrangement supports comfort when discussing bodily experiences and encourages a sense of familiarity and shared understanding.

Participation remains voluntary throughout, and the workshop structure creates an inclusive setting in which contributions can be voiced and acknowledged in different ways. The activity supports engagement without requiring uniform forms of

participation. Participants can enter the discussion gradually, work through materials at their own pace, and contribute through speaking, selecting, combining, arranging, shaping, and presenting. This flexibility is important in a context where the topic may involve discomfort, vulnerability, or hesitation.

In line with the methodological orientation of the research, the workshop format is implemented across multiple iterations, with different participants involved in each session. The protocol maintains a stable core structure, while small adjustments are made in response to contextual conditions, participant composition, and the exploratory development of the research. These variations support the progressive refinement of the activity and allow observations and feedback from practice to inform subsequent sessions. The specific conditions of each workshop, including setting, participants, and focus, are introduced in the following section. The workshop steps are then described to clarify the core structure that guided the activity across iterations.

3.3.3 Step-by-step activity definition

The following steps describe the structure of the workshop activity and clarify the purpose of each phase. They explain how each task supports the methodological aims of the study and how participants are guided from initial reflection to material exploration, artefact creation, and shared discussion. The activity uses the symptom labels, physical-variable labels, and Data-Probes kit described above, together with two complementary elements integrated into the workshop sequence. The symptom definition card supports the initial ice-breaking activity, while the assessment tablecloth supports feedback collection at the end of the session.

⁕ Step 0 [Before the workshop]

Participants receive an onboarding email with brief information about the research. The email includes the consent form and information sheet, which participants are asked to read and return signed by the day of the workshop.

The purpose of this initial step is to prepare participants for the activity while establishing an environment of informed, voluntary, and comfortable engagement. The onboarding email introduces the aims of the research and provides clear information about what participation involves, helping participants approach the workshop with awareness and reassurance. Sharing the consent form and information sheet in advance supports transparency and allows participants to make an informed decision about their involvement before attending the session. By providing information without requiring participants to disclose personal experiences in advance, this step centres participant agency and creates the

conditions for a more gradual and comfortable introduction to the reflective work that will take place during the workshop.

⁎ Step 1 [Welcome and introduction on workshop day]

As participants arrive, they are welcomed into a room arranged with seats around a central table (Figure 3.8). While taking their seats, each participant is invited to write on paper about their experience of UTIs and, where relevant, antibiotic resistance. The guiding prompt remains open, such as “What is your experience of UTI and antibiotic resistance?”, so that participants can describe their experience in their own words and share only what they feel comfortable disclosing. They are encouraged to keep this paper with them throughout the session, as it may later help them recall specific episodes, sensations, and details during the discussion of symptoms. Once this initial writing phase is completed, a slide presentation introduces the project and guides participants through the session.



Figure 3.8: workshop setup with participants seated around the table. Picture from the second workshop session, May 2024, London.

The purpose of this step is to welcome participants into the workshop while giving the first written reflection an active function within the session. Writing at the moment of arrival allows participants to settle into the space and begin from their own experience before the collective discussion starts. The open prompt supports a personal and self-directed description, while the written note remains useful throughout the activity as a reference participants can return to when recalling specific episodes, sensations, or details during the later discussion of symptoms. At the same time, these initial accounts provide a first record of how participants describe their experience before engaging with the shared vocabulary, materials, and group exchange introduced in the workshop. This makes them useful both within the activity, by supporting recall and reflection, and within the research, by allowing comparison with the expressions that emerge after the workshop.

⁎ Step 2 [Definition of symptom: 10 minutes]

To open the discussion, each participant receives a 20 × 10 cm paper card and is invited to write a personal definition of what a symptom is, based on their own experience and feelings (Figure 3.9). The prompt asks participants to “imagine explaining what a symptom is to a new friend who does not speak your language well and is hearing this word for the first time.” This wording encourages simple and direct descriptions, helping participants begin from familiar language rather than medical terminology. After writing their definitions, participants read them aloud and briefly introduce themselves, sharing their names and reasons for taking part.

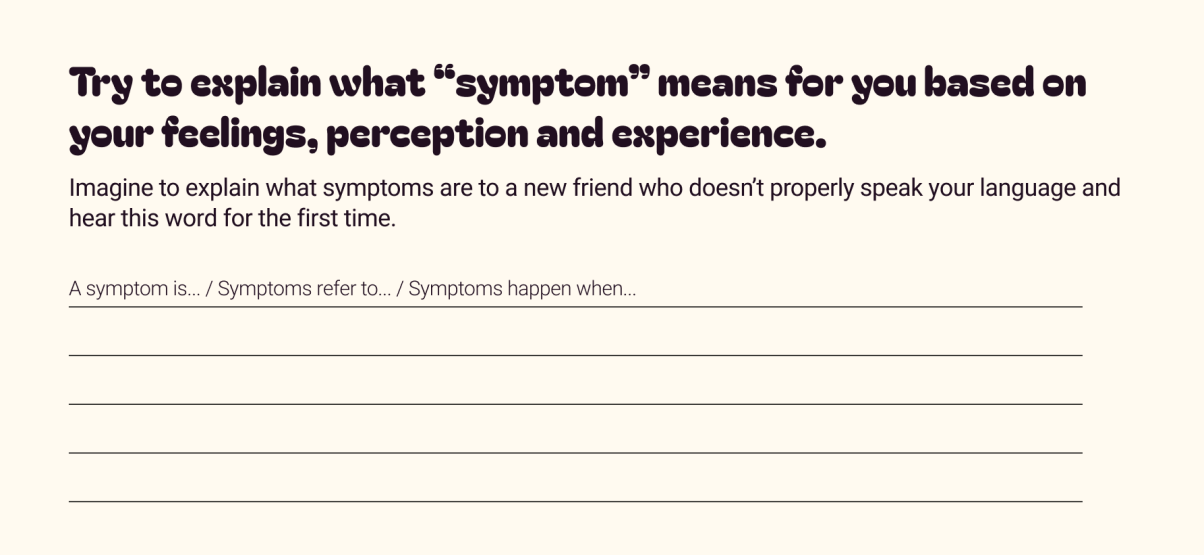


Figure 3.9: printed card used in the ice-breaking exercise, inviting participants to describe their own understanding of a symptom.

The purpose of this step is to ground the workshop in participants' own understandings of what a symptom is, while initiating dialogue and establishing a shared conceptual starting point. The card serves both as an individual reflection tool and as a shared opening device for the group. It gives participants a manageable and personal way to enter the discussion, supporting a gradual transition into a topic that can be intimate or difficult to articulate.

Asking each participant to write a personal definition encourages independent reflection before their views are influenced by others. Reading or discussing these definitions within the group then transforms individual reflections into a collective exchange, making visible the diversity of interpretations that exist even before discussing UTIs specifically. This activity also functions as an icebreaker. By introducing themselves and briefly explaining their reasons for taking part, participants begin to build familiarity and trust within the group.

Through this combination of personal reflection and shared articulation, the step establishes an open and inclusive environment for exploring experiences that are subjective, sensitive, and often difficult to verbalise. In this way, the symptom definition card supports a comfortable start to the conversation while preparing participants for the later collective work of identifying, comparing, and shaping symptoms through the workshop materials.

⁕ Step 3 [Symptom identification: 10 minutes]

Participants identify UTI symptoms they typically experience. Pre-prepared labels with common symptoms extracted from the literature help initiate the process. The purpose of this step is to help participants focus on the specific sensations and experiences that characterise their UTIs, creating a shared foundation for the material exploration that follows. By inviting participants to identify the symptoms they typically experience, the activity encourages personal reflection while also revealing points of overlap or divergence within the group. The use of pre-prepared labels drawn from clinical and academic literature serves as a prompt to initiate the process, supporting participants who may find it challenging to recall or name their symptoms spontaneously. These labels, introduced at the beginning of chapter 3, act as starting points rather than constraints, allowing participants to confirm, adapt, or expand upon established symptom categories based on their own lived experience. In this way, the step bridges biomedical terminology and personal interpretation, setting the stage for deeper discussion and material articulation in subsequent activities.

⁎ Step 4 [Symptom relevance: 20 minutes]

Participants collaboratively order the symptom labels by relevance. Guiding questions include: what symptoms matter most in your experience? Why are these symptoms important? Empty labels allow participants to add missing symptoms. By the end of this phase, the group produces a collectively ordered set of symptoms they consider characteristic of infections such as cystitis.

The purpose of this step is to encourage participants to collectively interpret and prioritise the symptoms associated with UTIs, creating a shared understanding of what matters most in their lived experience. By collaboratively ordering the symptom labels by relevance, participants move beyond simple identification toward active sensemaking, discussing why certain symptoms feel more significant, disruptive, or indicative of infection. Guiding questions prompt deeper reflection and invite participants to articulate the reasoning behind their choices. Empty labels allow them to add symptoms that may be absent from biomedical lists, ensuring that the collective output reflects the full range of experiences present in the room. Through dialogue, negotiation, and comparison, the group co-produces a collectively ordered set of symptoms they consider characteristic of disease such as cystitis (Figure 3.10). This shared interpretation becomes an important reference point for the subsequent materialisation of symptoms through physical variables.

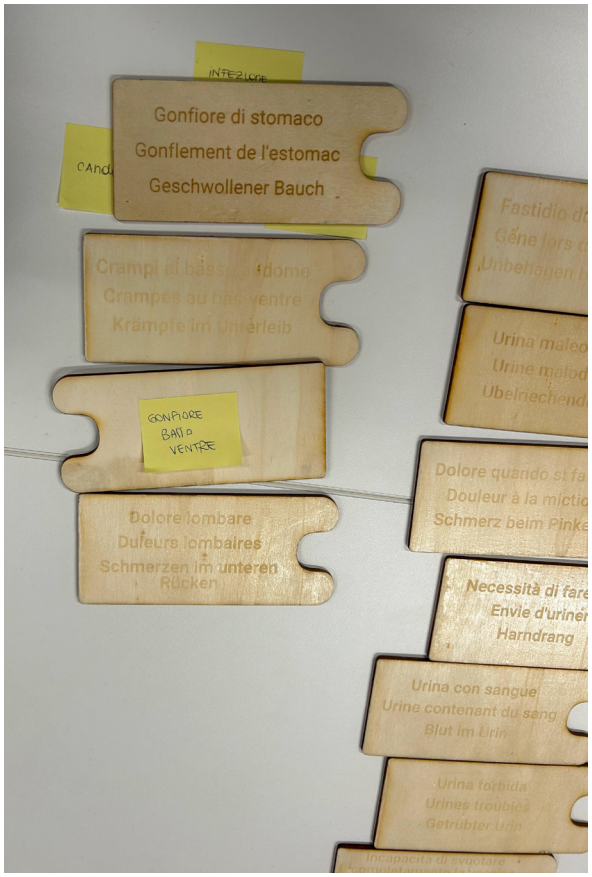


Figure 3.10: symptom labels ordered by participants according to their perceived relevance. The arrangement results from a negotiation phase designed to encourage dialogue and comparison. The image shows the back of the labels, where translations are provided in Italian, French, and German to reflect the languages spoken in Switzerland. Picture from the first workshop session.

⁎ Step 5 [Introducing the concept of shaping: 5 minutes]

The research's approach to representing symptoms through objects is introduced using slides and case studies from data physicalization to clarify what shaping entails. The purpose of this step is to familiarise participants with the idea of representing symptoms through the creation of physical forms, preparing them for the material engagement that follows. A short slide presentation introduces the concept of shaping by drawing on examples and case studies from data physicalization, illustrating how abstract or subjective experiences can be translated into tangible objects. These precedents help clarify the interpretative nature of shaping, showing that the aim is not to produce accurate models but to externalise sensations through material properties. By grounding the activity in recognisable examples, this step reduces uncertainty, builds confidence, and equips participants with a shared understanding of what the forthcoming making process invites them to explore.

⁎ Step 6 [Familiarisation with materials: 10 minutes]

Participants explore the material units of the Data-Probe kit. Cubes, spheres, and triangular prisms made of wood, polystyrene, and rubber foam in different sizes are distributed on the table. Participants help arrange these objects by matching them with cards indicating shape, material, and size.

The purpose of this step is to introduce participants to the material units that will later serve as the building blocks for shaping their symptoms, ensuring they feel comfortable handling and interpreting the components before engaging in more demanding creative tasks. Participants are invited to explore a selection of cubes, spheres, and triangular prisms made from wood, polystyrene, and rubber foam in different sizes. By physically manipulating these objects and collaboratively arranging them according to cards indicating shape, material, and size, participants begin to notice the sensory qualities and variations that each unit affords. This hands-on activity encourages tactile curiosity and reduces any apprehension associated with making, while also laying the groundwork for understanding how material properties can be used to express aspects of their embodied experience. Through this process of guided exploration, the group develops a shared vocabulary of forms and textures that will support the expressive and interpretative work of the subsequent steps.

⁎ Step 7 [Introduction of physical-variable labels: 10 minutes]

Participants are introduced to labels describing physical variables such as shape, colour, dimension, and weight, drawn from the literature.

The purpose of this step is to familiarise participants with the conceptual tools that will support the translation of their symptoms into material form. Participants are

introduced to the set of labels mentioned above which describes physical variables such as shape, colour, dimension, and weight, selected from the literature on physicalization and materially mediated interpretation. Presenting these variables explicitly helps clarify the kinds of material qualities that can be used to express different sensations and states. By exploring the meaning and potential of each variable, participants begin to consider how physical properties might correspond to aspects of their embodied experiences. This shared understanding provides an essential conceptual bridge between earlier reflective discussions on symptoms and the forthcoming making activity, ensuring that participants feel equipped to use the material kit purposefully and confidently.

⁎ Step 8 [Association of symptoms with physical variables: 30 minutes]

Participants match the symptom labels defined earlier with labels describing physical variables (Figure 3.11). Labels are designed as interlocking puzzle pieces to support pairing. Empty labels can be added for missing physical properties. Participants must explain and justify their choices, ensuring the vocabulary reflects their perceptions and interpretations.

The purpose of this step is to guide participants in developing a shared interpretative vocabulary that links their symptom experiences to specific material properties. Participants are invited to pair the symptom labels identified earlier with labels describing physical variables, using interlocking puzzle pieces designed to support deliberate and thoughtful matching. This structured format encourages them to consider how sensations such as pressure, heat, or sharpness might be expressed through qualities like size, texture, or weight. Examples such as associating “swollen stomach” with “size” or “bloody urine” with “texture” help illustrate how material attributes can externalise embodied experience. Crucially, participants explain and justify their choices to the group, transforming the activity into a collaborative negotiation of meaning. Through this dialogue, the group co-creates a shared vocabulary that will inform the shaping of Data-Probes in the next step and anchor the material expressions in collectively recognised experience.

⁎ Step 9 [Shaping the artefact: 30 minutes]

Each participant individually selects, assembles, and modifies materials to create an artefact representing their symptoms (Figure 3.12). Guiding questions include: what shape do your symptoms evoke? What feeling does the symptom provoke? Which object could express this feeling, and why?

The purpose of this step is to enable participants to translate their personal symptom experiences into tangible forms through individual making. Each participant selects, assembles, and modifies the available materials to create an artefact that represents how they perceive and feel their symptoms. Guiding questions prompt

reflective engagement, inviting them to consider what shape their symptoms evoke, what sensations or emotions the symptoms provoke, and how these qualities might be expressed through specific objects or material properties. This hands-on process encourages introspection, enabling participants to externalise experiences that are often difficult to articulate verbally. Working individually also gives them the freedom to explore their interpretations without the influence of others, while still drawing on the shared vocabulary developed earlier in the session. Through this material engagement, participants generate physical expressions of their symptom stories, deepening their self-awareness and preparing for the collective reflection that will follow.



Figure 3.11: second set of labels introducing physical variables. Participants explored the labels to associate specific material features with the symptom labels previously selected (on top of the image).



Figure 3.12: participant selecting and assembling Data-Probe components to represent her symptoms through material form. Both the pictures are from the second workshop session, organised in London, on May 2, 2024.

During this phase, each participant works on a paper tablecloth placed on the working surface (Figure 3.13, and 3.14). The tablecloth has a practical function, as it protects the table from dirt and possible damage caused by handling and assembling materials. It is also developed as a complementary tool for reflection and feedback within the workshop. Printed directly on the tablecloth is a series of short questions designed to collect participants' impressions while they are still engaged with the materials and tasks.

What material* would you have liked to have?

*physical material available on the table to "shape your symptoms".
Please, tick your answer.

- ◯ I am happy with the material provided.
- ◯ The material was ok but I would have used different materials, such as...
- ◯ I felt the material was not appropriate for the activity and to discuss the topic. Instead I would have used...

Did you feel engaged?

Please, tick your answer.

- ◯ Yes! :)
- ◯ Not really
- ◯ Not at all :(
- ◯ Any other answer?

What is a "variable"?

What phase was most difficult to understand?

Because not clearly explained or because contents were too difficult.
Please, tick your answer.

- ◯ **Phase 00:** Intro presentation to the project
- ◯ **Phase 01:** Symptom definition
- ◯ **Phase 02:** Symptoms identification, selection and organisation of labels
- ◯ **Phase 03:** Intro to physical materials and properties
- ◯ **Phase 04:** Identification and selection of material variables with labels
- ◯ **Phase 05:** Setting the rules to shape the symptoms (associating labels)
- ◯ **Phase 06:** Shaping activity
- ◯ **Phase 07:** Presentation of the artifacts
- ◯ None of the above

Did you feel uncomfortable?

Please, tick your answer.

- ◯ I was comfortable in the situation
- ◯ I was a little uncomfortable sometimes
- ◯ I was completely uncomfortable
- ◯ Any other answer?

What phase was most difficult to perform?

Because I did not know what to answer or because I was not able to do what required.
Please, tick your answer.

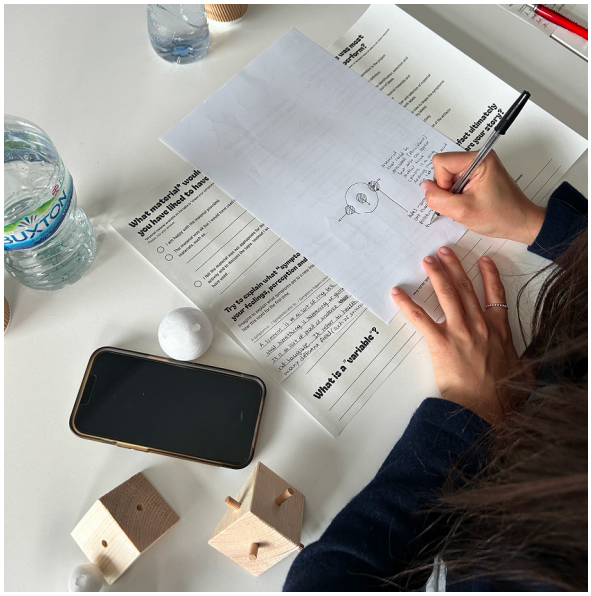
- ◯ **Phase 00:** Intro presentation to the project
- ◯ **Phase 01:** Symptom definition
- ◯ **Phase 02:** Symptoms identification, selection and organisation of labels
- ◯ **Phase 03:** Intro to physical materials and properties
- ◯ **Phase 04:** Identification and selection of material variables with labels
- ◯ **Phase 05:** Setting the rules to shape the symptoms (associating labels)
- ◯ **Phase 06:** Shaping activity
- ◯ **Phase 07:** Presentation of the artifacts
- ◯ None of the above

Was the artefact ultimately helpful to share your story?

Please, tick your answer.

- ◯ Yes! :)
- ◯ Not really
- ◯ Not at all :(
- ◯ I would like to specify my answer:

Figure 3.13: tablecloth provided to protect the table and collect feedback on the activity.



[On the right]

Figure 3.14: participant annotating the tablecloth and recording the meanings assigned.

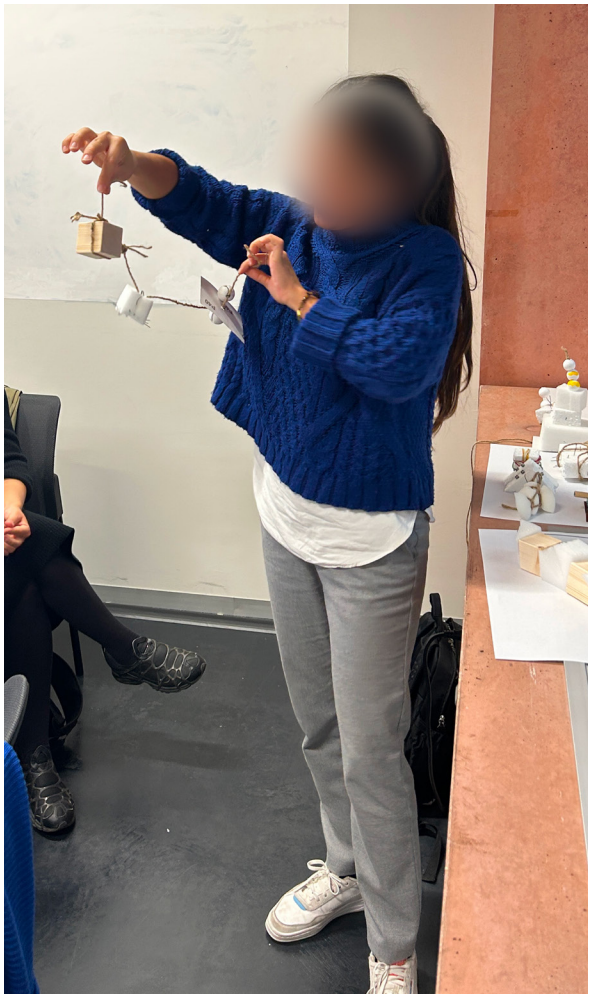
⁎ Step 10 [Reflection and presentation: 30 minutes]

Participants present their artefacts, explaining material choices and reflecting on their personal experiences of the condition. Discussion is encouraged, allowing others to engage with the representations.

The purpose of this final step is to create a space for participants to articulate, share, and make sense of the physical representations they have created.

Each participant presents their artefact to the group, explaining the material choices they made and reflecting on how these choices relate to their personal experiences of the condition (Figure 3.15 and 3.16). The discussion that follows allows others to engage with the representations, offering recognition, empathy, or alternative perspectives. Emphasis is placed on clarifying how specific materials correspond to particular sensations or experiences, reinforcing the interpretative link between physical variables and embodied symptoms. This reflective exchange supports greater self-awareness by encouraging participants to articulate experiences that may be difficult to verbalise directly. At the same time, it offers a socially acceptable and supportive way to express intimate or emotionally complex aspects of illness. Through shared interpretation, the step consolidates the collective understanding developed throughout the workshop and strengthens the connection between individual experiences and the broader participatory inquiry.

At the end of this phase, participants are invited to complete any remaining feedback on the assessment tablecloth. This closes the activity by connecting their reflections on the artefacts with their reflections on the workshop process itself.

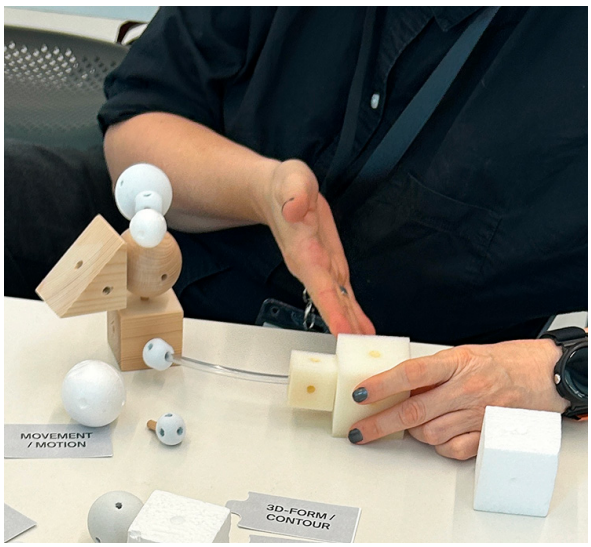


[On the left]

Figure 3.15: participant presenting their artefact built with Data-Probes components. First workshop session, on the left (Mendrisio, 2023).

[Below]

Figure 3.16: participant explaining her design choices during the fourth workshop session, held at the Cumulus Conference in Monterrey, 2024.



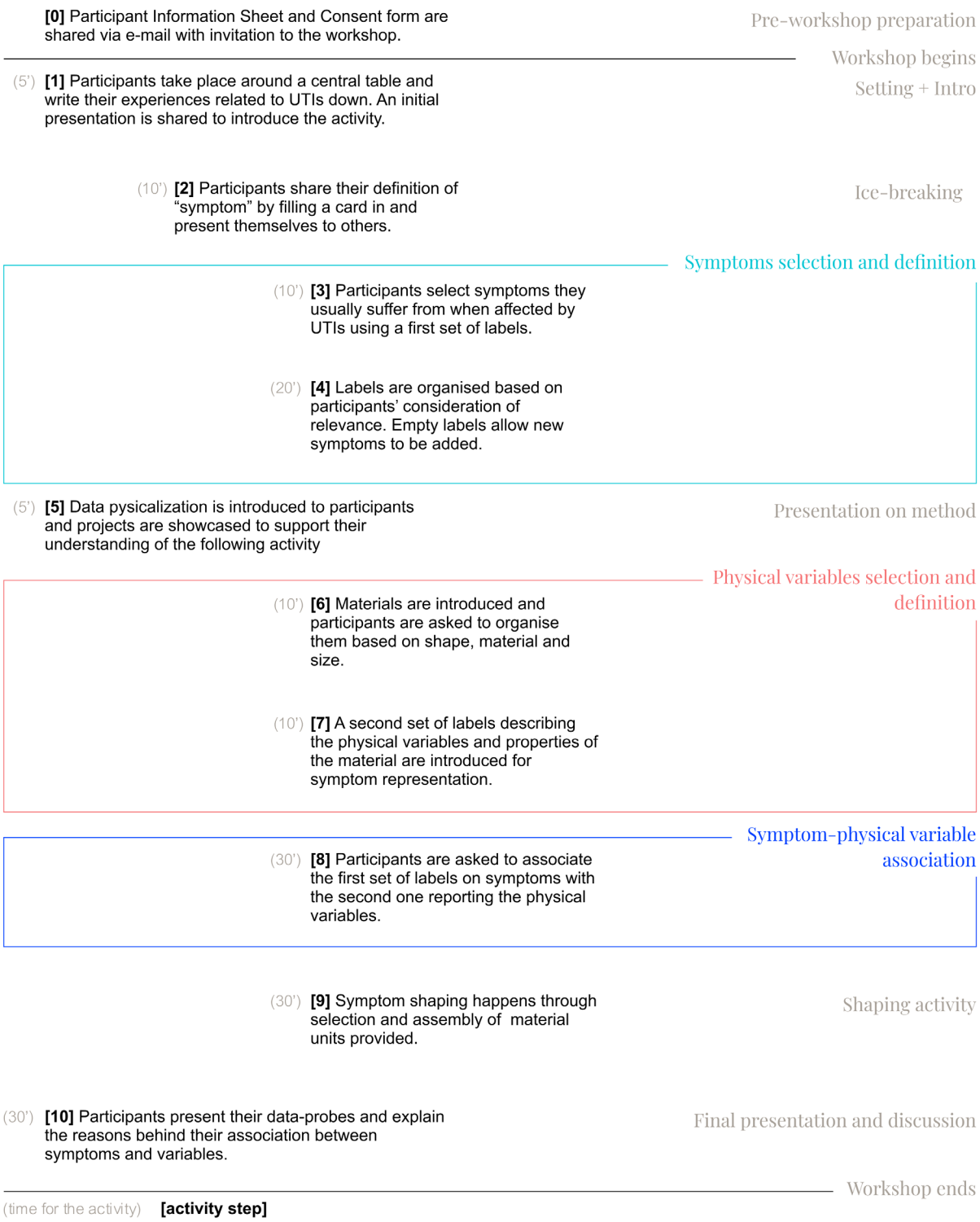


Figure 3.17: overview of the workshop steps and activity flow, based on the detailed protocol described above.

3.4 Data collection framework

The workshop format is designed to generate a range of qualitative data types that emerge across different stages of the activity. Each task produces specific forms of material or verbal output, which together build a multi-layered dataset combining textual, visual, and embodied expressions of symptom experience. In Table 1, I summarise the data formats generated in each phase, the collection methods used, the actions required from participants, and the purpose of collecting each data type.

Data description	Collection modality	Collection support	Data initial format	Data format for analysis	Action required to participant	Purpose of collection
(A) Personal stories and experiences	Individual	Online form	Written description	Text	Writing	Initiate self-reflection and assess communication style
(B) Symptom definition	Individual + Group	Paper cards + Audio-recording	Paper scan + Audio-transcript	Text	Writing + Verbal introductio	Stimulate reflection, support group alignment
(C) Biographic information	Individual	Audio-recording	Audio-transcript	Text	Oral self-introduction	Contextualise participant profile, clarify motivations
(D) Symptoms identification	Group	Labels + Audio-recording	Pictures + Audio-transcript	List of symptoms + Text	Selection, discussion, writing	Identify key symptoms and support conversation
(E) Physical variables identification	Group	Labels + Audio-recording	Pictures + Audio-transcript	List of variables + Text	Selection, discussion, writing	Familiarise participants with material vocabulary
(F) Symptom-variable association	Group	Labels + Audio-recording	Pictures + Audio-transcript	Table of associations + Text	Grouping labels, verbal dialogue	Map physical qualities to symptom experiences
(G) Artefacts	Individual	3D artefacts (Data-Probes)	Pictures	Image + List of components	Selecting and assembling	Elicit embodied symptom expression through material construction
(H) Presentation of artefacts	Individual + Group	Audio-recording	Audio-transcript	Text	Verbal presentation	Analyse metaphor, vocabulary, and embodied narratives

Table 1: collection modalities, methods, participant actions, and purposes are summarised in the table for each data type relevant to the study.

The descriptions that follow provide a concise explanation of each category.

(A) Personal story and experience of the disease

Participants submit open-format written narratives prior to the activity via a Microsoft online form. These unstructured text files offer direct insight into their lived experiences and communication styles. Texts are compiled into a single file for cross-reference with other datasets to identify emerging patterns and correlations.

(B) Symptom definitions

Participants respond to a printed prompt on paper cards, using an open format constrained only by a five-line space. These definitions are used as an introduction occasion for individual presentations to the group. Audio recordings of verbal presentations are transcribed and compared with written input. Cards are scanned for storage purposes.

(C) Biographic information

I asked participants to introduce themselves at the beginning of the workshop, sharing their motivation for attending, relationship to the condition, age group, and place of residence. These verbal introductions are audio-recorded and later transcribed to capture contextual insights. Participant profiles are used to inform interpretation of other data types, enabling cross-analysis by role, experience, and demographic context. Statements are categorised to identify typologies (e.g., patient, caregiver, health professional), which support comparative and intersectional readings across workshop outputs.

(D) Symptoms identification

Participants select and organise symptom labels collectively. Layouts (typically hierarchical) are documented via sequential photography. The final configuration, along with any added or discarded symptoms, informs frequency analysis and relevance mapping. Conversations are transcribed to capture reasoning behind choices and enrich the information on selection.

(E) Physical variables identification

This step replicates symptom identification but centres on material properties. Participants engage with predefined variable labels. Language translation may be required for participants who are not native speakers. The way participants describe and interpret variables during translation also provides valuable insights into their conceptual understanding. Photographs document how participants

arrange the labels, while audio recordings capture their reasoning, personal interpretations, and tactile impressions that inform and justify those choices.

(F) Symptom-variable association

Labels are physically grouped to reflect perceived connections. Spatial arrangements are photographed and recorded in structured spreadsheets to track co-occurrence patterns. Audio transcripts offer critical insight into participant rationale and interpretive frameworks.

(G) Artefacts

Participants construct 3D artefacts using modular material units. Each artefact is photographed from optimal angles to document components. A bill of materials complements each image, aiding in comparative analysis. Probe artefacts are later disassembled to preserve materials for future sessions.

(H) Presentation of artefacts

Participants verbally present their artefacts, linking them to personal health experiences. Audio recordings are transcribed for thematic analysis. Language used to describe components is mapped back to physical features to explore how embodiment and metaphor facilitate symptom expression.

3.4.1 Analysis aims

Originally, cultural probes were not designed to be analysed or to extract specific information. Instead, insights were drawn from what the materials allowed the researcher to observe and understand (Gaver et al., 1999). Similarly, data physicalizations are generally not created to be decoded in detail, as their purpose is to communicate data through form, rather than to support precise interpretation or retrieval of specific values.

However, the role assigned to Data-Probes in this research differs from the methods it relies on and therefore requires a defined structure for analysing the outcomes they generate. Establishing this structure first requires clarifying the function that data assumes within the study and how the materials collected contribute to knowledge production. The following points define the main roles of the collected materials within the research process:

[A] expanding the medical knowledge related to a specific disease and condition (UTIs);

[B] improving the use of data physicalization practices in participatory

environments to support self-awareness and communication of intimate and health-related conditions.

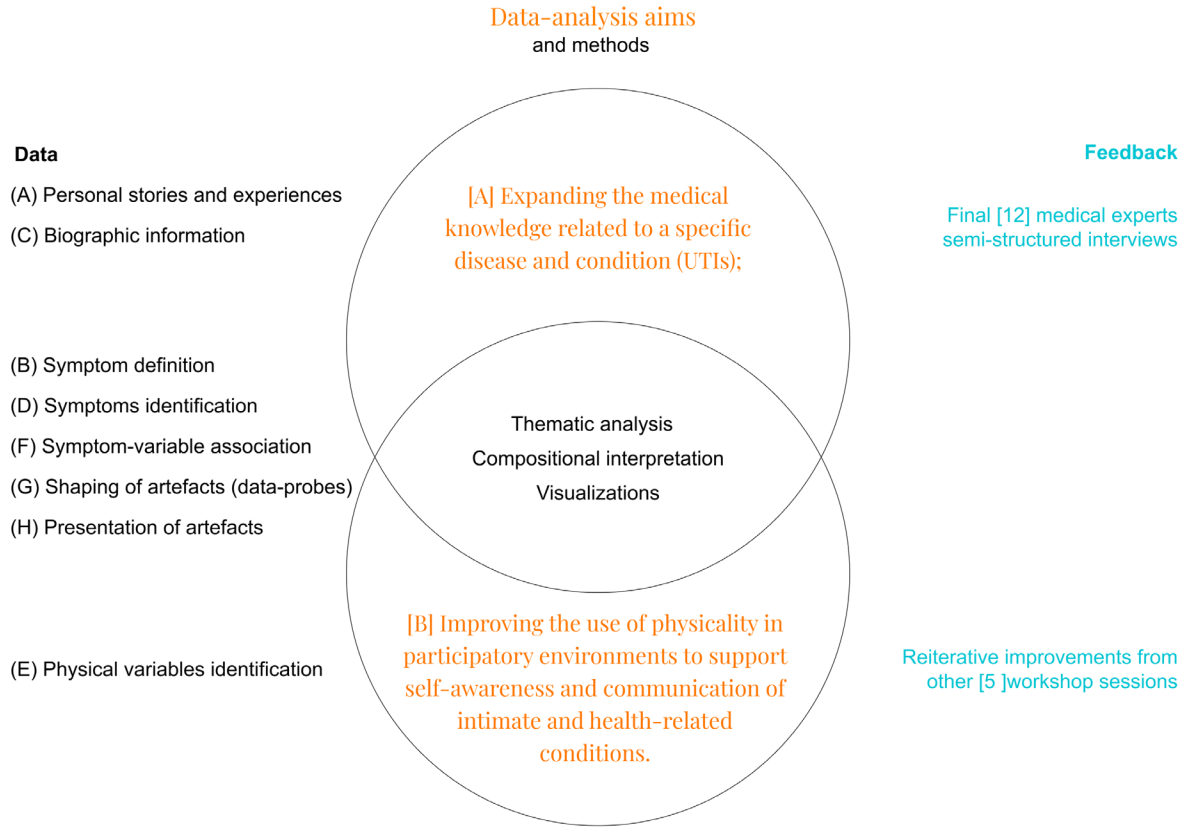
Accordingly, the analysis is organised around two complementary aims:

Aim [A]: exploring experiential knowledge of UTIs. This aim focuses on understanding how participants make sense of their condition through lived experience and includes:

- identifying symptoms not typically captured by clinical literature or biomedical frameworks;
- enriching the vocabulary, nuance, and descriptive range of symptom accounts;
- surfacing informal or alternative strategies for diagnosis, treatment, and prevention;

Aim [B]: assessing the methodological role of physicalization. This aim examines how physical materials influence the communicative and analytical dimensions of the workshop. It encompasses:

- understanding how materials shape engagement, articulation, and meaning-making;
- evaluating how the physicalization method supports interaction between participants and experts.



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Figure 3.18: overview of the research framework, showing the data collected in the workshops (left), the analytical aims and methods (centre), and the assessment strategy (right). Workshop feedback supported the iterative refinement of the method, while interviews with medical experts highlighted findings contribute to medical knowledge on UTIs.

3.4.2 Analysis methods

As illustrated above, the study primarily generates qualitative data. The process begins with participants' written stories, continues through structured and unstructured discussions during the workshop, and concludes with spoken descriptions of the artefacts created. Each workshop produces a full audio recording of group interaction, later transcribed for analysis. Written notes complement the transcripts by capturing contextual cues and non-verbal aspects of interaction. Printed cards, labels, and other support materials are also analysed, as they contribute to understanding the interpretive strategies used during the activities.

Analysis of the physical artefacts requires dedicated methods. Each object is photographed from multiple angles and accompanied by a structured description detailing its form, arrangement, and material components. These descriptions allow comparison across artefacts and support integration with written and spoken narratives. Artefact documentation provides an essential complement to transcripts, enabling the identification of correspondences between verbal descriptions, material choices, and embodied interpretations of symptoms.

Given the varied origins and formats of the data, I adopt mixed methods (Poth, 2023) and multimethod research (Muratovski, 2022) for the analysis. Following, I present the analysis strategies selected to address the two purposes outlined above [A and B]. Thematic analysis is applied to written narratives, transcripts, and spoken descriptions to identify patterns in how participants articulate symptoms and engage with materials. Compositional interpretation is used to examine the artefacts, focusing on how their material configurations express experiential meaning and how these meanings connect to participants' accounts.

Together, these approaches support a structured examination of how embodied experiences of UTIs and other health conditions are expressed, shared, and transformed through material engagement within the workshop setting.

Thematic analysis

Thematic analysis is adopted in this project as the primary method for interpreting the qualitative data collected during the workshop sessions. It offers a flexible and systematic approach to identifying recurring patterns of meaning within qualitative

data, making it suitable for design research contexts that involve complex, subjective, and open-ended participant contributions. In this study, thematic analysis supports the interpretation of participants' verbal accounts, group discussions, and artefact presentations, allowing the analysis to address both the lived experience of UTIs and the methodological role of material engagement.

The analytical framework is primarily based on Braun and Clarke's approach to thematic analysis (2006, 2013). Their model provides the main structure for identifying, developing, and refining themes in relation to the research questions. The application of Braun and Clarke's approach in this is explained in Table 2. Additional references support the adaptation of this method to the specific needs of the study. Maguire and Delahunt (2017) clarify the practical implementation of thematic analysis as a step-by-step process. Saldaña (2013) informs the coding procedure by showing how coding decisions shape the development of themes. Nowell et al. (2017) support methodological rigour, with particular attention to transparency, consistency, and trustworthiness. Karlsen et al. (2017) offer a relevant example of thematic analysis applied to qualitative data within a healthcare setting.

Analytic steps based on Braun and Clarke (2006, 2013)	Analytic steps of the current study
Familiarising yourself with your data	Records of the workshop sessions were automatically transcribed and manually reviewed and completed. As facilitator, I actively play in the collection and for this reason already identified some initial analytic interests and thoughts. Selection of statements was operated across the different workshop sessions. Italian statements (from the first workshop session) were translated to English to make all the contents accessible and comparable. Additionally, a summary of the key contents was reported for each of the extracts.
Generating initial codes	Codes were initially assigned based on an inductive approach.
Searching for themes	Codes were reported on a unique page for comparison and re-organised. Themes were initially identified based on an inductive approach driven by the data. Some codes were moved, some other renamed or assembled.
Reviewing themes	Themes evolved into sub-themes as the need for a more refined grouping became apparent. Finally, sub- themes were grouped in higher-level themes which have been deductively defined based on how the contents contribute to the original questions. The interviews were listened to again, ensuring that all relevant themes had been captured.
Defining and naming themes	Themes have been named considering the main insights in the sub-themes. Medical experts' interviews conducted at the same time of the analysis allowed me to share preliminary findings and validate sub-theme definition. Finally, each theme was moved on a separate sheet of the table of analysis so to facilitate the reading.
Producing the report	Themes organised the order of writing the report. Contents are first described, using extracts from statements, and later interpreted.

Table 2: description of the analytic steps, based on Braun and Clarke (2006, 2013).

Within this research, a theme is understood as a pattern that captures something important about the data in relation to the research questions. It is not treated as a repeated word or phrase, but as an interpretative structure that organises insights around shared concepts, concerns, or experiences. Themes therefore help connect individual accounts to broader patterns across the workshop material, while still preserving the situated and subjective nature of participants' contributions.

The analysis uses terminology drawn from Braun and Clarke to maintain consistency. The data corpus refers to the full body of qualitative material collected during the project, while the data set refers to the specific portion of the corpus selected for thematic analysis. Within this data set, data extracts are individual segments that are coded because they hold meaning in relation to the research focus. The analysis involves continuous movement between the full data set, the coded extracts, and the emerging interpretation. Writing is also part of this process, as it supports the gradual development of descriptive accounts, the refinement of themes, and the clarification of relationships across the material.

The study combines different forms of thematic engagement. Themes can be developed inductively, when they emerge from the data itself, or deductively, when they are shaped by pre-existing concepts or analytical lenses. In this research, the analysis is primarily guided by the research questions and by the theoretical framework developed in Chapter 2, while remaining open to patterns that emerge from the workshop material. This creates a balance between attention to participants' own accounts and interpretation through the concepts of embodiment, material engagement, participation, and physical variables. The analysis also works across both semantic and latent levels. At the semantic level, it focuses on the explicit content of participants' accounts, including how they describe symptoms, experiences, materials, and artefacts. At the latent level, it examines the assumptions, relations, and meanings that shape these accounts, including how participants make sense of symptoms through material and discursive practices. This combination is appropriate for the study because the workshop data includes both direct descriptions of experience and more interpretative forms of meaning-making that emerge through discussion, association, and artefact construction.

The thematic analysis is conducted using transcripts derived from the available audio recordings of the workshop sessions. Five sessions are included in the broader workshop programme, although the nature of the recordings differs across them. In sessions four and five, the distributed organisation of group work makes continuous recording of the full sessions impractical. For these sessions, the analysis therefore focuses on the final group presentations, when participants describe their artefacts individually. This difference in the recording format is taken into account during the interpretation of the data. Initial transcriptions are generated automatically

using Microsoft Teams and then manually reviewed against the audio recordings. This verification process supports accuracy and helps attribute statements to individual speakers, especially when participants work in close proximity and overlapping speech makes automatic identification difficult. Familiarity with the sessions, gained through facilitation and direct observation, supports this attribution process. In sessions four and five, where participants work in stable groups from beginning to end, individual speaker distinction is not required for the purposes of the analysis. The final transcript files are provided in the Appendix.

The first workshop session is conducted entirely in Italian, as all participants are Italian speakers. The transcript for this session is maintained in the original language, with selected excerpts translated into English to ensure consistency, comparability, and accessibility for the reader. All subsequent sessions are facilitated and transcribed in English.

After transcription, markers are inserted into the text to indicate the beginning of each activity phase. This organisational step contextualises the discussions, identifies shifts in focus, and supports the extraction of key topics. It also allows the analysis to connect participants' statements to specific moments in the workshop process, such as symptom identification, symptom–variable association, artefact construction, and final presentation. This phase-based organisation is particularly important because the workshop is structured as a progressive activity, and participants' interpretations develop across successive moments of reflection, material engagement, and discussion.

Compositional interpretation

To complement the thematic analysis of written and verbal data, compositional interpretation is adopted to examine the visual and material artefacts created by participants during the workshop sessions. Coined by Rose (2001), the term "compositional interpretation" refers to a formalist method for analysing visual material by focusing on its internal organisation and aesthetic features. This approach originates in art historical practices, particularly those associated with the analysis of paintings, and is rooted in Irit Rogoff's notion of "the good eye." But, while "the good eye" assumes an evaluative stance based on the analyst's prior knowledge and expertise, compositional interpretation places emphasis on the visual qualities of the object itself, seeking to provide a structured and descriptive reading of form, colour, spatial arrangement, and visual effect, that are independent of subjective judgement or external context.

In this research, compositional interpretation is adapted to the analysis of three-dimensional artefacts produced during Data-Probe activities.

Although originally developed for two-dimensional imagery, the method translates effectively to physical objects, offering a systematic structure for documenting their formal and material characteristics. This adaptation is essential, as the artefacts stand as independent data items that express embodied experiences through material configuration. A descriptive method is therefore needed to capture their visual and tactile features with precision and consistency.

The artefacts produced during the workshop play a dual role within the methodology. On one hand, they operate as conversational mediators, helping participants articulate sensations, reflect on their experiences, and communicate aspects of UTIs that are difficult to express verbally. On the other hand, they function as analytical objects in their own right. Their shapes, textures, arrangements, and material combinations provide concrete evidence of how participants understand, conceptualise, and externalise their symptoms. This duality raises specific analytical questions: how should the artefact be read independently from its verbal explanation? What constitutes relevant descriptive information? How can material decisions be examined without imposing subjective assumptions?

To address these questions, compositional interpretation is used to produce a written description of each artefact that focuses strictly on formal qualities: shape, spatial organisation, material composition, surface treatment, colour, and any visible modifications. This documentation is followed by a structured listing of the components used in its construction. Through this descriptive layer, each artefact is established as a distinct data source, enabling comparisons across workshop iterations and supporting the integration of material evidence with verbal accounts. Once this descriptive foundation is established, the artefact is compared with the participant's spoken and written explanations through thematic analysis. This comparison highlights how material forms may reinforce, complicate, or diverge from the verbal account of symptoms. Beginning with compositional analysis ensures that interpretations remain grounded in what is materially and visually present, avoiding premature assumptions or over-reliance on narrative data.

This method is meant to prevent the artefacts from being reduced to illustrations of participants' stories. Instead, they are analysed as autonomous outputs that reflect experiential knowledge shaped through material engagement. Compositional interpretation therefore acts both as a descriptive tool and as an analytical bridge, connecting the sensory qualities of material form with the subjective narratives through which participants make sense of their symptoms. The full compositional interpretations, together with the contextual descriptions that situate participants' selection and use of components alongside their accounts of living with the condition, inform the analysis of results presented in Chapter 5. A complete version of this material is provided in the Appendix.

3.4.3 Ethics and approval

Ethical considerations play a central role in this research, as the data collected involve personal experiences and bodily information related to health conditions. Participants are invited to reflect on and share aspects of their physical symptoms, emotional states, and experiences of diseases. Given the sensitive and intimate nature of these contributions, particular attention is paid to informed consent, voluntary participation, data protection, and the creation of a safe and respectful environment throughout all phases of the study.

This research receives full ethical approval from Brunel University London's College of Engineering, Design and Physical Sciences Research Ethics Committee. Other approvals are obtained for intermediary stages and activities of the research. All the approvals can be found in the Appendix at the end of this thesis.

In addition to the approval granted by Brunel University, separate ethics approvals are granted from the institutions where local iterations of the workshop were hosted. Specifically from SUPSI University (Switzerland), which hosted the first and third workshop sessions; the Universidad de Monterrey which hosted the fourth session within the Cumulus conference and lastly, the University of Bern (Switzerland), where the fifth session was conducted at the invitation of Dr. Paola Pierri, coordinator of the Social Design course.

Participants are recruited as volunteers based on their lived experience or professional knowledge of UTIs. All participants receive an information sheet detailing the purpose, structure, and scope of the study. Informed consent is collected prior to participation. Participants were also informed, both in writing and verbally at the beginning of each session, that their involvement was voluntary and that they were free to withdraw at any point, without the need to give a reason.

The workshop format is designed to foster open participation without placing pressure on participants to speak or disclose sensitive information. For this reason, no turns of speech or prescribed intervention modalities are organised. As such, it is possible for participants to take part in the workshop without contributing verbally, if they chose to remain silent. The physical and creative components of the workshop offer alternative means of engagement, making participation accessible at different levels of comfort and expression.

At the end of each session, participants are invited to provide optional feedback and were encouraged to contact me directly if they wished to discuss any matters in private, including topics they did not feel comfortable addressing in the group setting. This post-session opportunity ensures that participants retain full control over how and when they share aspects of their experiences.

Together, these measures form the ethical strategy adopted in this research,

which prioritises participant autonomy, confidentiality, and emotional safety, and ensures that embodied and intimate accounts of health are handled with care and respect across all stages of the study.

3.4.4 Data collection and management

At the beginning of each session, I remind participants that the conversation will be audio-recorded. A non-invasive recording device is placed at the centre of the table. Audio recording serves as the primary method for capturing the conversation generated during the workshop and is considered the main source of data for this research. These recordings are essential for supporting the understanding of contextual nuances and participant interactions during analysis.

Participants provide consent to be photographed as part of the consent form, with the option to take part in the activity without being photographed. When a participant opts out, care is taken to avoid capturing their image. Any photographs in which participants are visible are anonymised to ensure privacy and are used exclusively for research purposes.

All audio recordings, transcriptions, and visual or written materials produced during the workshops are stored securely in accordance with Brunel University's data management policy. Recordings are kept on a password-protected network server and will be deleted upon completion of the research. No identifiable information is included in the recordings, and all personal data are anonymised during transcription to ensure confidentiality. Access to raw data is restricted to myself and my supervisors. When possible, I took field notes during the sessions, depending on my availability as both facilitator and researcher.

3.4.5 My role, as the researcher and facilitator

The workshop is the core of the methodology of my PhD research. Based on a preliminary review of the literature, I designed the structure of the workshop and developed the materials used during the sessions. I also took on the role of facilitator, guiding the activities, introducing each phase of the workshop, and doing my best to create a safe and welcoming environment where participants felt comfortable enough to take part and share intimate conditions.

Throughout the sessions, I paid close attention to maintaining a balanced and inclusive atmosphere. I actively worked to prevent any individual from dominating the discussion and tried to ensure that no participant felt pressured to speak or share more than they wished. My aim was to encourage open dialogue while respecting each participant's personal boundaries and pace of engagement.

These responsibilities shaped my understanding of the method and informed the refinements I introduce throughout the project.

3.5 Iteratively refined methodology

The workshop methodology develops through an iterative and practice-led process grounded in design research. Each workshop operates both as a space for data generation and as an opportunity to refine the method, revealing how the structure, materials, and facilitation support participants' engagement with symptoms, physical variables, and Data-Probes. This orientation aligns with co-design evaluation perspectives that emphasise the importance of observing how participants interact, create, and make decisions during the activity, recognising these processes as central to how meaning and value emerge (Manohar, Smith and Calvo, 2016).

This iterative orientation also draws on design research traditions in which making, testing, and reflection unfold as interconnected processes (Koskinen et al., 2011). Evaluation takes place in situ, through direct engagement with participants and attentive observation of the activity as it unfolds. This approach resonates with models of reflective practice (Schön, 1983) and iterative prototyping (Zimmerman et al., 2007), where methods evolve through cycles of enactment, observation, and adjustment. In this research, insights are gathered through real-time observation, post-session reflection, participant comments, and feedback embedded within the workshop materials.

The refinements introduced across the sessions respond to practical constraints, participant feedback, and observations of how effectively the physicalization process supports expression, interpretation, and self-awareness. One key feedback tool is the assessment tablecloth included in the workshop setup. Its printed prompts collect participants' impressions of the activity, including their engagement, their understanding of physical variables and Data-Probes, and their views on whether alternative materials could better support symptom representation. These feedback mechanisms inform adjustments to the clarity of instructions, timing of activities, facilitation, level of engagement, and expressive potential of the material kit.

The following section presents how the workshop evolves across iterations by outlining the main differences between sessions. It first explains the trajectory of the five workshops and clarifies how each one contributes to the refinement of the methodology. The first workshop session is then discussed in greater detail because it functions as the pilot session. Its specific research conditions are introduced, including setting, group composition, geographical and linguistic context, recruitment, participant background, thematic focus, and sampling rationale. Participant feedback

and expert input from this session inform the definition of the final activity protocol. The remaining sessions are then described before the chapter moves to the analysis of results.

3.5.1 Trajectory of workshop sessions and participants

This section introduces the five workshop sessions conducted as part of the research and clarifies how they are referred to throughout the analysis. The abbreviation WS is used to identify each workshop session, followed by its chronological order number, from WS1 to WS5. Across the five sessions, the study involved fifty-two participants in total. Table 3 provides an overview of the participants reached during the research, organised by workshop session, date, and location, and indicates the condition discussed in each context. In WS1 and WS2, supervisors were also present. Their contribution remained aligned with the participant role adopted during the activity and is therefore reported collectively alongside the other accounts. The five workshop sessions differ in topic focus, participant composition, material configuration, and mode of participation. Presenting them together at this point clarifies the trajectory of the empirical work and shows how the methodology develops across the study. The first sessions focus specifically on UTIs and form the core material for analysing how women describe, interpret, and physicalise their symptoms. The later sessions extend the activity to other intimate and embodied conditions, providing further insight into the adaptability of the workshop format and the role of physical variables across different contexts.

This overview therefore serves two purposes. It situates the workshop sessions within the overall research trajectory and clarifies how each session contributes to the development of the final methodology. The following descriptions introduce each session in chronological order, outlining its context, participants, focus, and methodological relevance.

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Table 3: overview of participants across the five workshop sessions, organised by session, date, location, disease discussed, participant role where different from patient, and Data-Probe artefact identification number used in the analysis.

WS session	WS date	WS location	Disease discussed	Data-Probes ID
WS1	24/10/2023	Mendrisio (CH)	[Medical expert]	Data-Probe 1
WS1	24/10/2023	Mendrisio (CH)	Recurrent cystitis	Data-Probe 2
WS1	24/10/2023	Mendrisio (CH)	Severe episode of cystitis	Data-Probe 3
WS1	24/10/2023	Mendrisio (CH)	Candidiasis	Data-Probe 4
WS1	24/10/2023	Mendrisio (CH)	Recurrent cystitis + sever episode	Data-Probe 5
WS1	24/10/2023	Mendrisio (CH)	Not sure - probably candidiasis	Data-Probe 6
WS1	24/10/2023	Mendrisio (CH)	Occasional episode of cystitis	Data-Probe 7
WS1	24/10/2023	Mendrisio (CH)	Occasional episode of cystitis	Data-Probe 8
WS2	02/5/2024	London (UK)	Cystitis + other kind of complications	Data-Probe 9
WS2	02/5/2024	London (UK)	Occasional episode of cystitis	Data-Probe 10
WS2	02/5/2024	London (UK)	Recurrent cystitis	Data-Probe 11
WS2	02/5/2024	London (UK)	Occasional episode of cystitis	Data-Probe 12
WS2	02/5/2024	London (UK)	Other kind of infections	Data-Probe 13
WS2	02/5/2024	London (UK)	[Medical expert]	Data-Probe 14
WS3	24/05/2024	Mendrisio (CH)	Recurrent cystitis + fungal infections	Data-Probe 15
WS3	24/05/2024	Mendrisio (CH)	Occasional episode of cystitis	Data-Probe 16
WS3	24/05/2024	Mendrisio (CH)	Other kind of infections	Data-Probe 17
WS3	24/05/2024	Mendrisio (CH)	Recurrent cystitis + candidiasis	Data-Probe 18
WS3	24/05/2024	Mendrisio (CH)	Occasional episode of cystitis	Data-Probe 19
WS3	24/05/2024	Mendrisio (CH)	Occasional episode of cystitis	Data-Probe 20
WS4	15/10/2024	Monterrey (MX)	Flu-Covid	Data-Probe 21
WS4	15/10/2024	Monterrey (MX)	Intolerance to lactose	Data-Probe 22
WS5	25/10/2024	Bern (CH)	Sore throat and tonsillitis	Data-Probe 23
WS5	25/10/2024	Bern (CH)	Stomach-ache	Data-Probe 24
WS5	25/10/2024	Bern (CH)	Vomiting-anxiety-bellyache	Data-Probe 25
WS5	25/10/2024	Bern (CH)	Unknown	Data-Probe 26
WS5	25/10/2024	Bern (CH)	Well-being (opposite to illness)	Data-Probe 27
WS5	25/10/2024	Bern (CH)	Unknown	Data-Probe 28
WS5	25/10/2024	Bern (CH)	Insomnia	Data-Probe 29
WS5	25/10/2024	Bern (CH)	Neck pain	Data-Probe 30
WS5	25/10/2024	Bern (CH)	Back pain	Data-Probe 31a
WS5	25/10/2024	Bern (CH)	Insomnia	Data-Probe 31b

The first workshop session [WS1] functions as the pilot session and focused exclusively on UTIs. It involved women with lived experience of the condition and used a more open set of raw materials, with the support of a practice-based medical expert, to test the general direction of the method. This first session is especially important for refining the sequence of activities. In the initial version of the protocol, the shaping phase took place before the association of symptom and physical-variable labels. Participant feedback showed that this order made later collective agreement more difficult, as each person had already engaged independently with the materials. For this reason, the protocol was adjusted so that the association phase preceded shaping, allowing symptoms and material qualities to be discussed collectively before participants moved into individual construction.

WS2 introduces the first prototype of the material kit and expanded the thematic focus to include other intimate infections, while still working with women with lived experience. In this session, the presence of a research-oriented medical expert supported reflection on the broader applicability of the method and its relevance beyond the initial pilot setting. WS3 continues this development by using a redefined prototype that incorporated flexible connectors and by involving interaction design students in Switzerland. The session remained centred on UTIs and intimate conditions, while the absence of an expert gave greater prominence to participants' own interpretations and to the internal dynamics of the workshop process.

While WS1, WS2, and WS3 remain closely connected to the core focus on UTIs and other intimate infections, WS4 and WS5 introduce broader conditions and changes in the mode of participation. These developments emerged from the earlier sessions, which already suggested that the approach could support reflection and communication beyond UTIs alone, particularly because participants often connected their experiences to other intimate and embodied conditions. This opened the possibility of testing the method within a broader thematic frame while maintaining its attention to symptom interpretation and embodied experience.

The setting of WS4 contributes directly to this shift. Because the session took place in a conference context, participation included people of different genders and with different experiences of conditions. This required opening the focus beyond women's experiences of UTIs alone and created an opportunity to examine how the workshop operated with a more heterogeneous group and with self-selected conditions brought by participants themselves. WS4 also marks a methodological development in the role of participation. Earlier sessions mainly concentrated participation within reflection, discussion, and the association of labels, while artefacts were shaped individually. In WS4, participation extended more directly into the shaping of the artefacts themselves, allowing collaborative construction to become part of the methodological testing.

This direction is reinforced in WS5. In that session, the larger number of participants made collaborative shaping particularly suitable from a practical point of view, since the available kit could more effectively support group engagement than fully individual construction. At the same time, this setting provided an important occasion to test whether collaborative shaping could strengthen the flexibility and robustness of the method in a larger workshop context.

Taken together, the five sessions show a clear progression from a focused exploratory pilot to a more flexible, transferable, and scalable workshop format. WS1 establishes the overall direction of the method and generated the first major protocol adjustment. WS2 introduces the first prototype kit and broadened the thematic focus. WS3 refines the material system and emphasised participant-led interpretation. WS4 opens the workshop to broader conditions and tested collaborative shaping in a heterogeneous setting. WS5 consolidates this direction and examined the method in a larger educational context. Across these iterations, summarised in Table 4, the protocol evolved through practice, gradually defining a methodology able to adapt to different groups, conditions, and participatory arrangements.

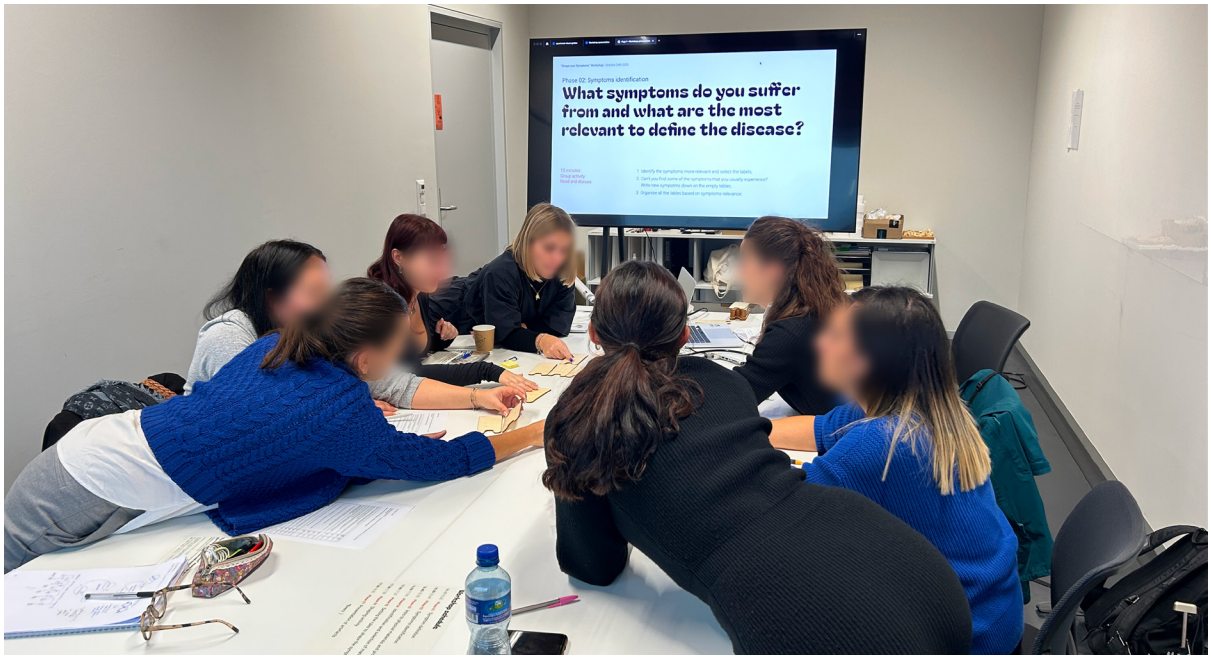
Aspects	WS1	WS2	WS3	WS4	WS5
Primary focus	Test method for UTIs	Test refined kit + broaden conditions	Compare multiple intimate infections	Open to other conditions + group shaping	Open to other conditions + group shaping
Condition scope	UTIs only	UTIs + other intimate infections	Compare multiple intimate infections	Any self-selected condition	Any self-selected condition
Participants	[8] Women with lived experience (design background)	[6] Women with lived experience (design background)	[6] Women with lived experience (interaction design students)	[8] Mixed gender (international conference audience)	[24] Mixed gender (social design students)
Language (location)	IT (Switzerland)	EN (UK)	EN (Switzerland)	EN (Mexico)	EN (Switzerland)
Material kit	Raw material	First kit prototype	Kit prototype redefined (+flexible connectors)	Final version of the kit	Final version of the kit
Shaping process	Individual shaping	Individual shaping	Individual shaping	Group shaping	Group shaping
Medical expert presence	Present (practice-based)	Present (research-based)	None	None	None
Purpose for analysis	Establish UTI findings + refine method	Establish UTI findings + test generalisability	Establish UTI findings + test generalisability	Methodological refinement	Methodological refinement

Table 4: summary of the evolving aspects across the five workshop sessions.

3.6 The first workshop session as initial methodological assessment

WS1 plays a central role in defining the protocol presented in this chapter. As the initial implementation of the method, it offers the first opportunity to test how the workshop structure, materials, and facilitation work in practice, and how the theoretical and methodological principles of the research can be enacted through the activity. For this reason, WS1 is introduced before the remaining sessions and discussed in greater detail. The session is first described through the same contextual information later provided for the other workshops, including setting, participants, focus, and material configuration. This description is followed by an analysis of participant feedback and the contribution of the medical expert involved in the session. This feedback informs the clarification of the activity sequence, the refinement of the material kit, and the adjustment of the protocol before its application in subsequent workshops.

Figure 3.19 shows participants seated around a central table at SUPSI University in Mendrisio, where this first session took place. The pilot focuses on observing how participants engage with the tasks, how the materials support or limit expression, and how the facilitation strategy responds to the presence of both participants with lived experience and medical experts. Feedback gathered from participants, together with insights from the expert interview, informs a set of refinements to the materials, the facilitation strategy, and the organisation of the tasks. These adjustments shape the subsequent version of the protocol and prepare the ground for the workshop sessions that follow.



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Figure 3.19: Picture from the first workshop session. 24 October 2023, Mendrisio (CH).

3.6.1 WS1: 24 October 2023 – SUPSI, Mendrisio (CH)

As outlined above, the first workshop functions as the implementation of the activity, testing the initial protocol, material set, facilitation strategy, and role of the medical expert within a UTI-focused session.

Group composition

A total of eight participants attended this session:

- 1 medical expert: a nurse with six years of professional practice and a master's degree in nursing sciences. Her experience includes work in a gynaecology clinic and in an elderly care home.
- 7 participants with lived experience of intimate infections, all working in design-related fields, including communication and information design:
  - 3 with recurrent UTIs;
  - 2 with a single episode of UTI;
  - 1 who initially believed she had a UTI but later recognised candidiasis;
  - 1 with general experience of intimate discomfort.

Geographical and linguistic distribution

This session took place at SUPSI University in Mendrisio. As the research emerged from the SPEARHEAD project, Switzerland served as the initial and primary context for methodological testing. Mendrisio, located in the Italian-speaking region of Switzerland and bordering Italy, brought together both Swiss and Italian participants. For this reason, the workshop was conducted in Italian, with occasional use of English terminology, particularly where design vocabulary is more commonly expressed in English.

Recruitment and participant background

Participants were recruited through a snowball sampling approach, beginning with colleagues in design-related fields and extending to people in their networks with lived experience of recurrent UTIs or other intimate health concerns.

This ensured a group that combined relevant symptom experience with familiarity in exploratory, material-led forms of engagement. Their background in design, particularly communication design and information-focused practices, supported early-stage methodological testing, as participants were equipped to comment not only on the articulation of symptoms but also on the clarity, coherence, and expressive potential of the developing Data-Probe method. A medical expert with practice-based experience in gynaecology and elderly care was intentionally included to observe how clinical perspectives interacted with experiential accounts within a participatory setting.

Thematic focus and evolution

At this initial stage, the workshop centred specifically on UTIs, consistent with the original focus of the SPEARHEAD project. However, the experiences shared during the session, including a case in which symptoms initially interpreted as UTI were later diagnosed as candidiasis, highlighted that intimate health conditions often overlap, coexist, or are misinterpreted. This insight became pivotal for the methodological evolution of the study, prompting a shift in subsequent workshops from a narrow UTI-specific lens toward a broader consideration of women's intimate infections and the ambiguities inherent in disease recognition.

Aim and sampling rationale

The primary aim of WS1 was to pilot the full structure of the workshop, test the clarity and sequencing of activities, and assess the usability of the initial material components. A strategically varied sample of women with different levels of UTI experience allowed the method to be tested across a range of symptom histories and levels of familiarity with the condition. Participants' design expertise ensured that the session could focus on methodological refinement and evaluating whether the tasks were intuitive, whether the physical kit enabled meaningful expression, and where adjustments were necessary. The inclusion of a practice-based medical expert enabled examination of whether the workshop format could mitigate hierarchical dynamics and support open dialogue between clinical and experiential knowledge. Together, these sampling decisions established a controlled yet diverse environment in which to assess and refine the emerging methodology before applying it to broader participant groups.

3.6.2 Feedback from participants

As the first implementation of the workshop, WS1 generated specific feedback on the clarity of the protocol, the timing of the activities, and the accessibility of the materials. The adjustments discussed below have already been incorporated into the final methodology presented earlier in this chapter. For this reason, some activities or details may appear here in their original form, before they were revised into the definitive protocol. Presenting this feedback makes the iterative development of the method explicit, showing which aspects of the first session required adaptation and how these changes shaped the workshop steps used in the following sessions.

Protocol adjustment

During the first session, participants were asked to submit a written description of their experience in advance by completing an online form. Not all participants completed this step. To ensure consistency across sessions, the protocol was revised. Time is now reserved at the beginning of each workshop to allow participants to write their narratives on a printed card if they have not submitted them beforehand. This adjustment ensures that all participants contribute their account and that narrative data is collected in a comparable manner across sessions.

Material availability and organisation

The material assortment made available during the pilot workshop is shown in Figure 3.20 and included a diverse selection of geometric units designed to offer participants multiple tactile and expressive possibilities. The kit comprised cubes made of wood, polystyrene, and foam rubber, each available in three size ranges, which are small (2–4 cm), medium (4–6 cm), and large (6–10 cm). A corresponding set of spheres was provided in the same size gradations and produced in wood, polystyrene, and steel. Additional shapes included wooden cylinders and triangular prisms in polystyrene and foam rubber. These components were arranged on a printed paper grid, Figure 3.21, intended to help participants navigate the options.

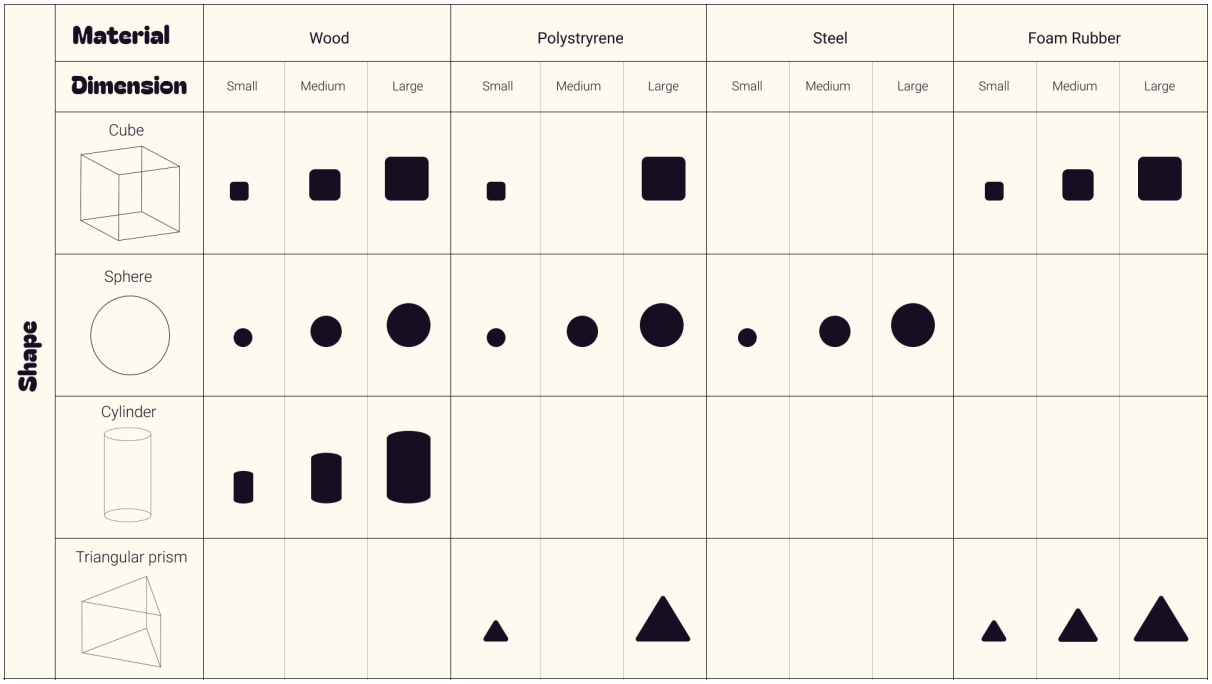
During the pilot, however, this organisational system generated confusion. Because not all shape–material–size combinations existed, the incomplete grid suggested a structure that the material kit could not fully support. Participants occasionally struggled to locate specific units, and the grid implicitly framed the materials in ways that did not reflect the openness of the activity. In response, in later sessions, I replaced the grid with labelled tags naming each material unit, such as “Small wooden cube” or “Large foam sphere.” Participants will be asked to place the materials next to the corresponding tags at the beginning of the session, creating an

initial familiarisation step that supported orientation and encouraged agency during shaping. The expert who attended the pilot echoed these concerns. She appreciated the tactile and expressive qualities of the materials but observed that the structured A0-format grid unintentionally acted as an interpretative frame. For example, participants might infer that larger shapes represent more severe symptoms. This observation aligned with participants' own remarks about the difficulty of navigating the grid. The expert therefore recommended presenting materials in a more randomised and unstructured manner to avoid bias and to preserve the personal, exploratory nature of the activity. She further suggested broadening the palette of materials by including paper, fabric, and colour, which could expand expressive possibilities and reduce the implicit influence of the grid.

Figure 3.20: material components arranged on a paper grid according to shape, material, and size. The empty cells indicated expected but unavailable components, which created confusion among participants.



Figure 3.21: paper grid used to organise the materials and help participants familiarise themselves with the available components and their features; the black shapes indicate the combinations of material, shape, and size presented in the first workshop.



Puzzle-shaped label adaptation

Participants reported that the laser-cut wooden labels used to describe material properties are difficult to handle because of their size, rigidity, and polished surface. Their smooth finish reduced tactile engagement, and their dimensions (13.5 × 7 cm) made them cumbersome during the activity. In response to this feedback, the labels have been redesigned as smaller paper tags (6 × 4 cm), which prove more flexible, approachable, and easier to manipulate. This redesign is applied both to the general descriptive labels and to those representing the physical variables, ensuring greater comfort and accessibility across all stages of the workshop.

Capturing limitations

Post-it notes are introduced in later iterations to give participants a way to express preferences for materials not included in the kit which were not properly recorded during this pilot session. This approach clarifies that the purpose of the workshop is not to perfect the kit, but to observe how physical variables support expression. Despite constraints, participants demonstrated strong and meaningful engagement, confirming the adequacy of the available materials.

Adjustments to facilitation and expert involvement

During the pilot, the medical professional was originally asked to participate in the same way as other participants. This approach proved unsuitable, as clinical expertise does not necessarily correspond to personal experience of UTIs. To resolve this, a set of targeted questions will be prepared specifically for medical experts. These questions will be asked during moments when participants engage in individual tasks, enabling experts to contribute reflections without disrupting or influencing the group dynamic. This strategy saves from the need for additional sessions while generating valuable insights during the workshop itself.

3.6.3 Insights from the medical expert interview

Alongside participant feedback, WS1 included a medical expert whose role was to provide a clinical perspective on both the topic of UTIs and the workshop methodology. The expert took part in the activity as a participant with professional knowledge, contributing to the discussion while also observing how the method supported symptom communication, patient awareness, and clinical interpretation.

This perspective complemented the feedback provided by other participants. While participant comments mainly addressed the experience of taking part in the

workshop, the expert interview offered insight into the medical relevance, clarity, and possible limitations of the approach. The reflections discussed below therefore clarify how the first implementation of the workshop was received from a healthcare perspective and how this feedback informed the refinement of the protocol, materials, and future role of experts within the method.

Interview modality and purpose

The pilot workshop included a healthcare professional based in Switzerland whose profile offered a relevant but distinct perspective within the group. She had practised as a nurse for six years and had recently completed a master's degree in nursing sciences. Her professional background included work in gynaecology clinics, where she supported expectant mothers and young women, giving her a strong foundation in women's health. At the time of the workshop, she worked in a care home for older adults, where urinary tract infections are a frequent clinical concern encountered almost daily. Although she had not personally experienced UTIs, she brought valuable professional insight through her clinical practice.

To clarify her role in the workshop and refine the involvement of experts within the methodology, a forty-five-minute online semi-structured interview was conducted one week after the session. The interview explored her perspective on the overall functioning of the activity, including which aspects worked well, which phases is more difficult to understand or perform, and which workshop goals appeared to be most effectively achieved. Further questions addressed her level of engagement, the suitability of the materials and vocabulary, the interaction with other participants, the possible value of having another expert present at the table, and the extent to which she felt useful during the activity. Particular attention is given to how she understood and defined her own role within the workshop. The full interview guide and transcript are provided in the Appendix.

Overall, during this conversation, the expert expressed a positive evaluation of the method. She noted the usefulness of material prompts for externalising personal experiences of illness and connected the approach to storytelling practices used in nursing education. She also identified the final model-making activity as a meaningful moment of synthesis for participants. The interview generated several themes concerning the usefulness of the activity, the clarity of the workshop phases, and the relevance of the method for healthcare contexts. These themes are presented below, together with the adjustments introduced in response.

Need for clarity in diagnosis and scope

The expert noted that some participants described symptoms more aligned with

candidiasis than with UTIs. To prevent confusion, she recommended clearly defining UTIs and their symptoms during recruitment and at the start of the workshop, distinguishing UTIs from other conditions such as candidiasis or vulvodynia, and providing a brief medically grounded overview of UTIs. Similarly, participants' feedback also indicated a need for clearer framing of the condition.

Distinguishing signs from symptoms

The expert emphasises the importance of distinguishing between signs, which are clinically observable, and symptoms, which refer to subjective experiences. Introducing this distinction through short explanations or visual cards could help participants describe their perceptions with greater precision and support collaboration with healthcare professionals.

Taking this feedback into account, the thesis expands the literature review on this topic and clarifies how the methodology engages with embodied perception. This distinction becomes a useful conceptual anchor for framing the role of materials in the workshop, showing how participants interpret and externalise subjective sensations through physical variables.

Reordering workshop phases

The expert recommended beginning with an individual exploration of materials to allow participants to develop intuitive and embodied associations before being exposed to verbal prompts or group input. Early exposure to others' interpretations may inadvertently constrain expressive possibilities or discourage more intimate reflections. In response, the revised methodology introduces an initial phase of independent material exploration, followed by the request to the group to classify and organise the material components.

Clarifying the expert's role

The medical figure expressed concern about being the only clinician in a group of patients, as participants occasionally turned to her for medical guidance. She recommended either involving multiple experts or assigning them the role of observers or facilitators rather than co-participants. She also noted that participants' questions stemmed from genuine interest rather than fear, suggesting that expert presence is valuable when roles are clearly communicated.

Together, participant feedback and the expert's reflections clarify the main adjustments needed after the pilot session, informing the refinement of the protocol, the material kit, and the facilitation strategy consolidated in the final protocol.

3.7 From the first workshop session to others

The first workshop plays an important role in shaping the methodology. Participant feedback and the medical expert interview highlight aspects of the activity that require adjustment, informing refinements to the organisation of tasks, the facilitation strategy, and the supporting materials. WS1 therefore establishes the main methodological structure adopted in the following sessions.

The method continues to develop through the four subsequent workshop sessions, which generate further observations and more focused adjustments. The definitive methodology presented earlier in this chapter results from the structure progressively developed and adapted across all five workshop sessions. Having summarised the main differences across the sessions above, the following sections introduce each workshop in detail. Each description outlines the setting, participants, thematic focus, and specific role of the session in the progressive development of the methodology.

3.7.1 WS2: 2 May, 2024 - Brunel University, London (UK)

The second workshop session applies the revised protocol in a new geographical and institutional context, testing the methodology with a larger group and strengthening the focus on recurrent UTI experiences.

Group composition

A total of six participants attended this session:

- 1 medical expert: a PhD student in healthcare with a research focus on AMR.
- 3 women who suffered from UTI:
  - 1 with recurrent episodes;
  - 2 with a single lifetime episode (one of whom is a Brunel PhD student in Design);
- 2 women with other intimate health concerns, unrelated to UTIs.

Geographical and linguistic distribution

The workshop took place at Brunel University in London and was conducted entirely in English. This geographical shift from Switzerland to the UK allowed

the methodology to be tested within a different cultural, institutional, and linguistic context.

Recruitment and participant background

Participants were recruited through university networks and academic contacts. Although many had backgrounds in design, their expertise did not centre on information design or data representation, making this session an opportunity to observe how individuals with broader creative training engaged with material-based approaches to symptom communication. The group also included a PhD researcher specialising in antimicrobial resistance (AMR), who played the role of the medical expert. In contrast to the practice-based clinical expertise present in WS1, this expert contributed a research-oriented perspective on infection management and antibiotic use, offering a different form of professional insight and enabling the study to examine how clinical and experiential knowledge interacted within the workshop.

Thematic focus and evolution

Insights from WS1 showed that participants often confused UTI symptoms with those of other intimate infections, revealing significant overlap in symptom interpretation. This finding prompted a deliberate broadening of the thematic scope in WS2. Recruitment was therefore opened to women experiencing a range of intimate health conditions beyond UTIs, acknowledging that symptoms such as irritation, inflammation, or discomfort may stem from conditions like candidiasis or non-specific intimate irritation. This expanded focus allowed the workshop to examine whether the method could support nuanced differentiation and comparison across diverse intimate health experiences while remaining relevant to UTI-related inquiry.

Aim and sampling rationale

WS2 was the first session to test the fully developed Data-Probe kit, following the exploratory material work of WS1. The aim was to assess how participants interpreted and used the structured components to represent their symptoms, and whether the method supported meaningful articulation of embodied experience across a heterogeneous group. Sampling was intentionally expanded to include participants with both UTI-related and non-UTI intimate conditions to evaluate whether the method could accommodate overlapping or ambiguous symptom profiles, which was an issue highlighted in WS1. The inclusion of an AMR specialist provided contextual knowledge and allowed observation of how expert input shaped or complemented the interpretative process.

Collectively, these sampling decisions enabled WS2 to refine the method's adaptability to a wider range of women's intimate health experiences and to inform the adjustments implemented in subsequent sessions.

3.7.2 WS3: 24 May, 2024 - SUPSI, Mendrisio (CH)

The third session tests the refined protocol again within the Swiss context, assessing the stability of the revised structure and the use of Data-Probes and physical variables in articulating UTI experiences.

Group composition

A total of six participants attended this session (from the MA of Interaction Design at SUPSI):

- no medical expert is present due to unavailability.
- 5 participants with lived experience of intimate or urinary infections:
  - 1 with recurrent UTIs;
  - 1 with combined experiences of cystitis and candidiasis;
  - 2 with single episode of UTIs;
  - 1 with fungal infections and occasional UTIs;
- 1 with other forms of intimate infection but no history of UTIs.

Geographical and linguistic distribution

This session was held again in Mendrisio, as WS1, but unlike the first workshop it involved international participants. For this reason, the session was conducted in English rather than Italian. This multilingual setting created an opportunity to observe how symptom interpretation and articulation unfolded when participants were required to express embodied experiences in a non-native language, highlighting the role of linguistic proficiency and translation in shaping the communication of intimate health concerns.

Participant recruitment and background

All participants were students enrolled in the Master in Interaction Design (MAInD) at SUPSI University, where the activity was promoted but participation remained entirely voluntary and unrelated to academic assessment.

The workshop was introduced within this environment as part of a research presentation delivered earlier in the academic year in the Multimodal User Experience Design in Products course, which provided an opportunity to invite interested students. Their background in interaction design offered familiarity with exploratory, design-led inquiry and with working through material and representational systems. This shared design literacy enabled more in-depth engagement with the methodological and expressive dimensions of the workshop while still allowing for the elicitation of authentic accounts of intimate health experiences.

Thematic focus and evolution

The thematic direction of WS3 was shaped by insights emerging from WS1 and WS2. Earlier sessions revealed that participants frequently experienced symptoms that overlapped across different intimate infections, demonstrating that UTIs cannot always be meaningfully isolated as a distinct category. WS3 therefore pursued a broader exploration of women's intimate conditions, encouraging reflection on the relationships, overlaps, and distinctions between UTIs and other infections such as candidiasis and fungal irritation. This thematic broadening enabled the workshop to test whether the physicalization method could support comparative reasoning across multiple conditions and surface the ambiguities and interpretative challenges associated with symptom interpretation. No medical expert was available for this session, which limited the presence of clinical knowledge during the activity and removed the possibility of addressing medical uncertainties in real time. However, this absence also created a valuable opportunity to observe how participants negotiated meaning, validated one another's accounts, and built shared understanding solely through peer-to-peer dialogue, without the influence of clinical authority.

Aim and sampling rationale

The primary aim of WS3 was to examine how the method functioned when working explicitly across multiple intimate health conditions rather than focusing solely on UTIs. Sampling was intentionally shaped to include participants with overlapping or intersecting experiences, such as recurrent UTIs, single episodes, candidiasis, fungal infections, and non-specific intimate discomfort, so that the workshop could explore whether and how physicalization might help differentiate or relate symptoms across conditions. Recruiting interaction design students ensured that participants were comfortable engaging in material experimentation and could offer informed reflections on the clarity and communicative potential of the physical variables and

shaping tasks. WS3 therefore played a critical role in expanding the methodological scope of the study and in assessing the adaptability of the Data-Probe approach beyond a strictly UTI-focused context.

3.7.3 WS4: 15 October 2024 – Universidad de Monterrey (MX)

The fourth workshop extends the methodology beyond the initial UTI focus, testing how the workshop format can support discussion of other intimate and embodied conditions within an international design conference setting. Participation also expanded from individual artefact-making towards more collective forms of discussion, comparison, and shared reflection.

Group composition

A total of eight participants attended this session, which included 2 men and 6 women working across design and healthcare. Participants worked in group of 4 people each, for a total of 2 groups. The groups included women and men working across design and healthcare, reflecting the interdisciplinary nature of the conference context. Participants chose the condition they wished to explore, leading to work on a variety of common health experiences rather than exclusively on UTIs.

Because conditions were self-selected and not predefined, participants represented a broader spectrum of health concerns, including recurrent infections, chronic conditions, and mental health experiences. This composition introduced gender diversity and a wider range of health topics compared to the first three sessions.

Geographical and linguistic distribution

This workshop took place in Monterrey, Mexico, during the international Cumulus design conference (2024). The event brought together participants from South America, North America, Europe, and Africa, creating a culturally diverse setting. The session was conducted in English, which served as the shared language among participants. This international and multilingual environment provided an opportunity to examine how the method operated across diverse cultural norms, comfort levels, and interpretative practices related to health.

Participant recruitment and background

Participants were recruited directly through the conference programme, with attendees opting into the session based on their interests. Many worked in design,

healthcare, or fields at the intersection of the two, and were therefore motivated by the relevance of the workshop's approach to their own practice. This resulted in a highly heterogeneous group in terms of expertise, age, cultural background, and familiarity with design-led research. Unlike earlier sessions, which focused on women experiencing intimate health conditions, WS4 invited participation from all genders. This shift aligned with the broadened thematic scope of the workshop and allowed the method to be tested across a wider demographic range.

Thematic focus and evolution

WS4, together with WS5, marked a deliberate methodological expansion intended to test the versatility and limits of the workshop beyond its earlier focus on UTIs and women's intimate infections. Opening the thematic scope was the first major change. Rather than working within a predefined condition, participants were invited to select the health issue they wished to explore. This shift allowed the method to be examined across a broader health landscape and made it possible to observe whether it could function effectively without the structure provided by a shared clinical topic. Because participants were no longer working within a predefined domain, symptom labels were removed to avoid constraining how each condition could be framed. Participants therefore generated their own vocabulary using blank labels, ensuring that the openness introduced at the thematic level was reflected in the representational process. As the workshop relied on group work, participants tended to select recognisable or commonly shared conditions to maintain mutual understanding. While this supported collaborative dialogue, it also created a limitation, since rare or highly individual health experiences were more difficult to address unless the workshop took place within a community that shared them.

A second methodological change concerned the shaping activity. In earlier sessions, shaping had been carried out individually, whereas WS4 introduced a collaborative approach. This change responded to insights from previous workshops that highlighted the importance of examining meaning-making as a collective, negotiated process. Collaborative shaping made it possible to observe how participants interpreted symptoms together, reconciled differing perspectives, and produced shared representations through joint material engagement.

Further adjustments included the introduction of the full set of physical variables identified by Hornecker et al. (2023). Earlier workshops employed a limited selection and excluded variables that did not correspond directly to the material kit. WS4 included all variables in order to explore whether participants might still find interpretative value in properties that were not visibly present. This decision was informed by feedback suggesting that participants were able to conceptualise or imagine physical qualities beyond those physically available.

Together, these methodological extensions broadened the scope of the workshop beyond intimate health and enabled examination of how the method supported the articulation of physical, mental, and chronic conditions when participants selected the topic themselves, created their own symptom vocabulary, and engaged in collective meaning making.

Aim and sampling rationale

The aim of WS4 was to extend and stress-test the methodology beyond its original focus and participant base. The session explored whether the physicalization method remained coherent and meaningful when applied to health experiences unrelated to UTIs, when used with mixed-gender groups, and when shaping was performed collectively. It also assessed whether the method could accommodate the full set of physical variables proposed by Hornecker et al., rather than a curated subset. Conducting the workshop within an international design conference provided a diverse participant sample with varying approaches to discussing health and different levels of familiarity with design-led inquiry. This diversity offered a demanding and informative context in which to evaluate the robustness and inclusivity of the method, generating insights critical for understanding its potential application beyond the intimate health focus of earlier sessions. For this reason, the data generated informed methodological refinement rather than the thematic analysis of UTI symptoms.

3.7.4 WS5: 25 October, 2024 – University of Arts, Bern (CH)

The last session further explores the transferability of the method by applying the workshop in an educational design context, with attention to broader embodied conditions and alternative modes of participation.

Group composition

This session involved approximately 24 participants, forming six groups of about four people each, with an additional two individuals choosing to work independently. Similarly to the WS4, participants were mixed-gender students enrolled in the Social Design MA programme at the Berner Fachhochschule. As in that occasion, participants selected the condition they wished to work on, which meant that the activity covered a broad spectrum of health and wellbeing concerns rather than UTIs specifically. Consequently, conditions explored in the session included the followings:

* recurrent or occasional infections;

* chronic discomforts;
* mental health–related symptoms;
* other self-identified health experiences

This diversity allowed further testing of the method's ability to accommodate a wide range of embodied conditions.

Geographical and linguistic distribution

The workshop took place in Bern, in the German-speaking region of Switzerland, but the session was conducted in English. This choice reflected the international composition of the student cohort and ensured a shared working language, particularly as I, as the facilitator, do not speak German.

Participant recruitment and background

Participants were recruited through the Social Design MA programme, for this reason, all attendees had experience with collaborative design processes and socially engaged approaches. Their background supported engagement with the exploratory and reflective nature of the workshop. As in WS4, the cohort included people of different genders. The freedom to choose which condition to explore generated a broad range of entry points into the activity and created an open, exploratory context in which to test the adaptability of the methodology.

Thematic focus and evolution

This session continued the methodological expansion introduced in WS4, in which participants defined the health condition they wished to work on rather than responding to a predefined UTI-centred structure. WS5 followed the same protocol as WS4, allowing the method to be examined as a more general approach to embodied health communication. The wider thematic scope led to richer interpretative possibilities, such as the representation of chronic pain, psychological states, or diffuse forms of discomfort, and demonstrated how the method operated when participants engaged with experiences that are not necessarily medicalised or diagnostically precise.

Aim and sampling rationale

The aim of WS5 was to further examine the robustness, flexibility, and transferability of the methodology by situating the workshop within a different educational and

cultural environment and by giving participants full autonomy in defining the condition they wished to explore. Sampling a large cohort of Social Design students offered a valuable test of the method. Their design training supported collaborative making and conceptual exploration, while their exposure to socially oriented methodologies aligned with the participatory ethos of the workshop. Their diversity in terms of gender, nationality, and lived experience allowed the workshop to be tested across a broad spectrum of interpersonal dynamics.

This session also enabled examination of how group-based shaping influenced engagement, negotiation, and interpretative depth, particularly when dealing with conditions that include emotional and psychosocial aspects. Testing the method under these conditions clarified which aspects of the workshop were essential, which could be adapted, and how the method could be applied outside the context of specific inquiry. For the same reasons as in WS4, the feedback and data generated during this session were analysed with a focus on methodological refinement rather than on the specific topic of UTIs.

The following section situates these workshops within the geographical and healthcare contexts in which they took place, providing background for understanding how participants' accounts were shaped by different systems of care, cultural expectations, and pathways for seeking medical advice.

3.8 Geographical context and healthcare settings

The workshop sessions took place across different geographical and healthcare contexts. These contexts shaped how participants understood symptoms, accessed care, interpreted diagnostic uncertainty, and described their experiences of treatment. Introducing them here provides background for the analysis presented in the following chapters, where participants' accounts refer to different systems, expectations, waiting times, costs, and pathways for seeking medical advice.

This section focuses on Switzerland, Italy, and the United Kingdom. Switzerland is included as the principal site of the research, where most collaborations and sessions took place. Italy is included because the Mendrisio workshops were conducted in Ticino, an Italian-speaking Swiss region with cultural and healthcare connections to neighbouring Italy, and because some participants referred to experiences within the Italian system. The United Kingdom is considered because one workshop session was conducted in London, where participants' expectations were shaped by the National Health Service.

The aim is not to evaluate these systems, but to situate participants' experiences within the institutional and cultural conditions that informed how they understood, communicated, and acted upon intimate symptoms.

In Switzerland, access to medical care is organised through mandatory basic health insurance, which covers primary care, specialist consultations, diagnostic tests, and hospital treatment. Patients contribute through an annual deductible and a co-payment, while the insurer covers the remaining eligible costs. Access routes vary depending on the insurance model. Some people can consult a doctor directly, while others are required to contact a designated GP, HMO centre, or telemedicine service before arranging further care. These arrangements affect how quickly patients seek help, whether they consult a GP, gynaecologist, pharmacy, permanence clinic, or emergency department, and how they weigh costs when symptoms appear (FOPH, 2025a, 2025b). For suspected UTIs, the usual pathway involves describing symptoms to a healthcare professional, followed where needed by urine testing to confirm infection and identify bacteria before treatment, especially in complicated, persistent, or recurrent cases.

In Italy, the Servizio Sanitario Nazionale provides universal access through regionally organised healthcare services. The general practitioner, or medico di medicina generale, usually acts as the first point of contact, while specialist visits and diagnostic tests may involve co-payments known as ticket fees unless exemptions apply. Regional variation can affect waiting times and access to diagnostic services, which may lead some patients to use private consultations or laboratories for faster assessment (Ministero della Salute, n.d.). For suspected UTIs, the pathway commonly begins with symptom recognition and consultation with a GP, who may prescribe urine analysis or urine culture when infection is suspected. Urinary infection is commonly associated with symptoms such as frequent urination, burning, and pain during urination, which are used to guide the decision to seek medical assessment and diagnostic testing (Istituto Superiore di Sanità, 2021).

In the United Kingdom, the National Health Service provides care largely free at the point of use. Patients usually access their registered GP as the primary entry point for non-emergency healthcare, with specialist care generally requiring referral. For UTIs, the pathway may involve a GP, pharmacist, NHS 111, urgent treatment services, or Accident and Emergency, depending on symptom severity and availability. NHS guidance states that a pharmacist or GP may carry out a urine test, although this is not always required, and that treatment may include self-care advice, pain relief, a short course of antibiotics, or delayed antibiotic prescribing (NHS, 2024). In England, the Pharmacy First service also allows community pharmacists to manage uncomplicated UTIs in women aged 16 to 64, supporting access without an initial GP appointment in relevant cases (NHS England, 2025).

Presenting these healthcare systems helps clarify the conditions under which participants developed their attitudes towards symptoms, diagnosis, and treatment. Differences in insurance arrangements, costs, first points of contact, access to urine testing, pharmacy involvement, and waiting times can influence whether participants seek care immediately, manage symptoms independently, or wait until symptoms intensify. These factors are important for interpreting the workshop discussions because participants' descriptions of UTIs were shaped not only by bodily sensation but also by previous encounters with healthcare systems and by expectations about how their symptoms would be recognised.

Building on this contextual background, the chapter now moves towards its conclusion by drawing together the methodological decisions developed throughout the chapter, including the role of physical variables, the design of Data-Probes, the workshop protocol, the iterative refinement of the sessions, and the contextual conditions that shaped the empirical work.

3.9 Conclusions on the methodology

This chapter has defined the methodological framework developed for this research by introducing physical variables, the associated labels, the Data-Probes, and the Shape Your Symptoms workshop protocol. Together, these elements form a participatory and material approach through which embodied symptoms can be identified, discussed, and translated into tangible artefacts. The chapter has also explained how the methodology develops through iterative refinement. The pilot workshop was especially important in shaping the protocol, while the later sessions contributed further adjustments that strengthened the structure, materials, and facilitation of the activity. In this way, the method takes form through implementation as much as through initial design.

The workshop presented here represents the methodological configuration developed through this research, while also pointing towards other possible adaptations that could emerge in response to different contexts, conditions, and research aims. To support future work and guide those who may wish to adopt or further develop this approach, the following section outlines the current limitations of the method before the thesis moves to the analysis of the activity results.

3.9.1 Limitations

While this research adopts a rigorous and transparent methodology grounded in design research and qualitative enquiry, several limitations must be acknowledged.

First, the inherently interpretative nature of both thematic analysis and compositional interpretation introduces a degree of subjectivity, as meaning and pattern recognition depend on my perspective as the researcher. Although reflexivity and documentation of methodological decisions are maintained throughout, the absence of multiple coders or participant validation limits the intersubjective reliability of the findings. This limitation is further reinforced by the central role of the researcher in both facilitating and adapting the workshop sessions. The success of the format thus partly depends on tacit knowledge and contextual sensitivity, which challenges its reproducibility and scalability in other settings or by other practitioners. Second, the iterative design and embedded assessment approach, while suitable for experimental and participatory formats makes cross-session comparison more complex. The methodological structure prioritises process and insights over replicability, which aligns with the research intention but constrains broader application.

The physical kit also introduces certain limitations. Constraints in material diversity and the structural rigidity of some components may have restricted expressive possibilities for some participants or required a degree of manual abilities that not everyone possesses. Although the kit is intentionally designed to minimise the influence of personal skill on both process and outcome, individual backgrounds and levels of familiarity with making can still shape how comfortably participants work with the materials. In some cases, attention to aesthetic qualities may overshadow the focus on embodied experience, which can reduce the clarity or validity of the resulting artefact as a representation of symptoms.

Limitations do not only regard the process of making but also the analysis of results. In this direction, evaluating the impact and success of a collaborative, open-ended methodology such as the one developed in this research presents specific limitations. As Shadlyn et al. (2022) note, assessing processes grounded in participant expression and co-creation is intrinsically complex, particularly when outcomes are non-standardised, context-specific, and shaped by individual interpretation. This challenge is amplified when working with qualitative data, where value lies not in measurable outputs but in the depth and resonance of the insights generated. Conventional academic indicators, such as publications or funding metrics, therefore, offer only a partial measure of success. Within design-led participatory research, alternative forms of evaluation become essential. The extent to which the work is legible, relevant, and meaningful to individuals or communities who experience similar challenges becomes a key indicator of its contribution. Engagement in related initiatives, such as workshops, exhibitions, symposia, or public presentations, also plays a role by providing opportunities for the work to be shared, questioned, and collaboratively refined. These forms of evaluation remain less formalised than traditional indicators yet align more closely with the aims of

participatory methodologies, which privilege dialogue, reflection, and contextual knowledge. On the other hand, the reliance on voluntary engagement reflects a broader limitation within participatory and co-creative research, where the ambition for inclusive involvement must be balanced with the practical difficulty of coordinating schedules, securing commitment, and ensuring availability. The gap between methodological ideals and the logistical realities of collaboration therefore remains an inherent constraint.

Recognising these limitations is important for situating the scope of the methodology presented in this chapter. They clarify the contextual character of the workshop format, the role of facilitation and participation dynamics, and the complexity of evaluating open-ended and material forms of interpretation. Further limitations that emerged through the application of the method are examined in the later analysis of methodological findings and returned to in the concluding chapter, where the scope, transferability, and future development of the approach are discussed more fully. Building on the methodological framework defined here, Chapter 4 presents the physical results produced through the Data-Probes, introducing the artefacts as material outcomes of the workshop process. Chapter 5 then examines the health-related insights generated through this methodology, focusing on UTIs and other intimate embodied conditions, while Chapter 6 analyses the methodological findings concerning physical variables, material engagement, gestures, and the structure of the workshop itself.

4. DATA-PROBE ARTEFACTS: MATERIAL OUTCOMES OF THE WORKSHOPS

Before moving to the analysis and its findings, this chapter presents the Data-Probe artefacts [DP], which are the physical outcomes created by participants during the workshops using the Data-Probe kit. Figures 4.1–4.31 provide a visual overview of how participants across WS1, WS2, WS3, WS4, and WS5 translated experiences of symptoms and health conditions into material form. Together, these images document the physical appearance of the artefacts, the variety of configurations produced, and the workshop contexts in which they were created. They establish the visual and material basis for the analytical chapters that follow.

To clarify how the artefacts were assembled and how Data-Probe components contributed to meaning-making, each artefact is examined through the compositional interpretation method introduced in Section 3.4.2 This method describes the physical characteristics of each artefact, including form, material, texture, weight, structure, and spatial arrangement. Where available, the compositional interpretation is complemented by contextual description, which situates the artefact within the moment of its creation and presentation by drawing on participants' explanations, interactions, and behavioural cues derived from the workshop conversation transcripts.

For WS1, WS2, and WS3, each Data-Probe artefact corresponds to an individual participant [P]. This one-to-one relation allows the analysis to connect material choices with personal accounts of symptoms and embodied experience. The numbering of the artefacts follows this relation up to DP20, where each DP number corresponds to the participant who created it. Where participant statements inform the interpretation of an artefact, timestamps from the audio recordings are provided in brackets to indicate the specific moment in the transcript to which the analysis refers. Full transcripts are available in the Appendix.

From DP21 onwards, corresponding to WS4 and WS5, this numbering no longer refers to individual participants because the artefacts were created collaboratively in groups. In these sessions, participants worked together on shared diseases

or conditions rather than on personal symptom experiences. For this reason, the analysis of these artefacts focuses on compositional interpretation, as the workshop structure did not support the collection of individual accounts of the disease.

Together, these artefact descriptions support the reading of the visual material by clarifying how each Data-Probe is assembled and what its main physical features are. They provide useful detail for interpreting the images, although the main analytical insights are developed in the thematic analysis that follows.

Data-Probe artefact 1

Compositional interpretation

The artefact is composed of six distinct formal elements arranged in a compact and layered structure. A blue-painted triangular prism occupies the central position, acting as the main visual anchor. Beneath it, a rectangular plane painted in a similar shade of blue extends horizontally, partially overlapped by a dark red sandpaper rectangle positioned at a slight angle. Two spherical volumes are placed at the base: one is a large white foam sphere with a smooth, cellular surface; the other is a smaller wooden sphere encased in a black wireframe structure that intersects its surface. A cylindrical wooden peg emerges from the top left corner, partially embedded behind the planes. The elements present a mix of geometric solids such as prism, spheres, and rectangles, crafted in contrasting materials and surface treatments.

Contextual description

During the artefact presentation, other participants said that P1 had created the most beautiful artefact. This was especially meaningful because she was the only person in the group without a design background. It was also the only time beauty was directly mentioned during all three workshop sessions. Although P1 said she had never experienced UTIs herself, her role as a medical expert clearly influenced how she approached the task. She described the illness from a professional point of view and used materials she was not familiar with to build the object. The sandpaper was used to show that life is not always smooth and that many people face difficulties, including health problems like UTIs. She used bright colours to express a sense of hope and to suggest that solutions and improvements are possible for patients. A small wooden sphere, held tightly by a wire structure, represented how every case is different. This idea is very important in healthcare today, where treatments are becoming more focused on each person’s specific needs. The fact that this came from someone who works in medicine shows how important it is to

recognise these differences when caring for patients. P1 felt the need to specify what the sphere does not mean. Participants usually point to what their choices are positively supposed to communicate. P1's clarification arises from her recognition of the intrinsic meaning of the sphere, despite her intention to deviate from it. She likely created the artifact with the concept of uniqueness in mind, as she claims, but came to understand through others' descriptions that it might be more naturally perceived in a different way. In the end, the light sphere represents effectiveness of the alternative remedies, as antibiotics are not the only solution, but "lighter" and less invasive cures might work as well, such as the acupuncture – to which a friend of her successfully underwent (P1, 01:52:24).



Figure 4.1: Data-Probe artefact 1

Data-Probe artefact 2

Compositional interpretation

The artefact is built vertically, with elements threaded together along a central cord. At the base, a large foam parallelepiped provides the main structure. It is placed horizontally and acts as the foundation for the composition. Attached to one of its lower edges is a square piece of sandpaper, slightly tilted and partially hidden behind the foam. On top of the base, two smaller blocks are stacked: a foam cube placed upright and a polystyrene parallelepiped leaning diagonally against it. The parallelepiped has a rougher texture compared to the smoother foam cube. Above the blocks, three small polystyrene spheres are arranged in a straight vertical line. They are stacked neatly, with a yellow-painted surface on the lowest one adding some colour to the composition. All parts are held together by a brown cord running through the centre, slightly visible at the top and bottom. The materials are light and soft, and the overall shape is simple but balanced. The vertical layout and the way pieces are stacked create a sense of structure and direction, with a gradual shift from large and wide at the base to small and round at the top.

Contextual description

At the start of her presentation, P2 admitted she had to remind herself what her artefact represented. While building it, she had sketched a small legend on the back of the tablecloth to keep track of its meaning. She explained that the structure was meant to represent a flow, both in terms of time and personal experience, related to urination. From the beginning, she clearly described her intention to recreate a timeline of the disease. This sequence helped her understand which actions or events might trigger pain or discomfort. P2 openly stated that she suffers from cystitis and used the artefact to make sense of the symptoms that appear before and during an episode. According to her explanation, the elements in the artefact follow a chronological order and reflect the physical sensations she experiences. The pins and small spheres symbolise the difficulty and discomfort in urinating, while a piece of sandpaper was used to show the worsening of the condition, especially the pressure behind the urethra. This material, originally provided only to modify other components, was instead used as a direct representation of the symptom. Through this process of reconstructing the timeline, P2 was able to recognise the role of nutrition in managing her condition. She now follows a specific diet when she senses the illness may return, especially in the days leading up to her menstrual cycle. She also noticed that other symptoms, such as abdominal swelling, often appear

before urination becomes painful. By becoming more aware of these early signals, she learned to act earlier and prevent more serious episodes. P2 first experienced the illness at the age of fifteen. At the time, she found it difficult to speak about it, associating it with sexual activity and feeling ashamed. Her initial consultation with a female gynaecologist led to a recommendation to use cranberry-based treatments, which were not effective. After a more serious episode years later, she received proper tests and a longer treatment with antibiotics and other medications. The disease continues to affect her daily life, especially her relationship with intimacy, as she now needs to follow strict hygiene routines after intercourse.



Figure 4.2: Data-Probe artefact 2

Data-Probe artefact 3

Compositional interpretation

The artefact consists of a sequence of seven individual modules, arranged horizontally in a line. Each module shares a similar structure but presents small variations. The base of each unit is a wooden cube or cylinder, acting as a stable support. On top of each base, a square or rectangular block of white polystyrene is placed. Most modules are topped with a triangular prism or pyramid made of the same white foam, oriented to point upward and slightly forward, creating a repetitive roof-like shape. The sixth module departs from this structure. It has a larger foam block at the top, covered with several small wooden spheres arranged in a grid. Below it, a piece of white sponge-like fabric is folded between the base and the upper foam block, adding a softer and more compressed element to the otherwise rigid composition. The seventh and final unit is separate from the others. It consists of a single white foam cube, placed directly on the surface without a visible base. A small metal chain or wire is attached on top of this cube, introducing a contrasting material and texture. Across the sequence, the artefact builds a visual rhythm through repeated shapes and balanced proportions. The use of identical or similar materials in each part creates coherence, while the gradual changes from one module to the next suggest variation within a consistent structure.

Contextual description

The participant chose to represent the evolution of her condition by focusing on five distinct phases of illness. Each phase corresponds to a separate episode of urinary tract infection, which she had never experienced before a particularly severe and recurring manifestation of the disease. The artefact presents these phases as connected and progressively worsening. Symptoms appear repeatedly across the stages, increasing in intensity and size. Feelings of instability are also progressively heightened, particularly in the later stages. The artefact is composed of multiple sculptural components, which the participant intentionally allowed to collapse during the presentation. This act mirrors the emotional insecurity and anxiety experienced throughout the illness. A central wooden cube increases in size across the phases, visually marking the growing burden of anxiety, though the participant does not clarify whether it represents the disease as a whole or a specific symptom. The final phase remains unresolved and is associated with fear regarding the impact of the illness on her daily and sexual life. This fear is symbolised through the inclusion of heavy metal elements. In describing her medical journey, the participant highlighted the difficulty

of accessing healthcare due to distance from her general practitioner. Initial episodes were treated remotely with antibiotics, without physical examination or testing. Only the final episode led to a direct consultation with a gynaecologist, who prescribed a targeted antibiotic and a six-month probiotic course. The participant attributed consistent relief to the use of probiotics, contrasting them with the diminishing effectiveness of antibiotics. The artefact structure reflects this cyclical recurrence, where each treatment was followed by a rapid return of symptoms.



Figure 4.3: Data-Probe artefact 3

Data-Probe artefact 4

Compositional interpretation

The artefact is built as a horizontal sequence of connected parts. On the left, several soft foam segments taper in size and are tightly bound with coarse rope. In the centre, two rough polystyrene blocks are placed side by side, forming a transition. On the right, a small cube is wrapped in colourful wires held by a yellow band, adding texture and contrast. The composition moves from soft and organic to rigid and structured, with materials changing along the line to highlight variation and progression.

Contextual description

P4 (01:38:56) focused her artefact on the experience of incontinence and its physical and social impact. Although she reported frequent urination as normal, she described a change during episodes of infection that introduced pain not previously felt. The artefact uses twine wrapped around the central structure to represent the effort to contain urination. The foam component stands for the genital area, where the retention of urine becomes a source of pain. Sharp or pointed elements mark the moment of release, described as painful peaks. Small spheres were used to indicate bodily discharges. Their repeated presence and small size reflect the frequency and

limited volume of these episodes. Beyond physical discomfort, P4 described a sense of social discomfort caused by malodour, particularly during episodes of candidiasis. She expressed concern that others might notice the smell, which led to feelings of social exclusion and embarrassment. Rubber bands were chosen not only for their unpleasant smell but also for their metaphorical value. Their tightness symbolises the constraint she feels, described as being trapped in a cage. P4 explained that she no longer relies on antibiotics as she once did. Instead, she uses probiotics as a preventive measure. Although this shift does not stop the illness from recurring, it helps to reduce the severity of symptoms. She also noted the importance of nutrition and hygiene habits in managing the condition. This reflection contributed to a broader group discussion about the role of lifestyle practices in reducing dependency on antibiotics. Participants mentioned preventive strategies such as drinking water, cranberry-based products, and mallow herbal teas. While these methods do not eliminate the condition, they were valued for their potential to limit its progression.



Figure 4.4: Data-Probe artefact 4

Data-Probe artefact 5

Compositional interpretation

The artefact is composed of four elements connected vertically by a twisted rope. At the top, a white foam sphere passes through a red rectangular piece of sandpaper. Below it, a soft white block features a black grid and is pierced by several black pins. The rope continues downward, forming a loop before reaching a small wooden cube tied at the bottom. The composition moves from rough and spiked textures at the top

to a smoother and heavier form at the base, with varied spacing and knots giving rhythm to the vertical structure.

Contextual description

P5 (01:41:48) created a temporal artefact using a rope to represent the unfolding of a past episode of cystitis. She described the event as something that, with time, feels smaller in memory, yet still significant. Two small spheres were used to symbolise the alternating sensations of cramps and burning, which she associated with the early phase of the illness. The discomfort and embarrassment of needing to urinate while in social settings was expressed through the rough surface of the materials. As the condition worsened and incontinence began, she represented the resulting feeling of isolation through a wooden cube covered with pins. A knot in the rope marks the moment she sought medical help (01:44:00), making her the first participant in the workshop to clearly identify the involvement of a doctor. This turning point reflects a shift in how the illness was managed. A heavier object, described by the participant as a “boulder,” symbolises the escalation of the condition, which she linked to a period of personal and professional strain. She expressed regret for not having taken preventive measures and also noted that the doctor’s delayed response contributed to the worsening situation. Eventually, she sought treatment at the hospital, where antibiotics were administered without success. The artefact suggests that the illness remains unresolved. A loop in the rope allows the story to close back on itself, representing the recurring nature of the infection. P5 described this experience as ongoing and exhausting (01:44:45). Although she recognised her role in not addressing the symptoms early, she also pointed to the lack of timely medical support as a factor in the continued progression of the illness. As a result, she now carries antibiotics with her in case of recurrence.



Figure 4.5: Data-Probe artefact 5

Data-Probe artefact 6

Compositional interpretation

The artefact is composed of three wooden blocks and three foam pieces threaded along a thin wire. The blocks are rectangular, placed in a curved sequence. Between each wooden block, a soft white foam element is inserted. The foam pieces vary slightly in shape but are cut to wrap partially around the wood. The entire composition is suspended by the wire, forming an arch. The combination of hard wood and soft foam, arranged alternately, creates a balanced structure with a regular rhythm and a contrast in texture.

Contextual description

P6 (01:29:41) structured her artefact as a sequence that connects physical symptoms with psychological responses. Each component of the composition represents a specific association between a symptom and a variable. The experience begins with bodily discharges and progresses toward emotional reactions, which increase in number toward the end of the episode. A triangular prism within the artefact is used to symbolise the feeling of worry. The linear arrangement emphasises how physical discomfort gradually gives way to emotional strain. Through this progression, the participant illustrated the interaction between body and mind, underlining how one can influence and intensify the other.



Figure 4.6: Data-Probe artefact 6

Data-Probe artefact 7

Compositional interpretation

The artefact consists of a single square block of white polystyrene. The surface and sides are pierced by numerous short, black metal wires that stick out at irregular angles. A thick brown rope is loosely wrapped and knotted around the block, crossing over itself multiple times and forming loops on the top surface. The contrast between the soft, light foam and the sharp wires creates a textured appearance, while the rope adds a sense of tension and enclosure around the form. The composition remains compact and centered, with all materials tightly interacting around a single core.

Contextual description

P7 (01:40:00) focused her artefact on a single symptom, drawing from her only episode of urinary tract infection. She described a specific pain experienced during urination, comparing it to the sensation of something sharp and rough moving through the body (01:41:21). Her artefact uses materials selected for their texture and form to recreate this physical feeling. Rather than representing a sequence or multiple aspects of the illness, the composition concentrates on embodying the intensity and location of the symptom within her body.



Figure 4.7: Data-Probe artefact 7

Data-Probe artefact 8

Compositional interpretation

The artefact is built on a large triangular base made of white polystyrene. Attached to its surface are five spherical elements (three in white foam and two in wood). The spheres vary in size and are placed on different corners and edges of the triangle, creating a scattered but balanced arrangement. Several short black wires protrude from the surface at irregular angles, along with two small silver pins near the center. The combination of soft, rough, and hard materials adds texture contrast, while the overall form remains flat and geometric. The elements are securely fixed and evenly distributed across the triangle.

Contextual description

This participant left the workshop before the end, so she did not present her artifact to others.

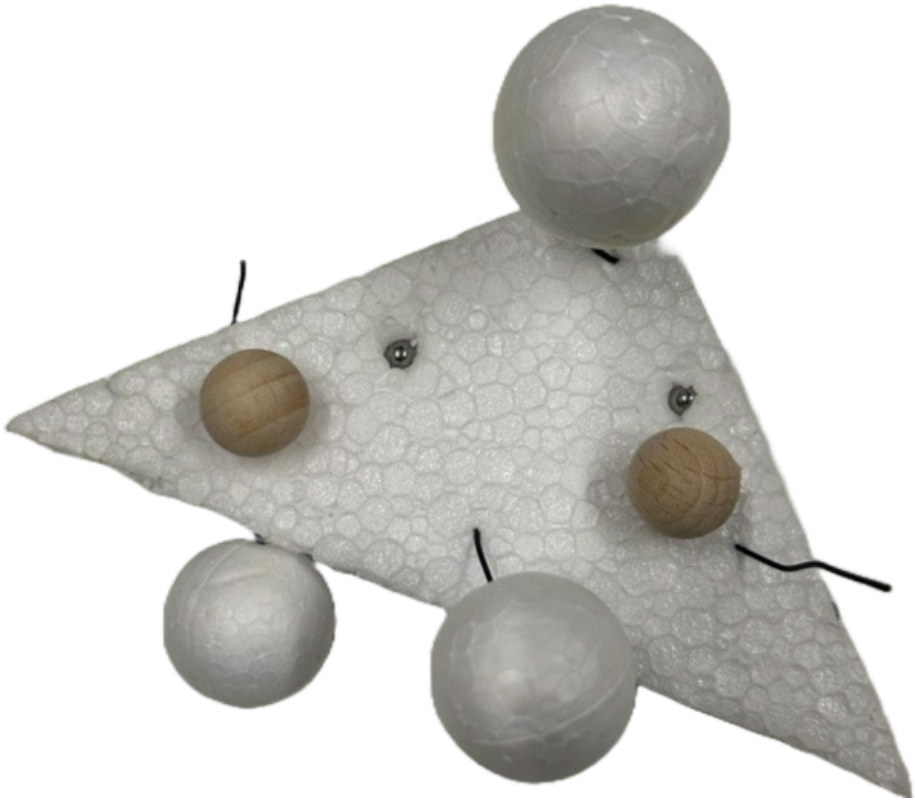


Figure 4.8: Data-Probe artefact 8

Data-Probe artefact 9

Compositional interpretation

The artefact features a central wooden pyramid as its core structure. Four additional elements extend outward from each face, connected through a thin wooden rod passing through their centres. Two of these elements are triangular wooden prisms, both with round holes drilled in the middle. The other two are rectangular blocks of white polystyrene, also perforated at the centre. The composition forms a cross-shaped arrangement around the central pyramid, combining smooth, rigid wood with rough, lightweight foam. All components are symmetrically distributed, creating a balanced and stable three-dimensional structure.

Contextual description

P9 constructed her artefact to express the sharpness and instability associated with her experience of pain and anxiety. She deliberately avoided spherical or smooth components, instead selecting only angular shapes (primarily triangles) to represent sharp sensations. Her goal was to create an asymmetric and unbalanced structure that would reflect her internal state. However, she expressed dissatisfaction with the final result, feeling that it remained too stable to fully capture the emotional unease she aimed to convey. Material choice played a key role in the composition. Wood was selected as the main component due to its weight, which she associated with the physical burden of pain. The perceived heaviness of the material aligned with the significance of the symptom being represented. To reflect the varied nature of her experience, she used a mix of materials, avoiding uniformity to better communicate the complexity and shifting quality of the illness. The combination of form, weight, and material diversity was intended to simulate the overlapping and multi-layered nature of her condition.



Figure 4.9: Data-Probe artefact 9

Data-Probe artefact 10

Compositional interpretation

The artefact is centred around a large wooden cube, serving as the base. On top of it, a white foam sphere is fixed with a wooden rod, supporting a rectangular foam block positioned vertically. Around the base, four additional components are attached: two wooden blocks (a cube and a triangular prism), and two white polystyrene shapes (a pyramid and a sphere), all with visible holes.

The elements are arranged with slight asymmetry, creating a layered and compact structure. The composition combines geometric solids made from wood and foam, with variations in texture and size, forming a dense three-dimensional assembly.

Contextual description

P10 based her artefact on a single episode of cystitis. In her explanation, she connected the urgency to urinate with the anxiety caused by the anticipation of pain. While the emotional response was clearly expressed, the use of physical variables in the artefact appeared less consistent. The representation lacked a clear structure, and the material choices did not follow a recognisable logic. As a result, the connection between symptoms and physical elements remained unclear, reflecting a more fragmented or intuitive approach to the translation of experience into form.



Figure 4.10: Data-Probe artefact 10

Data-Probe artefact 11

Compositional interpretation

The artefact consists of a dense cluster of geometric shapes made from wood and polystyrene. At the top, three wooden components (a cube and two triangular prisms) are positioned around a central wooden block with a short rod emerging from its surface. Below these, four white polystyrene spheres of varying sizes are arranged in a semicircle, forming the base. Each element has a visible central hole, indicating they were threaded or fixed. The composition contrasts the angular structure of the wooden parts with the rounded, smooth surface of the spheres, creating a balanced and compact volume.

Contextual description

P11 (01:05:50) described her artefact as a representation of the full experience of illness, structured from the base upward. She referred to it as a journey, indicating a sequential understanding of the events. The decision to start “from below” reflects a clear temporal logic, with each part of the artefact corresponding to a phase or symptom in the progression of the condition. During the presentation, P11 referred to a personal set of notes prepared while building the artefact (01:05:35). Although not requested, this written legend helped her explain the meaning of each component. This method was adopted by other participants as well, showing a shared need to support verbal reflection with written prompts while describing complex or emotionally charged experiences.



Figure 4.11: Data-Probe artefact 11

Data-Probe artefact 12

Compositional interpretation

The artefact features a central structure formed by intersecting wooden rods connected through a small foam sphere marked with two dark dots. From this core, three foam cubes are attached at different angles, creating a radial layout. A triangular wooden prism is fixed near the centre, with a fourth foam block positioned slightly below. All foam elements are pierced at the centre and show slight surface markings. The combination of soft cubes and rigid rods gives the composition a dynamic yet balanced form, with clear geometric repetition and contrast in texture.

Contextual description

P12 (01:09:50) focused her presentation on a single episode of UTI, describing a specific and personal experience without referring to recurrence. The artefact she created, which she referred to as “my model,” was designed to represent symptoms that are internal and invisible to others. She explained that while no one around her at university could perceive her condition, she was silently suffering. The artefact reflects this hidden aspect of illness, where pain is present but not outwardly visible. During the explanation (01:10:25), P12 shifted from speaking in the first person to using general terms, as though distancing herself from the narrative. This detachment may reflect discomfort in speaking about the topic openly. She acknowledged this difficulty directly (01:12:40), stating that it is hard to talk about such issues with strangers, doctors, or family, and easier with someone close, such as a sister. The participant mentioned that the medicine obtained from a pharmacy resolved her symptoms, and no follow-up with a doctor was needed. She concluded her presentation by stressing the importance of education in dealing with this type of illness. She pointed to pharmacists as trusted first points of contact (01:13:00), especially when people feel uncertain about how to handle the condition. A shared concern among participants was also raised in this context: the lack of trust in online sources, which were described as overly negative and often leading to fear rather than clarity.



Figure 4.12: Data-Probe artefact 12

Data-Probe artefact 13

Compositional interpretation

The artefact is composed of five main elements connected by wooden rods. At the centre, a wooden cube serves as the core, with a white polystyrene triangle attached to one side. Three triangular wooden prisms extend outward in different directions. A large wooden hemisphere is fixed at the bottom. All elements have central holes and are aligned to create a three-dimensional, radial form. The combination of angular wood and soft foam adds contrast, while the consistent use of rods and perforations creates a unified structure.

Contextual description

P13 (01:17:00) chose to focus her presentation not on her experience with UTI, but on the period following the insertion of a Mirena coil, prescribed to manage severe polycystic ovary syndrome (PCOS). She began by describing her medical condition and the effects of hormonal imbalance, including irregular cycles and other symptoms, without immediate reference to the artefact. Only after nearly two minutes (01:18:35) did she introduce the artefact, stating that it represents a state of normality. Her approach follows a pattern observed in other participants: choosing to depict wellness as a baseline, so that illness can be recognised by contrast.
In line with previous discussions on variable-symbol associations, she used form and texture to convey intensity. Sharp edges and pegs were selected to represent the peaks of pain, with their number and density linked to severity (01:19:00). The artefact functions as a formal abstraction of bodily discomfort, particularly as it relates to the hormonal treatment, rather than a direct narrative of illness events.



Figure 4.13: Data-Probe artefact 13

Data-Probe artefact 14

Compositional interpretation

The artefact consists of two spheres connected by a short wooden peg. On the right, a large wooden hemisphere with a smooth surface. On the left, a smaller white polystyrene sphere is aligned with it. The two forms are joined in a straight horizontal axis, highlighting the contrast between materials, sizes, and textures. The structure is minimal and symmetrical, with balanced proportions and a clear directional orientation.

Contextual description

P14: (01:15:55), who took part as an expert, created her artefact without drawing from personal experience of the disease. Instead, she focused on representing the general idea of symptoms and their progression. Spheres were chosen to symbolise symptoms broadly, with the material and size used to indicate their severity. Smaller polystyrene spheres stood for lighter symptoms, while a large wooden sphere represented the most intense ones. The association between material weight and symptom gravity was central to her approach: the lightness of polystyrene conveyed mildness, whereas the heavier wood conveyed seriousness. To connect the two, she used a short wooden peg, explaining that the progression from mild to severe symptoms can happen very quickly, sometimes within hours (01:16:15). Although not directly discussed during the session, the spatial arrangement of the elements also reinforces this point, with the short distance between components metaphorically representing the rapid development of symptoms. P14's artefact reflects a conceptual understanding of the illness, relying on metaphor and abstraction to communicate symptom escalation, rather than emotional or sensory associations.

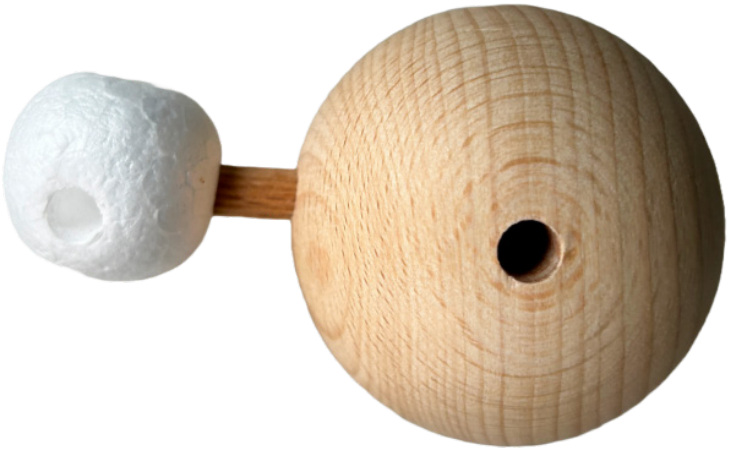


Figure 4.14: Data-Probe artefact 14

Data-Probe artefact 15

Compositional interpretation

The artefact is a tall vertical structure composed entirely of wooden elements stacked in a single column. It alternates between cubes and spheres, with occasional irregular shapes such as a triangular wedge. Each element has one or more drilled holes, allowing a transparent plastic tube to loop through the structure at three points. A small red label marked “rough textures” is placed on one of the middle blocks. The arrangement is symmetrical along the vertical axis, with a consistent spacing between shapes. The combination of curved and angular forms, along with the use of tubing, creates a dynamic yet stable construction.

Contextual description

P15 (B00:10:50) described her condition as a process shaped by recurring fungal and bacterial infections. Her most recent episode lasted a full year and was marked by varying degrees of discomfort, which she referred to as an “iteration of intensity of symptoms.” To represent this experience, she built a tall vertical structure made of nine stacked elements, alternating between cubes and spheres of different sizes. The shape and arrangement of the artefact resemble a totem, with height used to suggest the passage of time. P15 selected wood as the material to represent pain, associating its heaviness with the physical and emotional weight of the illness. Rather than isolating individual symptoms, she aimed to convey the full arc of the experience. The sequential layering of blocks reflects a timeline, consistent with patterns seen in other participants who reported prolonged or recurring illness. The artefact presents an integrated and evolving perspective, highlighting how symptoms intensify and accumulate over time.



Figure 4.15: Data-Probe artefact 15

Data-Probe artefact 16

Compositional interpretation

The artefact is composed of six elements arranged in a diagonal structure supported by a wooden base. At the centre, a white foam sphere is pierced by a wooden rod connecting two large foam blocks on opposite sides. A small wooden cube supports the sphere from below. On the right, two white polystyrene cubes are stacked vertically, both attached to the same rod. Coloured labels are applied to two of the foam pieces: a green label reading “flowy texture” and a blue one reading “spiky texture.” The combination of different textures and volumes creates a balanced, open composition with contrast between soft and rigid surfaces.

Contextual description

P16 (B00:18:47) aimed to construct an artefact that felt unstable, using imbalance as a way to reflect the condition of illness. She selected wood to represent the pain experienced during urination, which she described as the most intense and central symptom. This component was placed at the base of the artefact, symbolising both the physical foundation of the object and the starting point of the disease. The composition reflects a desire to convey vulnerability and disruption through material weight and structural tension.



Figure 4.16: Data-Probe artefact 16

Data-Probe artefact 17

Compositional interpretation

The artefact is built around a central vertical axis composed of foam and wooden elements. At the base and top, two white foam blocks enclose a central wooden sphere. Attached to the sphere are two small wooden cubes, placed diagonally and symmetrically. Several transparent plastic tubes extend outward from the top and sides, curving gently around the structure. The elements are pierced and connected by wooden pegs, creating a stable yet open composition with contrasts in texture, material, and orientation.

Contextual description

P17 (B00:15:20) did not have personal experience with UTIs and instead chose to represent an episode of epileptic seizure. She arranged her artefact as a sequence of elements, each corresponding to the order in which symptoms appeared. A triangular prism was selected to represent headache, chosen for its sharp edges, which she associated with the intensity and pointed nature of the pain. Sharpness was described as a recurring variable for expressing strong discomfort (B00:16:43). A wooden sphere was placed in the centre to represent heaviness, reflecting the weight of the pain. Nausea was symbolised by a large foam cube, selected for its size, meant to express the widespread and diffused sensation of that symptom. She noted a desire for the object to “flow,” reflecting the unpredictability of the experience, while also recognising that much of what occurred felt unclear or out of her control. The artefact was built to appear unsteady, though it rests on a solid foam base, which she initially referred to as a cube but later corrected as a parallelogram. This base symbolises the stable condition of the body in contrast to the chaotic activity in the head. A final foam cube was added at the top to suggest an additional weight pressing down from above (B00:16:50). Overall, the structure expresses instability and tension, grounded by a form that remains physically steady.

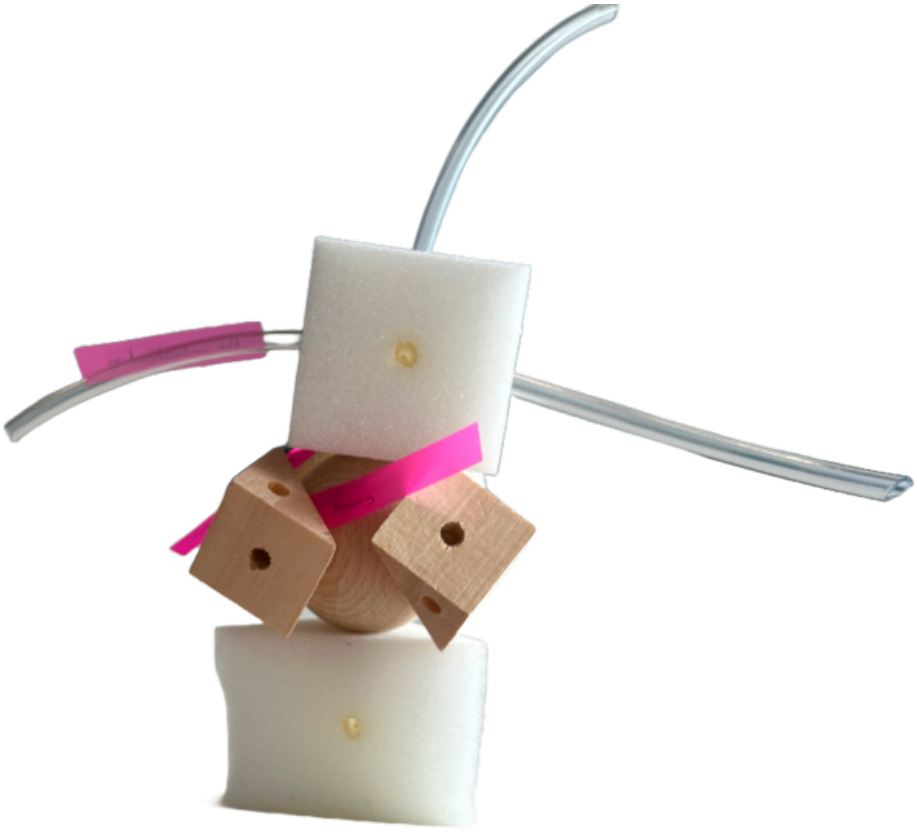


Figure 4.17: Data-Probe artefact 17

Data-Probe artefact 18

Compositional interpretation

The artefact is composed of several polystyrene elements, primarily cubes and one sphere, arranged around a central vertical axis. The pieces are pierced by wooden rods and tightly assembled into a dense cluster. A flexible transparent tube passes through one of the foam cubes at the top. The blocks are layered and angled, creating a compact, irregular volume. Most surfaces have small central holes, and the textures vary slightly between smooth and coarse. The overall structure is stable and closed, with a consistent use of white materials and repeated geometric forms.

Contextual description

P18 (00:03:04) chose to open the presentation session, motivated by the fragile construction of her artefact. She referred to the object as both an “artefact” and an “installation” (00:08:40), highlighting its intentional instability. The composition

was designed to reflect her mental and physical condition during illness. Rather than focusing on the symptoms themselves, which she had previously discussed, her explanation centred on material selection and symbolic form. The presentation concluded with a performative gesture: she gently touched the structure, causing it to collapse. The action was meant to echo the rapid deterioration she associates with the illness. The artefact was described as weak and unpleasant as made from materials she deliberately selected for their negative associations. In particular, she expressed strong aversion to polystyrene, citing both its texture and the noise it produces when rubbed together (00:09:26). This noise was described as triggering a painful internal reaction, adding a sensory dimension to the physical representation of discomfort. The material was perceived as disgusting, not necessarily for its visual appearance, but due to the sound and tactile experience it created. In her final reflections, P18 linked the artefact to the broader experience of illness, describing it as something she hates. The object, though physically weak and prone to collapse, encapsulated the simultaneous presence of multiple unpleasant symptoms. The moment of collapse was used to symbolise the speed at which the condition can intensify, resonating with observations previously made by one of the experts regarding the rapid progression of symptoms.



Figure 4.18: Data-Probe artefact 18

Data-Probe artefact 19

Compositional interpretation

The artefact features a horizontal base made of four wooden triangular prisms placed side by side. Each prism has wooden pegs inserted at different angles. On top of the two central prisms, vertical assemblies are built using a sequence of wooden blocks, white polystyrene spheres, and white foam cubes. The two upright structures are symmetrical, each composed of a wooden connector, a polystyrene sphere, and a foam cube at the top.

Contextual description

P19 structured her artefact starting from a solid base, symbolising the need to lie down during episodes of discomfort. She used material weight to distinguish between symptoms: heavy elements placed at the bottom represent tiredness, while lighter materials positioned above stand for nausea. The central section of the artefact was described as messy, intended to convey the sense that something is going wrong within the body. Through spatial arrangement and material contrast, P19 used the physical composition of the artefact to express layered sensations and a disrupted internal state. The layout reflects both bodily grounding and a gradual loss of balance.



Figure 4.19: Data-Probe artefact 19

Data-Probe artefact 20

Compositional interpretation

The artefact is composed of four separate groupings. The first includes two white foam cubes of different sizes, connected vertically by a transparent flexible tube. A pink label reading “more organic shape” is attached to the top cube. The second element is a wooden sphere pierced by four wooden rods extending outward in a cross-like arrangement. The third is a small wooden cube with a single peg inserted at an angle. The fourth is a triangular wooden prism that the author expressed the desire to colour. The components are distinct but share a consistent visual language, combining geometric shapes with simple interventions through rods and annotations.

Contextual description

P20 (B00:10:53) created three separate units in her artefact, each corresponding to a specific stage in the appearance of symptoms. She began with the most relevant and earliest one, which is pain during urination, that she represented using triangular prisms. The sharpness and irregularity of these forms were selected to reflect the intensity and pointed nature of the sensation. Her approach followed a clear temporal logic, with each material and shape linked to the order in which symptoms occurred. The second unit focused on internal swelling, specifically in the kidney and bladder. This was expressed using cubes of different sizes and textures, including rubbery materials to suggest stretchiness. A large cube was connected to smaller ones through a short transparent tube, placed close together to represent the physical feeling of constriction. The short connections and compressed layout reflected her sense of being hunched over and unable to move freely. The third unit featured a spherical form, which the participant contrasted with the rigidity of the other elements. Although the exact association with this sphere was unclear, she noted her preference for round, organic shapes to represent swelling. This was reinforced by a sticky note placed directly on the artefact, stating her desire to replace the rigid parts with more natural forms. According to her, swelling feels round and continuous rather than sharp, which influenced her material and shape choices in the final stages of construction (B00:12:06).

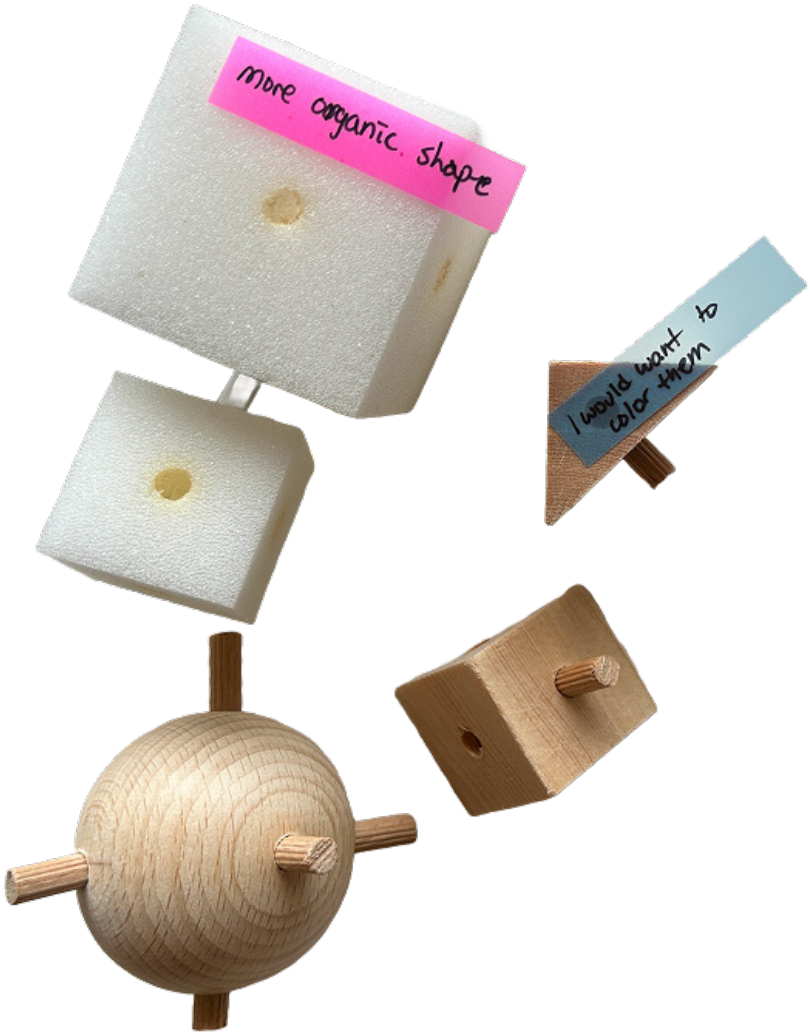


Figure 4.20: Data-Probe artefact 20

Data-Probe artefact 21

Compositional interpretation

The artefact is structured around a vertical central column made of stacked wooden and polystyrene cubes. At the top, three small blocks form a cluster, with a wooden sphere extending outward and connecting to a smaller white foam sphere through a curved transparent tube. Two additional transparent tubes extend from the central column to two symmetrical wooden hemispheres placed on each side. These hemispheres are pierced with multiple wooden rods radiating outward. The overall composition is balanced and symmetrical, with a strong vertical core and curved extensions forming a wide horizontal span. The contrast between rigid blocks and flexible tubes adds visual variety while maintaining a unified geometric language.

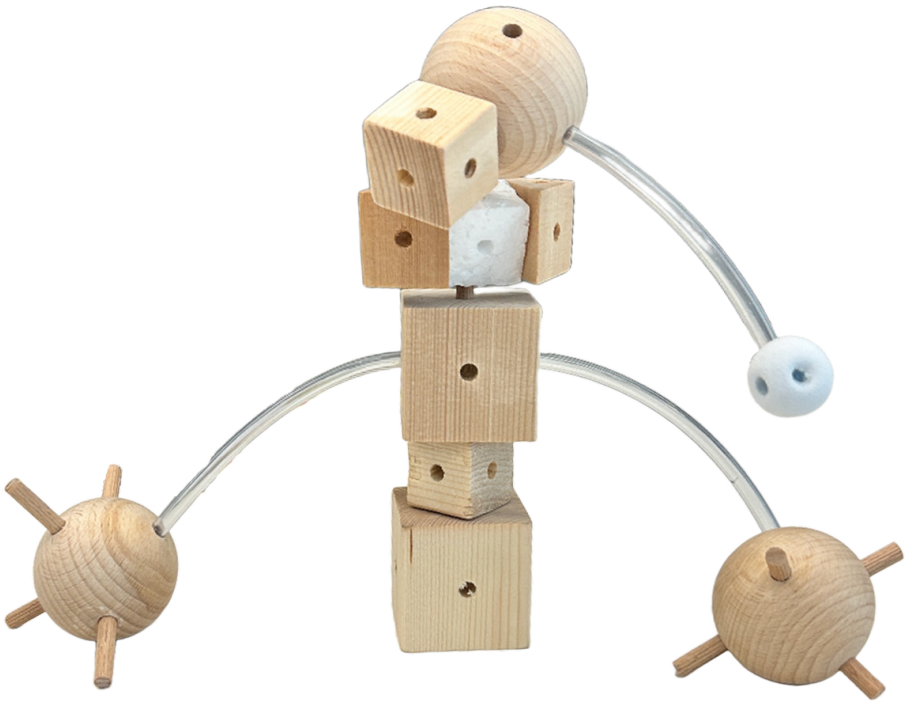


Figure 4.21: Data-Probe artefact 21

Data-Probe artefact 22

Compositional interpretation

The artefact is built around a vertical wooden axis anchored by a square base. Along the main structure, a combination of wooden and foam spheres is connected by small rods, forming a branched system. Near the middle, a larger wooden hemisphere is intersected by horizontal arms holding additional spheres. At the top, a larger white foam sphere is similarly extended with smaller wooden and foam balls, creating a symmetrical cluster. Off to the left, a foam cube is connected to the main structure via a transparent flexible tube, ending in a small foam sphere. The arrangement blends vertical growth with radial branching, using repetition of round forms and alternating textures.

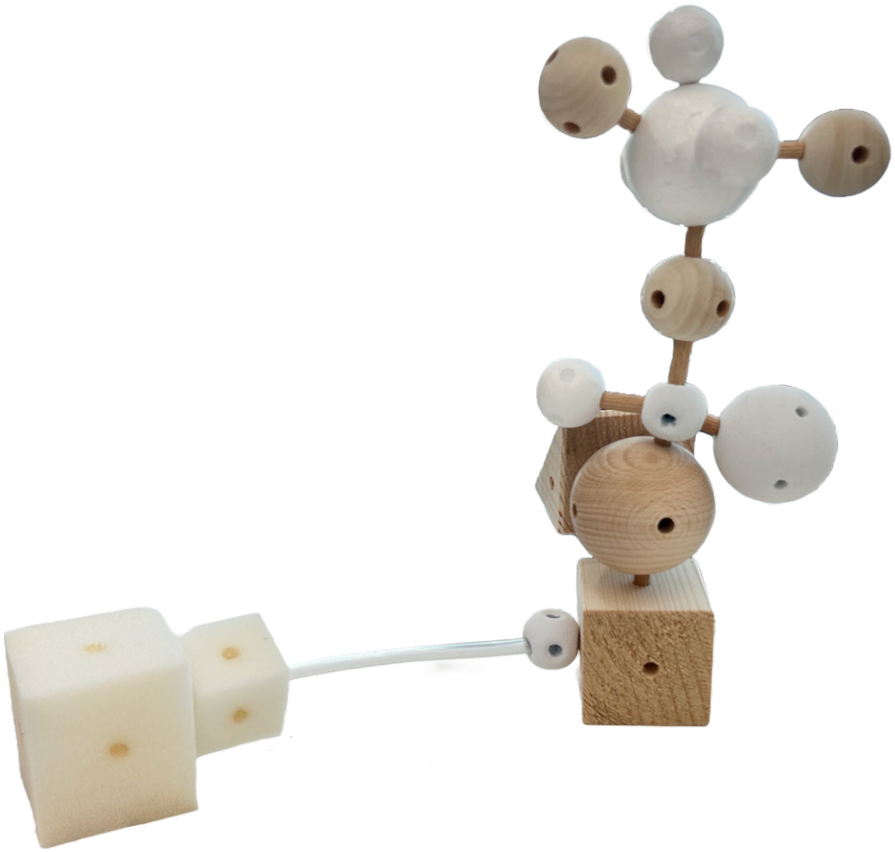


Figure 4.22: Data-Probe artefact 22

Data-Probe artefact 23

Compositional interpretation

The artefact is composed of a single transparent flexible tube curved into a shallow arc. A central wooden sphere anchors the structure, with five small foam blocks evenly spaced along the tube. Each foam piece is pierced through the centre and oriented in slightly different directions. The arrangement is lightweight and open, with a balanced distribution of forms across the arc. The combination of soft foam, smooth wood, and clear tubing creates a clean and minimal composition focused on repetition and rhythm.

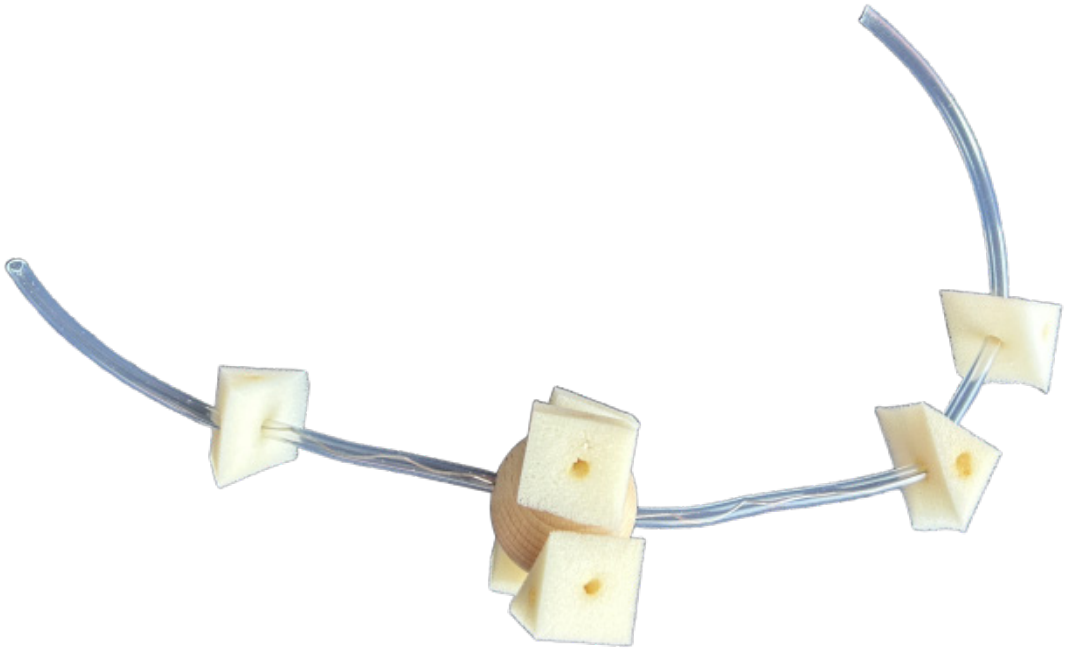


Figure 4.23: Data-Probe artefact 23

Data-Probe artefact 24

Compositional interpretation

The structure is vertically oriented and composed of three primary elements. A soft foam cube serves as the stable base. From it, a single flexible transparent tube rises in a gentle arc, connecting to a triangular white polystyrene block positioned at an inclined angle. A small white textured sphere, joined with a wooden peg, is mounted on top of the triangle, offset to one side. The components are simple, lightweight, and carefully arranged to form a minimal, upward-reaching figure. The overall composition suggests elevation and directional flow, with contrasting textures adding a tactile dimension.



Figure 4.24: Data-Probe artefact 24

Data-Probe artefact 25

Compositional interpretation

The composition is a vertically balanced structure comprising four distinct components. At the base lies a white polystyrene cube that serves as the foundation. Resting above it is a smooth wooden sphere, pierced with small holes, functioning as the central axis. From the top of this sphere, a transparent flexible tube arcs upward, connecting to a soft foam diamond tilted forward. On the left side of the base, a smaller white sphere is attached, creating a subtle lateral counterbalance. The materials (rigid, soft, and translucent) offer contrasting textures. The structure suggests upward extension and spatial awareness through lightness and asymmetry.

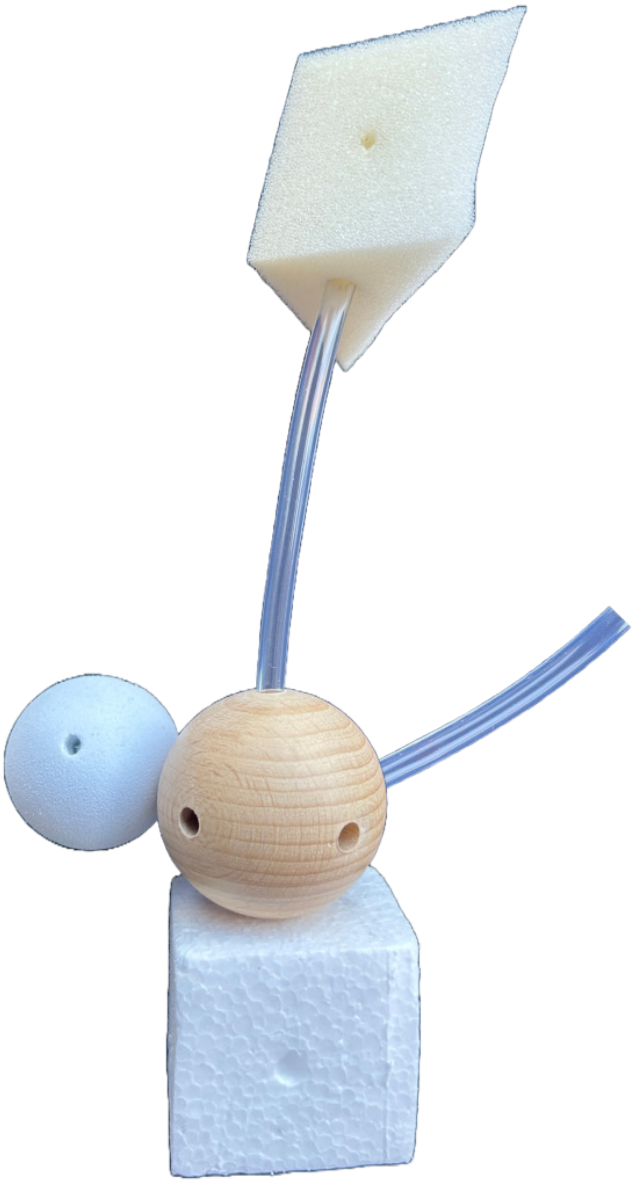


Figure 4.25: Data-Probe artefact 25

Data-Probe artefact 26

Compositional interpretation

The structure is organised around a large foam cube forming a compact, stable base. Affixed to its six faces are small white spheres, most of them pierced and fitted with wooden dowels, projecting outward like terminals. A transparent flexible tube loops from the rear side of the cube and attaches to one of the upper spheres, creating a semi-arch that introduces curvature to the otherwise cubic layout. At the top of the cube sits another sphere, slightly larger, mounted vertically on a dowel. The piece balances geometric clarity with distributed appendages, differently interconnected.

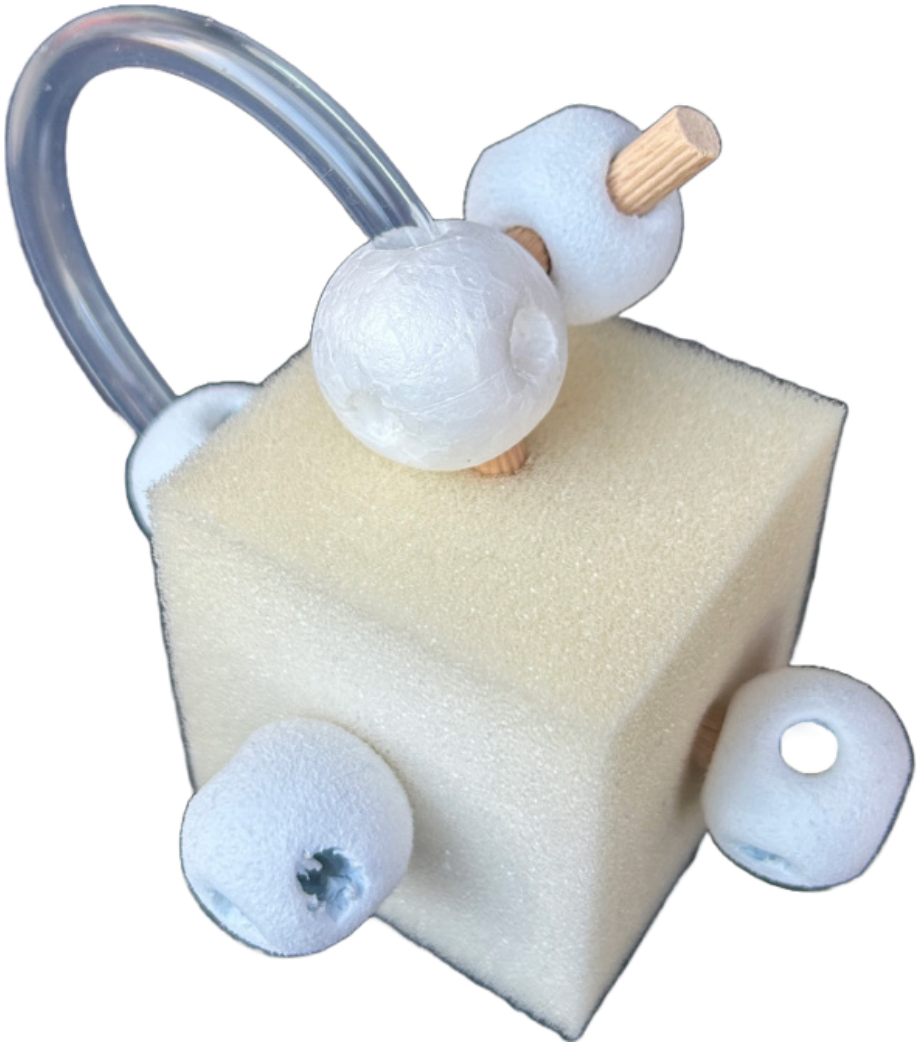


Figure 4.26: Data-Probe artefact 26

Data-Probe artefact 27

Compositional interpretation

The composition consists of an agglomeration of pale blue spheres of varying sizes, densely packed and joined through short connecting dowels. The overall form resembles a clustered molecule or a cellular mass, with no clear directional axis or symmetry. The repetitive use of the same spherical shape across different scales emphasizes continuity and cohesion. The presence of visible holes on each unit suggests potential for further expansion or interaction, while the matte texture enhances the organic and tactile quality of the object. The result is a compact, volumetric arrangement with a distinctly biomorphic appearance.



Figure 4.27: Data-Probe artefact 27

Data-Probe artefact 28

Compositional interpretation

The artefact consists of four identical triangular foam pyramids arranged in a symmetrical, radial configuration around a central white spherical element. Each pyramid is positioned with its base facing outward and its apex oriented toward the centre, forming a star-like structure. The convergence around the core creates a compact and balanced composition. A transparent tube and internal connectors are partly visible, anchoring the pieces together. The uniformity in material and colour enhances cohesion, while the pointed forms suggest directionality and tension radiating from the centre.

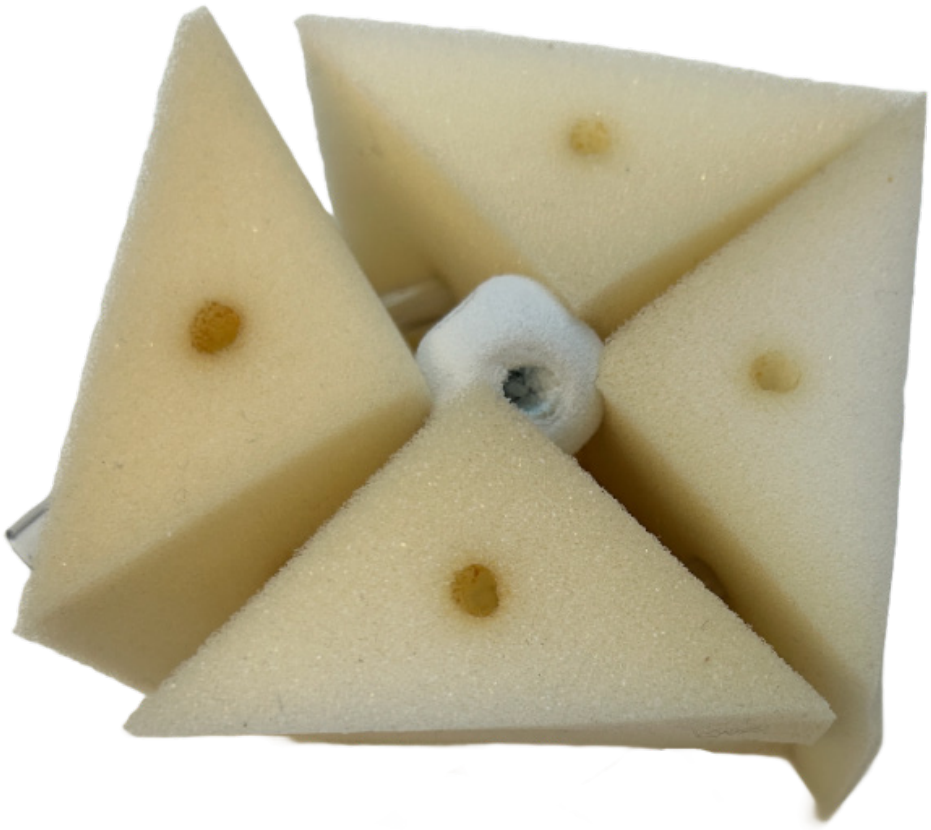


Figure 4.28: Data-Probe artefact 28

Data-Probe artefact 29

Compositional interpretation

A single cubic polystyrene element sits at the centre of the composition, perforated on multiple sides to accommodate four transparent flexible tubes. The tubes pierce through the cube and loop around or extend outward in different directions, creating a spatial structure that suggests movement and expansion. The contrast between the rigid, geometric cube and the curved, translucent tubing creates a dynamic interplay of tension and flow. The composition is open and minimal, with the tubes visually extending beyond the central mass, emphasizing directionality and spatial extension.

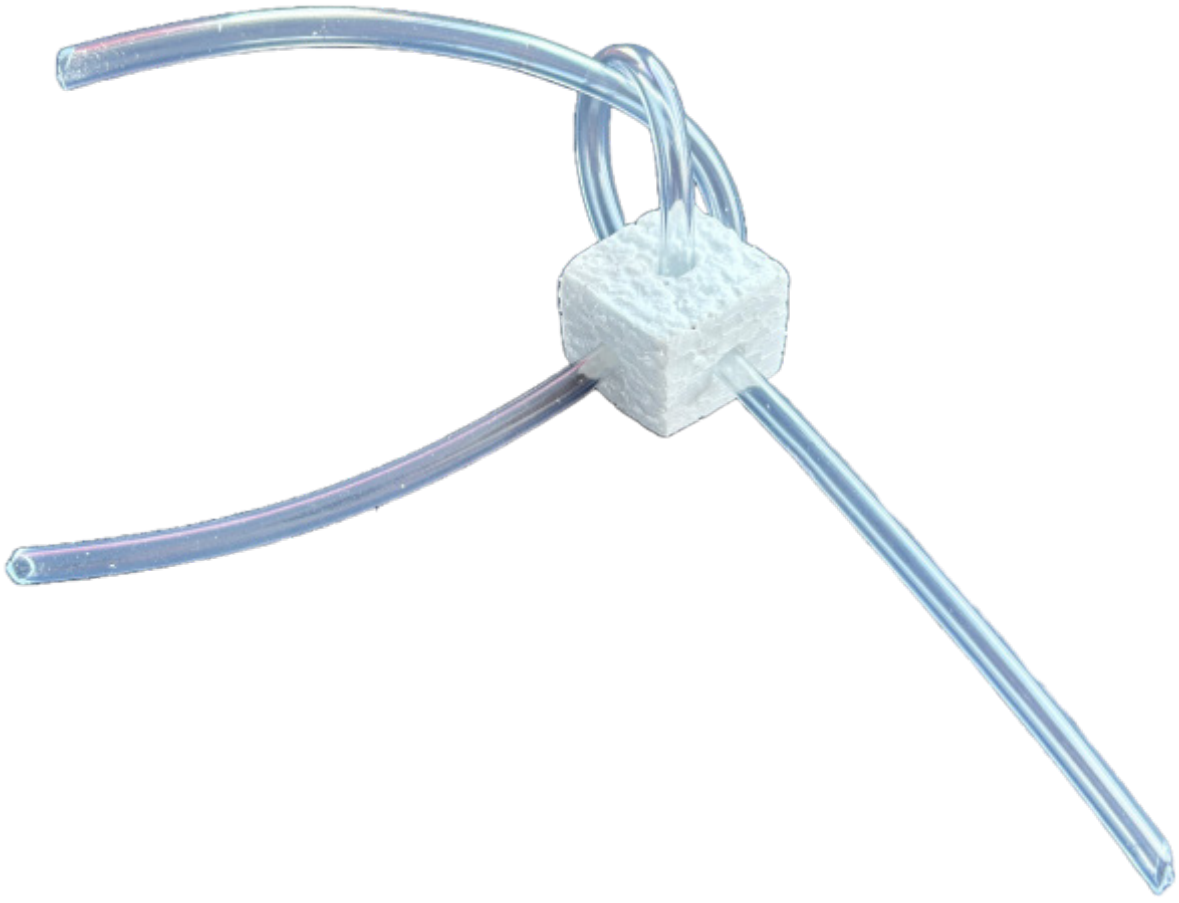


Figure 4.29: Data-Probe artefact 29

Data-Probe artefact 30

Compositional interpretation

The artefact consists of five triangular prism elements arranged around a central axis. The prisms are made of three different materials (wood, sponge, and polystyrene) each with a visible central perforation. The elements intersect at their bases, forming a star-like radial structure with the pointed ends facing outward. The alternating material textures create a visual rhythm, while the radial symmetry lends a sense of balance and cohesion. The structure is compact and self-contained, with no external connectors visible, suggesting stability and inward focus.

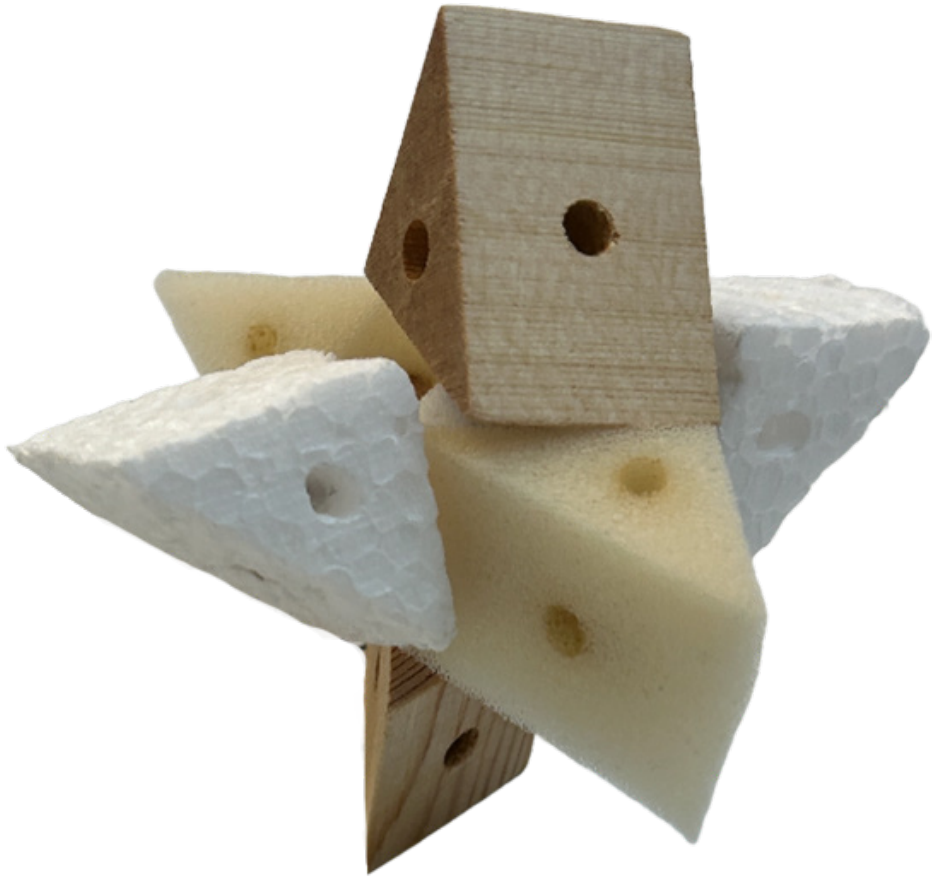


Figure 4.30: Data-Probe artefact 30

Data-Probe artefact 31

Compositional interpretation

The artefact is a vertical structure composed of multiple geometric solids, primarily cubes and triangular prisms, made from wood, polystyrene, and sponge. These elements are interconnected through clear plastic tubes and wooden dowels, forming a loosely stacked and articulated tower. At the top, a sponge pyramid is elevated above the main cluster by a flexible transparent tube, creating an impression of suspension or detachment. The central volume combines wooden and polystyrene cubes pierced diagonally and horizontally, with varied rotational orientations. The configuration emphasizes contrast between rigid, rectilinear alignment at the base and curved, upward extension at the top.

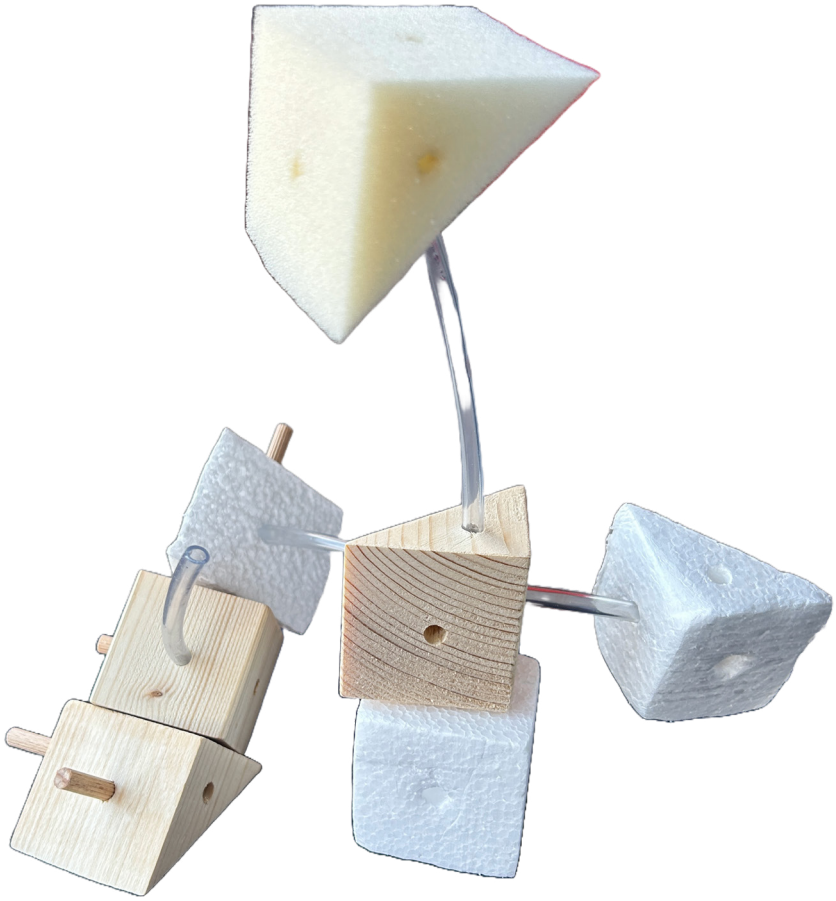


Figure 4.31: Data-Probe artefact 31

Building on this material overview, Chapter 5 moves to the thematic analysis of the workshop discussions. It examines how participants use discussion and artefacts to describe UTIs and other medical conditions, providing insights into how they interpret symptoms, diagnosis, treatment, and prevention, and revealing broader issues in the experience and communication of embodied health conditions.

5. FINDINGS ON HEALTH EXPERIENCES. BEYOND PHYSICAL SYMPTOMS

This chapter presents the analysis of the health-related knowledge generated through the workshop sessions. It begins with UTIs, which remain the main empirical focus of the thesis and the condition through which the research problem, research questions, and methodological framework are developed. It then considers the broader embodied and intimate conditions addressed in the later workshop sessions, where the activity extended beyond its initial focus through iterative refinement and the specific contexts in which those sessions took place. In this way, the analysis centres on healthcare knowledge while distinguishing between two related strands.

The first examines UTIs as the core condition of the research and provides the most detailed account of how participants articulated prevention, symptoms, diagnosis, consultation, and treatment through lived experience. The second turns to the other health conditions explored in WS4 and WS5, showing how the workshop also support the articulation of symptom experience, uncertainty, communication, and everyday management beyond the UTI case.

Across both parts, the analysis focuses on the knowledge participants contribute through their embodied and situated experiences. It examines how symptoms are described, how conditions are interpreted and compared, how uncertainty enters participants' accounts, and how experiences of support, consultation, and management are articulated. This structure preserves the centrality of UTIs within the thesis while showing that the workshop also generates meaningful health-related insights across a broader range of conditions.

Taken together, the chapter clarifies the specificity and wider relevance of the empirical findings. The UTI analysis provides the main healthcare contribution of the thesis, while the findings on other conditions show how the workshop supports the expression of diffuse, internal, and difficult-to-compare experiences beyond its original scope. The following chapter turns from topic-related findings to methodological analysis, examining how physicalization, physical variables, materials, and workshop structure contribute to eliciting these forms of knowledge.

To ensure traceability and link analytical insights to their original sources, interview quotes are referenced using participant numbers (P#) and the corresponding workshop session (WS#) in which they took part, for example (P1, WS1). As participants worked in groups during the last two sessions, quotes are indicated based on the group number, and workshop session, such as (G1, WS4).

5.1 Findings on UTIs

The first aim of the analysis aligns with the first aim of data collection of expanding medical knowledge related to a specific condition, in this case UTIs. It focuses on the knowledge that participants contribute to create through their lived experience of the disease. To support this aim, Table 5 organises the themes and sub-themes that emerged from the thematic analysis, providing a structured overview of the coded insights generated across the workshop sessions. The analysis follows the main phases of the disease trajectory: prevention, symptom detection, diagnosis, consultation, and treatment. These phases reflect the temporal logic through which healthcare experiences are commonly understood in both clinical practice and public health discourse. This framing also mirrors how participants describe their own experiences, often linking sensations, decisions, and emotional responses in sequences that are chronological or causal.

Organising the data around the disease trajectory supports a clearer understanding of how different stages of the illness are perceived, managed, and articulated. This order also highlights how participants use physical variables and materials to express particular aspects of their condition as it evolves. At the same time, this structure supports comparison across participants while respecting the complexity of individual narratives. The follow-up phase, which is normally part of standard disease management, does not appear in the data and is therefore not included in the thematic organisation.

To ensure clarity during coding and consistency in interpretation, each phase is defined in the introduction of each phase. This approach aligns with recognised practices in thematic analysis, where shared conceptual boundaries help organise and interpret interdisciplinary data (Braun and Clarke, 2006).

Theme 1.1	prevention	Theme 1.2	symptoms	Theme 1.3	diagnosis	Theme 1.4	consultation	Theme 1.5	treatments
Sub-theme	**hygiene**	Sub-theme	**clustering - ways of grouping symptoms**	Sub-theme	**body awareness**	Code	calling doctor vs auto-medication	Code	alternatives; alternatives/probiotics
Code	cleaning after defecating	Code	symptoms organisation based on the part of the body affected	Code	uncertainty	Code	pharmacists first point of contact	Code	antibiotic efficacy/inefficacy
Code	too much cleaning is harmful	Code	symptoms organisation based on order of appearance	Code	being able to recognise symptoms	Code	process	Code	multiple medications
Code	general cleaning	Sub-theme	**psychological implications**	Code	same symptoms but different causes	Code	remote consultation	Code	natural course - no medicines
Code	cleaning after sex	Code	physical and psychological have same importance	Sub-theme	**differences and similarities with other diseases**	Code	doctors only in case of true necessity - sometimes late	Code	supplements
Sub-theme	**food and drinking habits**	Code	as consequence of pain	Code	uti symptoms are valid/not valid for other conditions	Code	feeling guilty / shame to talk about	Code	Escherichia coli vs cystitis treatment
Code	drinking often	Code	anxiety/fear/panic	Code	giving birth	Code	non-specialist to ask	Code	medications from the pharmacy
Code	eating well	Code	anticipating pain	Code	candida			Code	recovery
Sub-theme	**other practices**	Code	effects on daily life	Code	Mirena coli (IUS)			Code	showering to cool down
Code	get medicines ready	Code	mental pressure caused by responsability	Sub-theme	**causes**			Code	side-effects
Code	heating the sit	Code	sharing alleviates the stress	Code	carelessness				
		Sub-theme	**definition / role**	Code	weak urinary system				
		Code	unusual condition	Code	sitting on cold surfaces				
		Code	common experience	Code	multiple factors				
		Code	uncomfortable feeling	Code	Escherichia Coli				
		Code	medical condition	Sub-theme	**recognising the disease /health literacy**				
		Code	non-health condition	Code	*initial conditions*				
		Code	intervention required	Code	*multiple aspects involved*				
		Code	tools are needed to recognise	Code	*escalation*				
		Code	effect	Code	*maybe not cystitis*				
		Code	positive aspect	Code	*first time*				
		Code	subjectivity	Code	*relation with menstruation*				
		Code	visible/not visible						
		Code	track of change						
		Code	language to ask for help						
		Sub-theme	**description**						
		Code	different aspects of the same symptom to cosider						
		Code	nuances of pain						
		Code	"bloated" instead of swollen						
		Code	friction						

Table 5: coding table for the thematic analysis of results on UTIs.

5.1.1 Workshop sessions and participants included in the analysis

This chapter analyses WS1, WS2, and WS3, where UTIs and related intimate infections form the explicit focus of the activity. These sessions remain directly connected to the main healthcare case of the thesis and provide the empirical basis for examining how participants describe, interpret, and materialise symptoms associated with UTIs.

The analysis includes women with lived experience of UTIs or closely related intimate infections, together with the medical experts involved in WS1 and WS2. Their contributions are examined through the multimodal dataset generated during the workshops, including written narratives, transcribed conversations, and verbal presentations of the artefacts.

By focusing on WS1, WS2, and WS3, the chapter keeps the analysis centred on UTIs and related intimate infections. This makes it possible to examine how participants use the workshop process to describe symptoms, compare experiences, and translate embodied knowledge into communicable forms.

5.1.2 Prevention

The Federal Office of Public Health (FOPH) defines prevention as the application of healthcare measures to prevent diseases. This includes providing information and motivation to encourage healthy lifestyles, aiming to prevent non-communicable diseases such as cardiovascular problems, diabetes, and cancer. The goal is to prevent disease or respond quickly and appropriately if people do fall ill. Preventive measures are typically categorised into three levels:

Primary Prevention: actions aimed at reducing the incidence of disease and health problems within the population. This includes universal measures to mitigate lifestyle risks and their causes, as well as targeted interventions for high-risk groups.

Secondary Prevention: systematic detection of early stages of disease, followed by interventions to prevent full symptom development. Examples include prescribing statins to reduce cholesterol and implementing measures to lower high blood pressure.

Tertiary Prevention: efforts to soften the impact of ongoing illnesses or injuries that have lasting effects. This involves helping individuals manage long-term, often complex health problems and injuries to improve their ability to function, enhance quality of life, and extend life expectancy.

In the scope of this study, prevention mainly focuses on primary prevention, considering the individual behaviours, routines, or medical actions adopted by participants to avoid the onset of UTIs or other intimate infections.

In this direction, results examine how participants describe prevention as an ongoing and situated practice shaped by bodily awareness, personal routines, previous infections, and uncertainty about what is effective. The findings show that prevention is not experienced as a single medical action, but as a continuous process of monitoring, adapting habits, interpreting bodily signals, and responding to perceived risk. Participants refer to hydration, hygiene, clothing, sexual activity, supplements, and self-care strategies, while also expressing uncertainty about whether these actions prevent infection or simply provide a sense of control. Overall, prevention emerges as an embodied and experiential form of knowledge, developed through repeated encounters with UTIs and adjusted through everyday practice.

The importance of backwords wiping and post-intercourse hygiene

Hygiene is officially recognised as one of the main factors in preventing cystitis and UTIs. Participants generally demonstrate a strong awareness of hygiene and become even more attentive when dealing with UTI conditions, as one participant noted: “When there is this kind of problem, you try to have extra attention.” (P4, WS1). Practices such as wiping backwords and using the washing after defecating

are important because prevent bacteria enter and spread in the urinary tract. Participants appear suggesting one another “when you wipe you as umm… yes it need to be backwards and not front.” (P19, WS3). This is reinforced by the expert intervention who raised that “99% of the infections that occur in women anyway happen precisely because, when one even cleans oneself, one should always bidet afterwards...” (P1, WS1). Using the bidet is recommended, but at the same time, it can lead to increased sensitivity to microbes: “with all the talk of hygiene, super hygiene and so on, we are a bit more delicate than in those countries.” (P1, WS1). This is especially true for countries where hygiene practices are high and so people are delicate and sensitive to infections.

Special attention is given to post-intercourse hygiene, as highlighted by one participant: “And also that after having sexual intercourse, you should always go to the toilet.” (P19, WS3). Urinating and washing after intercourse are considered essential for preventing cystitis. However, this necessity also impacts sexual life, as another participant shared: “Obviously, my sex life has changed. I mean, I can no longer think of having intercourse without going to pee and washing because I get anxious that the next day I might have cystitis.” (P5, WS1).

Food role is pivotal but (officially) underestimated

Drinking water appear helping both to prevent and improve the conditions at the early stage of the disease. This is suggested by doctors, “Like the doctor told me that I don’t drink a lot water” (P19, WS3), but also confirmed by people experience who autonomously drink on the initial symptoms to prevent the disease worsening “So if I can prevent it, I eat well at that time, I take my mallow tea....” (P2, WS1). Mallow tea and cranberry juice are mentioned, but their efficacy is noted only for the early stages of the disease, as they are ineffective in treating or curing advanced cystitis. Beyond hydration, the role of food emerges as especially significant. Several participants report that dietary adjustments can be as influential as drinking practices, and in some cases even more effective in managing early symptoms. One participant explains: “After taking a lot of antibiotics and drinking cranberries, I found that the food time that helps me the most” (P2; WS1). While the importance of drinking, particularly cranberry consumption, is widely cited in the literature, dietary recommendations are far less common. The conversation focused on the role of food in irritating the urinary tract, contributing to bacterial growth, or even disrupting the body’s natural defences that can lead to infection development. Some participants demonstrate careful awareness of these dynamics, adapting their diet in response to early signs of symptoms: “As soon as I feel something might happen, for three days I eat brown rice and things... a low fat diet, inflammatory things and nothing” (P2, WS1).

Another participant links symptom relief to eliminating gluten: “An infection that I can simply manage with a special diet and by eliminating gluten, as I recently did. The voracity with which this infection presents itself has been dampened” (P4, WS1). While this same participant later expresses uncertainty about whether she was experiencing cystitis or candidiasis, her account raises broader considerations about dietary triggers, especially for individuals with chronic inflammation or sensitivity to specific foods.

The discussion of food and diet also offers an interesting contrast to hygiene-based prevention strategies that are well established within the healthcare system. While hygiene is typically framed as a proactive measure aimed at avoiding infections altogether, participants tend to perceive hydration and diet as interventions applied once symptoms begin to appear. Prevention, in this context, is not understood as avoiding the first onset of disease, but as preventing escalation and recurrence. This experiential framing highlights the potential influence of diet on infection risk, which is neither widely recognised nor systematically communicated to patients.

These insights suggest that further exploration of dietary factors may be valuable, both clinically and in public health communication. Participants’ own accounts indicate that dietary awareness can help stabilise or reduce symptoms, and in some cases may contribute to avoiding future episodes. The experiential knowledge shared through the workshops therefore contributes to a more nuanced understanding of prevention, pointing to areas where current medical guidance may benefit from greater attention to nutrition, inflammation, and long-term self-management practices.

Get medicines ready

Another aspect related to prevention concerns the habit of carrying medicines and antibiotics, a practice that appears common among participants who experience recurrent infections. For some, this becomes an everyday precaution: “I have a first aid kit with me always, like I know how to deal with it without drugs” (P18, WS3). For others, it is linked specifically to travelling, as the uncertainty of recurrence motivates preparedness: “When I travel it becomes a circular thing, because it closes and comes back, so I always carry it around.” Several participants confirm adopting similar strategies (P5, WS1; P2, WS1).

This practice calls for a distinction between carrying general medicines and carrying antibiotics. Participants do not explicitly articulate this difference, yet it remains important. Over-the-counter remedies can be purchased easily when needed, while carrying antibiotics implies that individuals either obtained them

in advance or kept leftover medication from previous treatments. Acting on this assumption suggests a degree of self-management shaped by past experiences. However, relying on leftover or pre-obtained antibiotics assumes that the disease will manifest in the same way each time and require the same treatment, which is not necessarily the case. This observation highlights both the perceived need for autonomy in managing recurrent infections and the risks associated with self-directed antibiotic use.

Some participants express a sense of self-management in handling their condition independently: “I know how to fix it. I usually have one or two antibiotics with me.” (P18, WS3). At the time of this research, experiments are being conducted to empower patients by equipping them with standby antibiotics for immediate use when necessary (Schulz and Gabutti, ndr). This approach is particularly aimed at individuals who suffer from recurrent conditions, such as cystitis, who are followed by experts monitoring their evolution. Prescriptions are accompanied by specific education to ensure patient safety. Given that many recurrent patients are already accustomed to managing their own treatments, it may be valuable to provide targeted indications on responsible antibiotic use for everyone in the same condition.

However, while taking an active role in their own care can empower patients, decision-making can also be a source of stress and uncertainty. Even when well-informed, some individuals may lack confidence in making what they perceive as critical healthcare decisions. This issue will be further explored in the discussion on the psychological implications of symptoms in one of the following sections (“The mental anticipation of pain becomes pain itself”).

5.1.3 Symptoms

The concept and role of symptoms are central to this research. Within the analysis of results, symptoms are understood not only as medical signs but also as the interpretations of those signs by patients and healthcare professionals. For this reason, physical and psychological experiences are both considered.

This section examines symptoms as embodied experiences that participants interpret, monitor, and compare over time. The findings show that symptoms are not described only as isolated physical sensations, but as changing combinations of pain, burning, pressure, urgency, discomfort, fatigue, and emotional distress. Participants often recognise symptoms through their recurrence, intensity, timing, and relation to previous infections, showing how symptom knowledge develops through lived experience rather than through medical categories alone. At the same time, symptoms remain uncertain because they can overlap with other intimate conditions, fluctuate in severity, or appear before clinical confirmation is available.

For this reason, symptoms emerge as both bodily signals and interpretative problems, requiring participants to decide what they mean, when they indicate infection, and how they should be communicated to healthcare professionals.

The (underestimated) role of symptoms to increase agency

During the ice-breaking exercise and along the entire activity, participants described symptoms not only as indicators of illness but also as signals that shape understanding, decision making, and personal agency. Their definitions, mostly generated during the introductory exercise, reveal a broad conception of what a symptom is and what it does.

First, symptoms can be considered as early signals and forms of awareness. In this direction, several participants framed symptoms as signs that precede or anticipate illness. A symptom was described as “a clue to understand the problem” (P17, WS3), “a ring bell that helps you understand something that is going to happen” (P11, WS2), or something that “allows me to recognise what is changing inside my body and what might be wrong” (P7, WS1). These definitions emphasise temporal awareness and position symptoms as early warnings that help individuals monitor bodily change. Others perceived symptoms as consequences of underlying dysfunctions: “[A] symptom is an effect that the disorder has on your well-being” (P15, WS3), or “symptoms are what you feel and experience as a result of illness” (P20, WS3). These views interpret symptoms as outcomes rather than precursors, but they still highlight the value of attending to bodily signals.

Second, symptoms can also be understood as experiences that occur across different levels of perception. Participants identified symptoms on a spectrum ranging from subtle deviations to intense, disruptive sensations. Symptoms could be “something unusual… anything outside day-to-day normal behaviour” (P13, WS2) or, at the extreme, “a very uncomfortable feeling, sometimes painful, in some organs or parts of the body” (P18, WS3). Importantly, several participants noted that awareness itself becomes diagnostic: “When you urinate, you should not feel anything. But when you do feel it, it is problematic” (P1, WS1). This statement underlines the significance of noticing actions that normally remain unconscious.

Third, symptoms can also be seen as prompts for action and communication. Across sessions, participants described symptoms as triggers that initiate behavioural responses or motivate them to seek support. For some, symptoms signal the need to “change your habits” (P10, WS2), while for others they act as a language that allows them to seek support. One participant summarised this communicative function clearly: a symptom “helps me communicate with people who can help me… It is as if it is a language with which I can say what is happening and get help” (P3, WS1). Although symptoms are most often associated with illness,

participants also recognised their presence in non-pathological conditions such as pregnancy (P9, WS2) or alcohol intoxication (P19, WS3). This reinforces the idea that symptoms reflect shifts in bodily state, not only disease.

Fourth, symptoms can be understood through the interplay of visibility and invisibility. Participants often referred to the challenge of dealing with symptoms that cannot be seen by others. Many symptoms "can be internal… and are not so easy to see or perceive" (P11, WS2). This invisibility can protect privacy ("No one knows I have this problem, but I suffer from it," P12, WS2) yet creates difficulties in explaining needs or justifying behaviour to others, including clinicians. The tension between private experience and visible evidence reinforces the importance of improved communication tools.

Fifth, symptoms can be understood as constructs with multiple causes and uncertain meanings. Participants frequently emphasised that a single symptom is rarely enough to determine what condition is present. As one explained, "A combination of signs corresponds to a specific medical condition" (P17, WS3). This recognition reflects a nuanced lay understanding of clinical reasoning and underscores the uncertainty involved, since the same symptom may stem from different causes and require distinct forms of treatment, a challenge that is especially evident in the context of intimate infections. Participants also reflected on distinctions between subjective and clinical understandings of symptoms. One described "the intense symptom as a perception I have to explain to someone who must help me" and contrasted it with "something about a disease that is exact and manifests itself" (P4, WS1). This difference points to the fluctuating boundary between personal meaning making and biomedical classification.

Lastly, the importance of vocabulary and temporal framing becomes evident when considering how participants describe their symptoms. The word cloud generated from written definitions shows a predominance of broad terms such as "something", indicating difficulties articulating symptoms with precision. Most definitions focus on the present moment and rarely integrate reflections on past or future implications. Yet participants' narratives suggest that understanding cause-effect relationships and temporal patterns could support better recognition and management. Clarifying and expanding the vocabulary available to describe symptoms becomes essential in this context. Improved language enhances body awareness and health literacy, both of which contribute to stronger agency in managing intimate health conditions. One expert emphasised this need, noting that doctors often follow a standard sequence when evaluating symptoms, moving from general to specific indicators such as fever or shivering before identifying more targeted signs like bloody urine (P14, WS2). Helping patients speak with similar clarity could support more effective consultations.

Differentiating descriptions to generate knowledge

Across the many ideas of symptoms extracted from the ice-breaking exercise and visualised in Figure 5.1 participants frequently returned to the challenge of distinguishing between closely related sensations. In particular, the difference between discomfort and pain resurfaced throughout the workshop sessions, revealing how difficult it can be to articulate subtle variations in embodied experience.

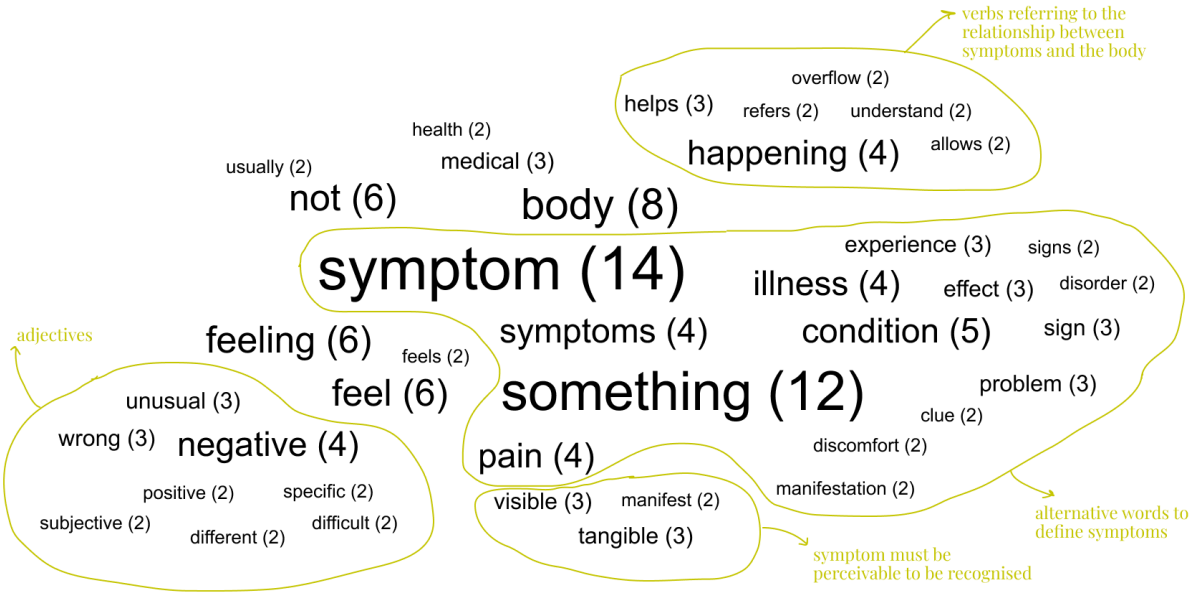


Figure 5.1: most used words provided by participants in their written definition of symptom. Frequency is written within brackets; yellow highlights clusters emerging based on the meaning of the words.

This pattern is further illustrated in Figure 5.2, which presents the symptoms identified through the workshop conversations and compares them with those reported in the clinical literature. The figure shows symptoms confirmed by existing sources, while those highlighted in purple indicate either new additions or descriptions that diverge from established definitions. The symptoms included in the figure are extracted from the conversations of the three main workshops and counted according to the frequency with which participants referred to them.

At first, participants made little to no differentiation between the two terms: “We have two labels discomfort and pain? We have two, we have duplicate discomfort, different pain, let’s put them next to each other. Is it different?” (P2, WS1). Several participants initially expressed the view that the sensations are essentially the same: “In my opinion discomfort and pain are the same” (P4, WS1).

As the activity progressed, however, the distinction gained importance, especially once participants began associating sensations with specific symptoms.

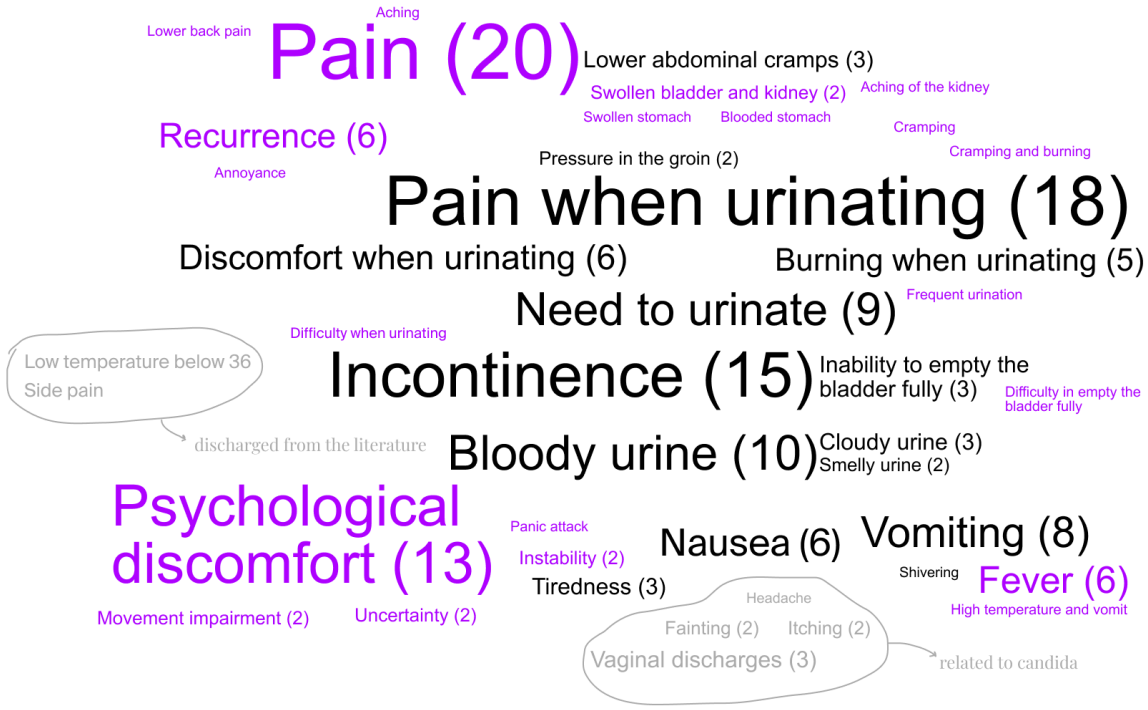


Figure 5.2: relevant symptoms extracted from the analysis of the workshop conversations compared to the literature. The black labels confirm the literature symptoms. In purple, new symptoms or different descriptions introduced by participants. Frequency of citation is written within brackets.

This process prompted more nuanced reflections based on personal experience: “Discomfort when peeing and pain when peeing. I guess this is more severe and then maybe this is more light” (P20, WS3). Toward the end of the exercise, participants offered even more precise terms. For instance, “burning,” when referring to urination, was identified as more specific and descriptive than the broader category of “pain” (P6, WS1). These discussions highlight how embodied engagement helps participants move from general expressions to more differentiated and meaningful descriptors. Identifying precise terms, nuances, and potential metaphors becomes especially valuable for communication, both within the workshops and in clinical contexts. This process aligns with the broader aim of enriching the vocabulary available to patients and supporting clearer, more accurate descriptions of symptoms.

The organisation of the labels of symptoms reflects this scale, as positively recognised by one of the experts: “It looks like they [symptom labels] have been ordered in when they first occur and then down here is when it gets more severe, which is really interesting because those are the ones that you went to first” (P14, WS3). The term “bloated,” when referring to the stomach, was preferred over the already available term “swollen.” P13 suggested it to P11, who is not a native English

speaker and was struggling to describe the sensation: “I don’t know how to say it in Italian [sic] when you feel like... full” (P13). Due to the language barrier, it is unclear whether the first participant intended to highlight a meaningful distinction between the two terms. Apart from a bloated stomach, other symptoms emerged during the activity that were not mentioned in the literature, include fever, swollen kidney and bladder, and panic attacks. Fever was identified in two workshop sessions (WS1, WS2), with one expert clarifying that it results from the progression of infection. For this reason, fever may not be considered an initial symptom, as it typically appears when cystitis develops into more severe conditions.

However, participants collectively agreed to include it in the list alongside the other symptoms. Imagining being able to precisely recognised the swollen of the kidney and the bladder sounds quite difficult, but even if this correspondence can not be tested, the participant explains as follow: “I think the way I’m considering it is because when you’re in a normal state, you don’t feel it feel your organs and they’re there. But like during an infection, you feel it and like you feel something’s there. So in my head it’s like it’s bigger now.” (P20, WS3). And also: “So in that sense, like something has stretched, something has like in just coupled in size, but like it has mass to it, it’s not something that’s just like transparent or like something that you can go through it, it like the swell in size and like volume.” (P20, WS3). Consistently, she makes use of materials to represent this feeling: “I experienced like the swollen kidney and bladder. And for me, I just sort of representative with like smaller cubes that are like more rubbery and stretchy and the bigger cube that’s connected with the very short clear tube because and I was like, hunched over like not being able to be, like, flexible and expand and myself. So I just felt very constricted” (P20, WS3).

The (mental) anticipation of pain becomes pain itself

More generally, participants also reflected on the broader categorisation of symptoms and what should be included within this notion. Across all workshop sessions, they emphasised the psychological dimension of UTIs as a central aspect of how the illness is perceived and experienced. One participant expressed surprise at the absence of mental symptoms in the initial labels, asking, “Because at the moment all the symptoms are the physical ones. Do you want me to think about the mental one too?” (P9, WS2). Others reinforced this perspective, describing symptoms as “possible disease, disorder, discomfort that may be physical or also perceived on a mental level, more psychological” (P5, WS1). Even the experts highlighted this duality, noting that symptoms may arise “either in a physical or psychological sense” (P1, WS1) or as “physical or mental side effects from your condition that you are facing” (P14, WS2).

Although one participant explicitly mentioned a “panic attack,” most referred to “anxiety” as the primary psychological manifestation. This anxiety was closely tied to the expectation of pain: “I do not think fear is quite the word, but probably anxious” (P9, WS2), especially in relation to painful urination, described as “the scary one” (P20, WS3). Pain when urinating, together with the disruption it causes in daily life, was frequently cited as the main trigger of psychological distress. Participants described how episodes affected work (“I have to work and the whole day is crushed,” P18, WS3) and intimate relationships (“the episodes affected my life, causing me anxiety especially toward sexual relations and everything that could cause that disease,” P3, WS1).

For many, anxiety intensified not only during an episode but also in anticipation of it. Recurrent infections amplified this effect, making psychological distress arise even before physical symptoms: “It is almost like you anticipate the pain that will come with it” (P9, WS2). One participant described anxiety as the most significant symptom of disease progression, exceeding the physical discomfort itself: “The most serious symptom in the end was for me the anxiety and fear I had of the illness, so that is represented by the wooden cube which is getting bigger and bigger because the anxiety is increasing, but it is less and less stable” (P3, WS1). Importantly, increased agency in managing the illness does not necessarily lessen this mental burden. While self-management can be empowering, it also places responsibility on patients in ways that feel heavy and at times overwhelming. As one expert observed, this shift “represents a big mental wave on your shoulders” (P14, WS3). The workshops therefore reveal a complex interplay between physical sensations, emotional consequences, and anticipatory fear, where psychological responses become as defining as the physical symptoms themselves.

5.1.4 Diagnosis

Diagnosis refers to the process of identifying a disease, condition, or injury from its signs and symptoms, often through a combination of clinical evaluation, patient history, physical examination, and diagnostic testing (WHO, 2022). This is a critical step in healthcare that informs treatment decisions and management strategies. In the context of this study, diagnosis is explored not only as a clinical determination made by healthcare professionals, but also through the lens of patients’ own interpretations, assumptions, and self-diagnostic practices. These lay diagnostic processes are particularly relevant in intimate infections, where ambiguity of symptoms and past experiences often influence recognition and response.

In this thesis, diagnosis is both a clinical process and an interpretative practice shaped by participants’ own experiences of symptoms, recurrence, and uncertainty.

The findings show that participants often engage in informal forms of self-diagnosis before seeking medical advice, drawing on bodily familiarity, previous infections, perceived symptom patterns, and comparison with other intimate conditions. At the same time, diagnosis appears as a point of tension, as participants describe uncertainty around test results, delays, misrecognition, and the difficulty of communicating sensations clearly within consultations. Overall, diagnosis emerges as a negotiated process in which clinical evidence, patient interpretation, and embodied experience interact to shape decisions about care and treatment.

Different causes of uncertainty

One key dimension of diagnosis concerns the uncertainty participants experience when interpreting early sensations. Many described the onset of symptoms as vague or indistinct, such as feeling "something" without knowing whether it relates to urination or another bodily process (P18, WS3). This ambiguity highlights how recognising symptoms requires a certain level of bodily awareness, which several participants realised they initially lacked. As one noted, "Before, I had no perception even if I could see it maybe it has always been there but I could not recognise it" (P6, WS1). Uncertainty is compounded by limited health literacy and by the fact that similar sensations can stem from different causes. Interpreting early signs therefore involves not only noticing internal changes but also contextualising them in relation to one's normal bodily state and past experiences. Another dimension of diagnosis relates to the influence of experience, perception, and interoception in recognising symptoms. Participants who had lived through several episodes of infection reported a heightened ability to detect early signs, showing how experiential knowledge helps build internal sensitivity. Interoception, understood as the perception of internal bodily states, plays a significant role in this process. Subtle changes in bladder fullness, pressure, or irritation were often described as early warnings. Although research on interoception is still growing, existing studies suggest that developing bodily awareness can support faster recognition of illness. The workshop data reinforce this idea, as participants frequently acted on minor sensations that they had learned to recognise over time.

A further aspect of diagnosis emerges through the temporal progression of symptoms, which participants often described as unpredictable and fast-moving. Several explained that infections can escalate very quickly, with mild sensations becoming acute within a short timeframe. One participant captured this acceleration clearly: "Going from these light symptoms to worse ones can happen in a matter of hours. It is a very short bridge between the two" (P14, WS2). Others described the opposite scenario, where early sensations appear briefly and then disappear,

preventing the development of a full infection: “The time that is not that urgent there were times when the feeling went away, so it did not become a cystitis” (P10, WS2). These accounts highlight how crucial timing is for decision making. Without an understanding of how symptoms may evolve, individuals struggle to judge whether an emerging sensation requires immediate attention or whether it might resolve on its own, contributing to the broader uncertainty that characterises the diagnostic experience.

Diagnosis is also shaped by the embodied strategies participants use to reduce uncertainty. Several described testing their sensations through sensory interaction, such as taking a warm shower at the first sign of discomfort to determine whether the feeling truly indicates a UTI (P18, WS3). In contrast, participants experiencing more advanced symptoms sought cooling sensations for relief (P3, WS1). These contrasting approaches demonstrate that participants actively negotiate and produce bodily knowledge through experimentation. Ambiguous sensations lead participants to test and interpret what they feel, whereas the intensification of symptoms moves them toward seeking relief. Such embodied strategies reveal how individuals engage in forms of self-diagnosis that depend on iteratively sensing, comparing, and responding to their own internal states.

Blood confirms preliminary suggestions

Participants often described how recurrent episodes help them recognise early changes and anticipate the evolution of the disease. One participant explained this progression clearly: “At first what happens is that I notice frequent urination, darker and darker which is followed by swelling in the lower abdomen, the swelling in the lower abdomen then becomes a discomfort, a difficulty in going to the bathroom” (P2, WS1). Through repeated experiences, she also identified what she called “pre-symptoms”: “There is always this swelling first, so over time I learnt a little bit to recognise the pre-symptoms” (P2, WS1). These initial signals are subtle and cannot be linked with certainty to any specific condition, yet participants reported being able to interpret them as the onset of cystitis. This suggests the development of an implicit bodily knowledge that enables individuals to read and correlate different sensations over time.

The relationship between cystitis and menstruation was also frequently mentioned. Some participants identified the recurrence of symptoms just before their period: “This thing always happens to me before my period it tends to happen to me” (P5, WS1). For others, the ability to distinguish between menstrual blood and blood caused by a UTI enabled the recognition of the disease. One participant described the moment of noticing a distinctly different colour: “It was a blood that I recognised

for the first time not the blood of menstruation but a blood almost as if I had cut myself, very bright, orange" (P2, WS1). During the workshop, the presence of physical variables on the table, especially colour, helped her articulate this realisation by pairing the symptom with a specific material attribute.

Participants consistently identified blood in the urine as the first clearly visible symptom (P14). This visual cue was often followed by sensations of incontinence, described not only as a frequent urge to urinate but also as painful and intrusive: "Firstly you have pain when you are peeing, but the point is that you feel like you always have to pee" (P18, WS3). The combination of visible and sensory signals played an important role in strengthening participants' confidence in recognising the condition.

Several accounts highlighted how the infection can progress when early signs are ignored. One participant recalled reaching "the last stage, which was the most severe, resulting in a very serious infection with vomiting and fever" (P3, WS1). Another linked vomiting directly to the onset of infection: "When the infection came, I also had vomit" (P5, WS1). According to the medical experts consulted, such symptoms indicate not common cystitis but more advanced conditions such as urethritis or pyelonephritis.

Too busy to care

A recurrent theme in the workshops concerns the role of carelessness and delay in the development of UTIs. Participants frequently acknowledged ignoring early signs, often because symptoms appeared mild or ambiguous at first. One participant reflected on this pattern directly: "I was told it had developed into an infection precisely because I had neglected it my negligence is definitely associated with not keeping an eye on it. If you have symptoms, call the doctor immediately also the fact that I did not have a remedy right away meant that this thing was already neglected on my part" (P5, WS1). This account reveals how hesitation, uncertainty, and a lack of immediate access to care can collectively contribute to the progression of the infection. The difficulty of contacting a doctor when symptoms emerge also plays an important role. Several participants described waiting until the situation became urgent, expecting immediate support as soon as they reached out. This expectation, and the frustration surrounding unmet availability, appears frequently in the data and is examined further in the section on consultation.

Another participant traced her earlier misconceptions about the causes of the disease to feelings of blame and shame. Having contracted cystitis at sixteen, she initially believed it was linked to "having too much sex," which prevented her from seeking help from family or clinicians. Only after undergoing specific investigations

during a later, more severe episode did she understand that “it was not just because I was having too much sex but there were also many other things” (P5, WS1). Her account illustrates how stigma and misinformation can delay recognition and treatment.

Participants also described attributing UTIs to personal vulnerability, such as having a “weak immune system,” which one participant associated with experiencing cystitis at least once a year (P18, WS3). The same participant linked her condition to exposure to cold surfaces: “Maybe it is just because I sit on the cold you sit on the cold stone, tomorrow for sure you develop cystitis” (P18, WS3). Even though no other participant mentioned this belief, it remains common in everyday narratives. During the period of this research, several colleagues also avoided metal chairs outdoors for this reason. While medical experts later dismissed this correlation during interviews, the persistence of this belief raises questions about the cultural and experiential origins of such associations. Discussion of causes also included references to *Escherichia coli*, identified by experts as the most common bacterium responsible for cystitis, especially when linked to inadequate hygienic practices (P1). However, the clinical distinction between different infections was not always clear to participants. One participant, for example, described experiencing a severe *E. coli* infection that required a completely different treatment from her usual cystitis therapy, even though the symptoms seemed the same (P2, WS1). Her later question highlights the confusion many individuals face in distinguishing between bacterial causes and symptom presentation, as she asked, “Is that a different disease, the fact of having *E. coli* in the urine at very high levels?”. This confusion underscores the need for clearer communication around the causes of UTIs and the rationale behind different treatment approaches.

UTI’s intersecting other conditions

Participants frequently described uncertainty when distinguishing UTIs from other intimate conditions, particularly candidiasis. Several openly acknowledged difficulty recognising which illness their symptoms referred to. One participant explained, “I do not know if I am talking about cystitis or candida, I have not figured it out yet. The fact is, however, that I treat with antibiotics, the symptoms are what are on the table” (P4, WS1). This confusion reflects both the overlap of certain sensations and the challenges individuals face in differentiating conditions that affect the same bodily area. Even when participants recognised the distinction, discussions about UTIs often led to references to other intimate health issues that share similar discomforts but have different causes. As one participant noted, “I think that could also be for other symptoms as well and other conditions” (P13, WS2). The difficulty in drawing

boundaries also emerged when another participant asked, “Are these symptoms related only to UTIs or just general symptoms?” (P20, WS3), signalling that the symptomatic markers of the activity were not always immediately identifiable as UTI-specific. Participants also related UTI sensations to experiences of other bodily events, such as giving birth (“When I gave birth, I had a lot of these sensations, and it is almost like feeling anxious” (P9, WS2) or the insertion of a Mirena coil (P13, WS2). These comparisons demonstrate how intimate conditions are often understood through a continuum of embodied experiences rather than as isolated medical events. By drawing parallels across conditions, participants worked to describe sensations in more relatable and communicable ways.

As will be further discussed in the section dedicated to the workshop structure, allowing such cross-condition perspectives can enrich the descriptive detail of symptoms and help participants convey the nuances of intimate bodily experiences. At the same time, this variety complicates comparison across participants. When descriptions arise from conditions outside the scope of the workshop, representations become misaligned, making it difficult to draw disease-specific insights or develop consistent mappings between symptoms and material expressions.

5.1.5 Consultation

Consultation in healthcare refers to the interaction between a patient and a healthcare provider with the aim of discussing symptoms, concerns, diagnoses, or treatment options. This phase is a core component of the care pathway that enables clinical assessment, shared decision-making, and therapeutic alliance (NICE, 2022; WHO, 2016). Consultations may vary in formality, setting, and duration, but they remain fundamental to initiating and maintaining medical care. In this study, the concept of consultation is extended to include both formal medical encounters and informal advisory interactions, revealing how patients seek and interpret professional input, especially in relation to ambiguous or recurring symptoms such as those associated with urinary tract and intimate infections.

This section examines consultation as a moment where participants seek recognition, clarification, and support for symptoms that are often difficult to describe or clinically confirm. The findings show that consultations are shaped by the quality of communication between patients and healthcare professionals, including whether participants feel listened to, believed, and taken seriously. Participants describe formal medical appointments alongside more informal exchanges with pharmacists, family members, or other trusted figures, showing that advice-seeking often extends beyond the clinical encounter. Overall, consultation emerges as a relational process

in which embodied experience, professional interpretation, and trust influence how participants understand their condition and decide how to act.

Doctor availability and patient urgency are inversely related

An emergent pattern in the workshop conversations concerns the relationship between the urgency felt by patients and the availability of medical professionals. Although doctors are central figures in the management of UTIs, they appear only marginally in participants' discussions. In the first workshop, the doctor is mentioned for the first time after more than an hour and a half of conversation, and a similar delay occurs in the second session. Only in the third workshop do participants refer to medical experts at the beginning, during the symptom definition exercise. This limited presence suggests that the doctor enters the narrative primarily when problems escalate rather than at the onset of symptoms.

In analysing participants' accounts, I observed a recurring pattern in how they navigated healthcare access during UTI episodes. One participant explained the uncertainty she experienced when waiting to access care: "It becomes an infection… it was really, really painful and it is not stable because you never know if it will go away or get worse, also depending on the availability of the doctor" (P11, WS2). Yet urgent needs frequently collided with limited access. As one participant recalled, "When I needed her, she did not answer me" (P5, WS1). This mismatch between patient urgency and medical availability often left individuals to manage early symptoms on their own.

The primary motivation for contacting a doctor was the need for antibiotics, as expressed by a participant who noted, "If you do not find the doctor right away, you do not get the antibiotics" (P11, WS2). For recurrent infections, some participants relied on phone consultations in which doctors validated previously prescribed treatments, allowing them to self-manage episodes without an in-person visit (P4, P18).
In one case, the lack of timely contact with a doctor had serious consequences. A participant ignored her symptoms until they became severe; by the time she sought help, her condition required immediate hospitalisation and intravenous antibiotics (P5, WS1). Another participant described a similarly escalated episode that finally prompted proper clinical investigation: "I had a strong episode, with fever and blood… so I went to see a doctor. I had urine tests, blood tests, everything, and then I did a treatment of almost a month of antibiotics, washings, ova" (P2, WS1). These accounts show how delayed medical engagement can transform manageable symptoms into acute conditions requiring intensive intervention.

I interpret these accounts as showing a contradiction between patient behaviour and system responsiveness, with individuals postponing contact when symptoms

are unclear and encountering limited availability once the condition worsens. This gap intensifies uncertainty, shapes self-management practices, and influences how participants navigate the progression of the illness.

(Not) to talk about it

When analysing discussions about disclosure and communication, I identified a strong relational and emotional dimension shaping how participants sought advice or support. Sharing initial conditions and promptly act can be essential to avoid the point of no return. However, the intimate nature of the disease can create some discomfort, “especially with strangers or with doctors or with your parents. If you have a sister, it’s better” (P12, WS2). Someone from the same sex and close enough to be confident with appears the best person to ask for support: “I have this problem and If you have an older sister or some or some sister-in-law, maybe you can ask advice.” (P12, WS2). Misinterpretation further expand this feeling, as seen in the case of younger patients associating cystitis with the frequency of sexual activity: “I lived it as a shame no because for the cystitis I didn’t talk about it with my mother, even with the doctors, I was ashamed because there is maybe, I have too much sex” (P5, WS1).

Alternative (more efficient?) help

Participants described several alternatives to consulting a doctor when symptoms appear. Pharmacists were recognised as an accessible first point of contact, although not everyone was aware of the extent of their role in providing support. Many participants also turned to the internet to search for information about causes and treatments. However, the reliability of online sources was often questioned, as these searches frequently produced exaggerated or alarming interpretations that increased anxiety. As one participant noted, “If they search the information online if they search the right information is fine. If they didn’t search, search the good information, they will most scared about it and they will feel, oh, I’m nearly to die” (P12, WS2). These reflections highlight the need for resources that describe symptoms accurately and in ways that patients can recognise themselves. Participants emphasised that such sources should include expert guidance to ensure scientific validity, but also integrate patient experiences to avoid overgeneralisation. The initial review of the literature shows, however, that finding this balance remains a significant challenge.

A striking example of how patients personalise symptom interpretation came from a participant who explained her habit of describing pain using geometric imagery: “It’s when usually the doctor asks me what kind of pain you have. It’s usually like

associated with an angle. It might be sharp or tuned" (P18, WS3). This comment illustrates the creative strategies patients use to express discomfort and may reflect the influence of the workshop context, where shapes and materials were central to communication.

5.1.6 Treatments

In medical terminology, treatment refers to the management and care of a patient to combat a disease, alleviate symptoms, or promote recovery. This phase includes any intervention aimed at curing, mitigating, or managing a health condition, and may encompass pharmacological therapies, such as antibiotics, surgical procedures, lifestyle modifications, psychological interventions, and supportive care. In the context of this study, treatment refers specifically to the actions taken by participants, either prescribed by medical professionals or self-initiated, to relieve, manage, or eliminate symptoms related to urinary tract or intimate infections (NCI, n.d.).

This section examines prevention as an ongoing practice shaped by bodily awareness, previous infections, everyday routines, and uncertainty about what is effective. Participants describe prevention through actions such as hydration, hygiene, clothing choices, sexual practices, supplements, and self-care strategies, showing how prevention becomes embedded in daily life rather than limited to medical advice. The findings also show that these practices are often guided by experiential knowledge, as participants learn to recognise bodily signals, anticipate risk, and adjust behaviour through repeated encounters with UTIs. At the same time, prevention remains uncertain, since participants are not always able to determine whether these actions prevent infection, reduce symptoms, or simply provide a sense of control. Overall, prevention emerges as an embodied and situated form of knowledge developed through practice, repetition, and personal interpretation.

Antibiotic inefficacy mistaken for disease recurrency

Participants described varying experiences with the effectiveness of treatments for UTIs. For some, symptoms resolved quickly with common medication provided by a pharmacist. One participant explained, "After that the symptom is disappeared" (P12, WS2), while another recalled that "when I had it, the pharmacist gave me medication" (P13, WS2). Although pharmacists cannot prescribe antibiotics, they often support the management of mild conditions by suggesting appropriate remedies. For others, however, treatment was much less effective. Several participants described situations in which antibiotics failed to resolve the infection, intensifying both the physical and emotional impact of the illness.

One participant recounted, “I had cystitis, I was taking antibiotics. After a week my cystitis would come back” (P4, WS1). When symptoms never fully subside, the distinction between a single unresolved episode and multiple recurrent ones becomes blurred. As one participant reflected, “Until February, when I had consecutive episodes that I actually associate with a single episode… because I was never well in the whole illness” (P3, WS1). This confusion suggests that what is perceived as recurrence may sometimes be incomplete treatment, resistance to medication, or misalignment between the prescribed cure and the underlying condition.

More severe cases prompted participants to seek specialist care, leading to more extensive and prolonged treatment plans. One participant described undergoing “a cure of almost a month between antibiotics, scrubs, ova” (P5, WS1). Such multi-step regimens may produce additional side effects, which in turn can be mistaken for new or persisting symptoms. These experiences illustrate how the inadequacy or inefficiency of treatments complicate individuals’ understanding of their condition, reinforcing uncertainty about what constitutes a symptom, a side effect, or a sign of true recurrence.

Are these symptoms or side-effects?

Distinguishing symptoms from treatment side effects emerges as an important issue in participants’ accounts. Several individuals described difficulties determining whether sensations were caused by the illness itself or by the remedies they were using to manage it. One participant reflected on stomach bloating, explaining, “I also wanted to add stomach bloating, which I don’t really know if it was a symptom that was always present in my case, but I don’t know if it was related to the disease or an effect of the medication I was taking, because all the time I was also taking probiotics that have it as a side effect, so I can’t really define it. But it was a symptom” (P3, WS1). Another participant expressed similar uncertainty regarding nausea: “Maybe sometimes [I had] nausea but I don’t know if that was due to me taking the antibiotic” (P4, WS1). These accounts show how easily treatment-related effects can overlap with illness-related sensations, complicating the process of recognising, categorising, and communicating symptoms. Initially, distinguishing between the two appears essential for understanding the condition accurately. However, the ambiguity itself may offer additional insight. When symptoms and side effects coexist, they shape a combined experiential state that influences how participants interpret and describe their illness. Considering this blended condition may therefore enrich the way UTIs are communicated and understood, especially in contexts where treatment regimens evolve or extend over time.

Establishing a clear boundary between symptoms and side effects would require controlling treatment variables and assessing sensations under stable conditions. Although such control is difficult to achieve in clinical settings, the recurrent nature of UTIs means that similar patterns of treatment and response often repeat, potentially allowing these distinctions to be explored more systematically. Within this research context, the recognition of ambiguous or overlapping sensations serves as a reminder that illness experience is rarely linear and that both disease and treatment contribute to how individuals understand and articulate their condition.

Probiotics, from prevention to treatment

Participants often turned to alternative strategies when antibiotics proved ineffective or produced undesirable side effects. Probiotics were frequently described as essential for supporting recovery and stabilising the body during and after antibiotic treatment. One participant explained, “And only from there, with treatment, just with the probiotics for six months plus the antibiotic did I recover” (P4, WS1). Probiotics were also used preventively to avoid escalation of symptoms: “I’ve stopped taking antibiotics, I’m switching to probiotics that I’ve been recommended and that are actually calming me down… I manage to solve it, to not get to that stage where I’m sore” (P4, WS1). Participants who experienced recurrent UTIs demonstrated particular awareness of the value of probiotics in maintaining long-term balance.

Alongside probiotics, supplements and alternative practices were also mentioned. Some participants reported treating mild episodes with non-prescription options, as illustrated by the account: “I have had very mild cystitis that I have treated with blueberry supplements, but it has never evolved into something that really gave me serious symptoms” (P3, WS1). Acupuncture appeared as an indirect example from participants’ social networks: “I have friends who have treated cystitis with acupuncture and well, there are those who actually believe in it. Then there are so many things, even lighter things” (P1, WS1). Although the scientific validity of acupuncture for cystitis remains unproven, some participants considered its perceived benefits in relation to pain relief, inflammation reduction, or immune support.

Participants also referred to traditional beliefs and practices. One described heating the surface before sitting as a familiar method for avoiding infection, although this approach has no scientific basis and was not supported by medical experts. Only one participant expressed a preference for avoiding medication entirely, stating that allowing the body to undergo the natural progression of the illness is sometimes interpreted as a response to the body’s “request of attention” (P13, WS3).

Despite the variety of alternatives mentioned, antibiotics remained the most commonly referenced treatment, particularly for severe episodes.

Specific medications were rarely named, except for Monuril, based on Fosfomycin, which in Switzerland is prescription-only and considered a first-line treatment for UTIs, especially during pregnancy. Participants did not express general aversion to antibiotics; instead, they reserved their use for situations perceived as urgent, while preferring alternatives for mild episodes or preventive care. This pattern often created an overlap between treatment and prevention behaviours, as participants used supplements, hydration, and dietary adjustments both to manage early symptoms and to avoid deterioration. Within this perspective, prevention becomes part of treatment.

Recognising the stage of the illness, and being aware of what precedes and follows it, becomes essential for making appropriate choices about remedies and for avoiding unnecessary escalation. Participants with chronic experiences appeared particularly attuned to this balance, acknowledging that stronger interventions are not always the most effective and that maintaining health requires continuous preventive attention.

Relief in support of the treatment

Participants described a range of strategies used to seek relief during the acute phase of a UTI, often accompanying or supporting medical treatment. Depending on the severity of the episode, rest was considered essential: “I will stay at home. Like usually I prefer to stay in bed” (P18, WS3). Psychological implications also shaped recovery, as feelings of incontinence or loss of control often made individuals uncomfortable leaving their homes.

Fluctuations in body temperature further influenced symptom management. One participant explained that the combination of internal heat and the burning sensation associated with cystitis prompted her to seek cold sensations for relief: “I felt that heat is related to body temperature, but also the burning of cystitis and therefore, I was looking for cold in every way” (P3, WS1). While this approach does not treat the infection directly, it offers temporary comfort and helps individuals cope with pain and distress during the most intense moments of the disease.

These accounts emphasise that relief measures operate alongside treatment rather than replacing it. They support the person’s capacity to endure acute discomfort and can influence emotional stability and perceived control over the illness experience.

5.1.7 Summary of the findings on UTIs

Findings related to UTIs reveal how participants articulate their lived experience across the full disease trajectory, highlighting forms of situated knowledge often absent from clinical accounts. Table 6 summarise the key points and the highlights from the five themes identified in the workshop analysis that provide insights on the topic of UTIs. Preventive practices discussed in 5.1.2 emphasise habitual, gendered routines such as wiping direction, post-intercourse hygiene, and dietary strategies, with participants noting that the role of food and hydration is both significant and insufficiently acknowledged. Symptom expression in 5.1.3 section shows that recognising and describing bodily sensations is central to gaining agency, with the workshops enabling participants to distinguish subtle differences between burning, pressure, urgency, or discomfort. This specificity not only deepens personal understanding but also supports comparability across participants. The analysis also evidences how psychological anticipation becomes part of the symptom experience, with fear of pain amplifying distress even before physical sensations occur.

Diagnostic experiences (section 5.1.4) reveal persistent uncertainty caused by fluctuating symptoms, ambiguous bodily signals, and inconsistent access to medical evaluation. Participants often rely on personal heuristics, such as the appearance of blood, to validate preliminary suspicions when professional confirmation is delayed. Consultation dynamics in 5.1.5 point to an imbalance between the urgency felt by patients and the limited availability of clinicians, compounded by discomfort when discussing intimate symptoms. As a result, some participants seek alternative sources of support or advice. Treatment perspectives (5.1.6) highlight confusion between symptoms of the disease and side-effects of medication, alongside frustration with antibiotic inefficacy that is often mistaken for recurrence. Across these themes, the workshops reveal emotional, relational, and experiential dimensions such as anxiety, shame, vigilance, and relief, that shape how UTIs are lived, interpreted, and managed, providing a richer picture than biomedical descriptors alone. The following section extends the thematic analysis beyond UTIs by examining a different set of themes related to other healthcare conditions discussed during the workshops. This allows the analysis to consider how participants describe embodied experiences beyond the main UTI case and how these accounts broaden the understanding of symptom interpretation, communication, and care.

Theme (on UTI topic)	Key points	Higlights
T1: Prevention (section 5.1.2)	Participants described prevention as a set of habitual practices centred on hygiene, hydration, and diet.	The role of food and hydration was viewed as important yet often overlooked in clinical discourse. Post-intercourse hygiene and wiping direction were repeated as essential measures. Participants also relied on keeping medicines accessible as a form of preparedness.
T2: Symptoms (section 5.1.3)	Symptom articulation supported agency and improved personal understanding.	Participants distinguished between discomfort, pressure, pain, urgency, and mental anticipation, noting how expectation of pain becomes part of the symptom experience. They emphasised the need for more nuanced ways of describing sensations, which the workshop helped to express.
T3: Diagnosis (section 5.1.4)	Diagnosis was marked by uncertainty and difficulty in interpreting bodily signals.	Participants described relying on personal indicators, such as the appearance of blood, to confirm early suspicions when clinical assessment was delayed. Lack of immediate medical support intensified anxiety and confusion.
T4: Consultation (section 5.1.5)	Consultation experiences reflected a mismatch between patient urgency and clinical availability.	Participants often felt that time constraints limited discussion of intimate symptoms. Some avoided speaking about the condition unless necessary, while others sought alternative sources of advice when appointments were difficult to access.
T5: Treatment (section 5.1.6)	Experiences of treatment involved confusion between symptom persistence and side effects.	Antibiotic inefficacy was often interpreted as recurrence, and participants noted uncertainty about whether new sensations stemmed from the illness or the medication. The use of probiotics emerged as both a preventive and supportive measure during treatment. Emotional relief during treatment was also discussed as an important aspect of recovery.

Table 6: summary of key points and highlights from the five themes identified in the workshop analysis that provide insights on the topic of UTIs.

5.2 Findings on other health conditions

While UTIs remain the main empirical focus of this thesis, WS4 and WS5 also generated material related to other embodied and intimate health conditions. This section extends the thematic analysis beyond the UTI case to examine the forms of health-related knowledge that emerge when participants work with self-selected conditions. Table 7 presents the themes and sub-themes identified through thematic analysis of WS4 and WS5. The analysis is organised around four main areas that recur across the data, symptom and embodied description, uncertainty and overlap between conditions, consultation and help-seeking, and treatment or self-management strategies. These areas do not follow the full disease trajectory used in the UTI analysis, because the conditions addressed in WS4 and WS5 are more varied. Instead, the structure reflects the themes that offer the clearest

basis for comparison across participants' accounts. This organisation shows how participants describe symptoms, interpret uncertainty, reflect on support and communication, and situate health conditions within everyday coping practices. It also allows comparison across different conditions while preserving the specificity of individual and embodied accounts.

Theme 1	**Symptoms and embodied descriptions**	**Theme 2**	**Uncertainty and overlap between conditions**	**Theme 3**	**Consultation and help-seeking**	**Theme 4**	Treatment and self-management strategies
Sub-theme 1.1	Differentiated descriptions	Sub-theme 2.1	Relation with other conditions	Sub-theme 3.1	Doctor availability	Sub-theme 4.1	Home recovery
Sub-theme 1.2	Different aspects of the same symptom	Sub-theme 2.2	Uncertainty caused by the condition	Sub-theme 3.2	Alternative support	Sub-theme 4.2	Natural course
Sub-theme 1.3	Nuanced vocabulary	Sub-theme 2.3	Lack of body awareness			Sub-theme 4.3	Everyday coping
Sub-theme 1.4	Subjectivity	Sub-theme 2.4	Intersecting conditions				
Sub-theme 1.5	Invisible symptoms	Sub-theme 2.5	Whether symptoms are valid for one condition or another				
Sub-theme 1.6	Changes over time	Sub-theme 2.6	Lack of health literacy				

Table 7: overview of the themes and sub-themes identified through thematic analysis of WS4 and WS5, summarising the coded insights related to other health conditions addressed in the workshops.

5.2.1 Workshop sessions and participants included in the analysis

This part of the analysis draws on WS4 and WS5, where participants address conditions beyond UTIs. In both sessions, the conditions discussed emerge from participants' own experiences rather than from a topic assigned in advance. They therefore reflect what participants consider meaningful, recognisable, or relevant within the workshop context.

As outlined in Section 3.7, WS4 takes place in a conference context and involves participants of different genders and health experiences. WS5 takes place in an educational design setting and similarly invites participants to work with conditions selected from their own experience. These sessions also differ from the earlier workshops in the mode of participation adopted during shaping.

While WS1, WS2, and WS3 concentrate collaboration mainly in the discussion and association of labels before individual artefact construction, WS4 and WS5 extend collaboration to the construction of the artefacts themselves. This distinction is important because some insights emerge through collective negotiation during material making, as well as through verbal discussion.

The analysis includes participants in WS4 and WS5 who provided narratives, discussions, and artefacts related to conditions other than UTIs. Their contributions are examined through the multimodal dataset generated during the workshops, including written narratives, transcribed conversations, artefact presentations, and the material artefacts themselves. This scope makes it possible to analyse the kinds of health-related knowledge that emerge when the workshop is applied to self-selected conditions within a collaborative format.

5.2.2 Symptoms and embodied descriptions

This section examines how participants describe health conditions beyond UTIs through embodied and situated accounts. The analysis shows that participants do not only name conditions, but break them down into clusters of sensations, bodily locations, intensities, temporal changes, and affective states. Across WS4 and WS5, the workshop supports the articulation of conditions as lived experiences rather than as fixed diagnostic categories. This is especially visible in the way participants describe internal, invisible, or fluctuating symptoms through material qualities, metaphors, and comparisons.

Describing conditions through symptom clusters

A first finding concerns the tendency to describe conditions as combinations of symptoms rather than as single experiences. In WS4, the group working on flu-Covid described the condition through several coexisting and shifting sensations. They referred to “the condition of block nose and running nose that are alternating each other” (G1; WS4), connected this to throat irritation by explaining that they wanted to make “an itchy throat” (G1; WS4), and also described joint pain through metaphors such as “prisoner’s ball” and “a twisted knee” (G1; WS4). These descriptions present flu-Covid as a layered bodily state involving respiratory discomfort, throat irritation, and musculoskeletal pain. The condition is therefore not reduced to one dominant symptom, but expressed as a changing configuration of bodily effects.

A similar pattern appears in the discussion of lactose intolerance. Participants described the condition through fullness, bloating, lower-back pain, nausea, mental fog, and variation across the day. Fullness was defined as “the state of feeling full

quite quickly", while bloating was described as something that "starts going out of control" (G2; WS4). Nausea was explained through an internal image, as "a marble inside you", and the group also included "mental fog" (G2; WS4). These accounts show how participants differentiate between several internal sensations that overlap within the same condition. Lactose intolerance is therefore described as a distributed bodily experience, involving digestion, pain, perception, and mental clarity.

WS5 extends this finding by showing how participants describe conditions through connected bodily effects. In the discussion of fever and stomach-ache, one group explains that they want to represent stomach-ache "in a triangle, in a squishy triangle" (G5; WS5), before adding that "when we are having a fever, we also have the body cramps or the joint pains" (G5; WS5). Their conclusion that "everything comes together" (G5; WS5) is analytically significant because it shows how the condition is experienced as a cluster of interdependent sensations. The artefact and discussion therefore support the description of illness as a connected bodily state rather than a set of separate symptoms.

Expressing invisible and internal sensations

A second finding concerns the use of nuanced and metaphorical language to describe symptoms that are difficult to express through standard terms. Fatigue, for example, is not described simply as tiredness. Participants define it through "sound envelope and fuzziness or blurring" (G6; WS5), and explain it as a feeling that is "overwhelming" and "all around" while keeping the person "in your bubble" (G6; WS5). They also describe it as something that "isolates you" (G6; WS5). These descriptions combine sensory, spatial, and emotional qualities, showing that fatigue is experienced as an atmosphere that surrounds and separates the person from others. The workshop therefore elicits forms of expression that extend beyond conventional symptom vocabulary.

This same process appears in descriptions of pain. Neck pain is described as "something that would be moving" (G7; WS5), with "spikes" that are sometimes stronger and sometimes barely noticeable (G7; WS5). This account gives pain several qualities at once. It moves, intensifies, fades, and returns. Rather than treating pain as a stable sensation, participants describe it as dynamic and variable. The material discussion helps make these qualities explicit by encouraging participants to associate pain with movement, intensity, and changing form.

Several conditions discussed in WS4 and WS5, including mental fog, fullness, nausea, fatigue, and insomnia, are strongly felt but difficult to locate or show externally. Insomnia is described as "something really transparent" and "all connected" (P23; WS5), as well as "something... running all the time" (P23; WS5).

These descriptions convey a condition that is not visible from the outside but is experienced as continuous, active, and difficult to stop. The reference to transparency is particularly important because it suggests that some symptoms are present and perceptible to the person experiencing them, while remaining hard to make visible to others.

Describing symptoms as changing over time

Another finding concerns temporality. Participants frequently describe symptoms as processes that fluctuate, intensify, or return in stages. The group discussing lactose intolerance explains that "sometimes it's really bad, sometimes is not that bad. Sometimes is OK-ish" (G2; WS4), and adds that the condition changes across the day, beginning more manageably before worsening later (G2; WS4). Shoulder pain is also described through temporal progression. One participant describes softness as a desired state and "like a distant memory" (P24; WS5), while another explains that "my shoulder is coming in stages" (P25; WS5). These accounts show that symptoms are understood as changing experiences that unfold over time rather than as fixed states.

Positioning health as an embodied contrast

The workshop also elicits embodied descriptions of health as the desired opposite of illness. One participant explains health as "not when I'm ill, but when I'm not ill" (P22; WS5), and then describes it as a state where "everything is structured," "everything is in its way," and "everything fits into the place" (P22; WS5). This account shows that participants also use the activity to articulate what bodily coherence, energy, and well-being feel like. Health appears as an embodied condition of order, alignment, and vitality, rather than simply the absence of disease.

Taken together, these findings show that WS4 and WS5 generate rich descriptions of embodied health conditions beyond UTIs. Participants describe conditions through symptom clusters, internal sensations, metaphorical language, invisible discomfort, and temporal change. The conditions selected by participants also reveal a clear pattern. They tend to be common, embodied, and experience-led conditions such as flu-Covid, lactose intolerance, throat pain, fever, fatigue, insomnia, neck pain, and shoulder pain, alongside one account of the healthy body as a contrast to illness. These are conditions that are often recognised through everyday bodily interpretation rather than through immediate external visibility. The analysis therefore shows that the workshop is particularly suited to eliciting experiential knowledge about conditions that are diffuse, fluctuating, and difficult to compare through verbal description alone. At the same time, the richness of these

accounts also shows that symptoms often overlap and resist stable categorisation, which makes uncertainty an important focus for the following section.

5.2.3 Uncertainty and overlap between conditions

This section examines how participants describe uncertainty when symptoms are shared across different conditions, difficult to locate in the body, or hard to connect to a specific cause. Across WS4 and WS5, uncertainty does not appear as a lack of knowledge alone. It emerges as part of the work participants do to recognise, compare, and interpret embodied sensations. The findings show that participants often understand conditions through approximation, similarity, and negotiation rather than through fixed diagnostic categories.

Recognising overlap between conditions

A first form of uncertainty concerns the overlap between different conditions. In WS4, the group working on flu immediately questioned the boundary between flu and Covid, asking: “Is the COVID like... flu? Yes. Like COVID. Yeah. It’s the same symptoms” (G1; WS4). This exchange shows that participants recognise illness through familiar symptom clusters, but those clusters can belong to more than one condition. The similarity between symptoms therefore makes recognition possible while also making differentiation difficult.

This overlap also appears in the discussion of joint pain. While presenting the artefact, the same group explained that one part “could also be constipation” (G1; WS4). Similarly, the same material form can be interpreted in relation to more than one condition. The uncertainty does not come from the absence of sensation, but from the fact that similar bodily feelings may point to different causes. This shows how participants use comparison to make sense of symptoms whose meaning remains open.

Locating internal and ambiguous sensations

A second form of uncertainty concerns sensations that are strongly felt but difficult to locate or define. In the discussion of lactose intolerance, participants described fullness, bloating, lower-back pain, nausea, and mental fog, while also expressing hesitation about what exactly was happening in the body. One participant explained that “you don’t know what was really messed... the fullness” (G2; WS4). This statement captures the uncertainty of internal experience, where a sensation is recognisable but its source or structure remains unclear.

The same example shows the interpretative work required to describe internal sensations. Fullness was defined as “the state of feeling full quite quickly” (G2; WS4), while nausea was described as something that “felt like a marble inside you” (G2; WS4). These descriptions rely on metaphor, bodily attention, and comparison rather than directly observable evidence. They show that participants can describe what a symptom feels like even when they cannot fully explain where it comes from or what it indicates.

Understanding symptoms as shared across illnesses

WS5 reinforces uncertainty as a feature of symptom experience. In the discussion of fever and associated symptoms, one group noted that “any other disease or fever or body pain or any other disease that connects have all these symptoms connected with it” (G5; WS5). They then added: “Everything comes together” (G5; WS5). These statements show that participants understand symptoms such as fever, body pain, and headache as recurring combinations that may appear across different illnesses. Rather than acting as clear indicators of one condition, these symptoms form overlapping patterns that require interpretation.

This finding shows that uncertainty is not only linked to rare or unfamiliar conditions. It also appears in everyday illnesses, where symptoms are common but diagnostically ambiguous. Participants’ accounts therefore reveal how people move between recognition and doubt when bodily sensations resemble several possible conditions at once.

Using body location to reduce uncertainty

The relation between symptoms and body location also emerges as a resource for interpretation. In WS4, one participant reflected on the usefulness of arranging the artefact in relation to the human body, explaining that “the human shape really helps diagnosing, you know, the kind of symptom, locate what’s going exactly. For example, if I represent this thing somewhere else in this composition, I could not associate it with running nose” (G1; WS4). This statement shows that localisation helps participants stabilise meaning. Placing a material element in relation to a body part supports recognition and reduces ambiguity, especially when the same sensation or form could otherwise be interpreted in multiple ways.

This suggests that body awareness plays an important role in participants’ health knowledge. The workshop supports this process by allowing symptoms to be spatialised, compared, and discussed through material arrangements. Location becomes a way to organise uncertainty and connect sensations to possible interpretations.

Interpreting uncertainty as situated health knowledge

Across these accounts, uncertainty appears as a meaningful part of how participants understand health conditions. Participants are often able to describe how something feels, but the relation between symptom, cause, and condition remains open. Their discussions move through approximation, comparison, and negotiation, showing that embodied knowledge does not always align with stable diagnostic boundaries.

The conditions selected in WS4 and WS5 reinforce this point. Participants worked with flu, Covid, lactose intolerance, fever, fatigue, insomnia, neck pain, and shoulder pain, which are common and experience-led conditions often recognised through symptom clusters. These examples show how people distinguish, confuse, or connect conditions through lived bodily experience. The analysis therefore shows that uncertainty and overlap are not peripheral to participants' health knowledge. They are central to how conditions are experienced, compared, and interpreted.

5.2.4 Consultation and help-seeking

This section examines consultation and help-seeking as they emerge in WS4 and WS5. Unlike the UTI-focused sessions, these workshops do not generate detailed accounts of care pathways or specific healthcare actors. Instead, participants focus more strongly on communication, asking how embodied, complex, or difficult experiences can be made understandable within situations of support and care.

Communicating symptoms within clinical constraints

A first aspect concerns the difficulty of communicating symptoms in ways that feel useful within medical encounters. In WS4, after the presentation of the artefacts, one participant questioned whether more extended personal accounts could realistically fit within clinical practice, asking: "Because I think that's interesting in a research context. But then if you link it back to how much time people have, then I think doctors going, I don't want to listen to your podcast about any of your week was or whatever because they can't fit it in" (P; WS4). This statement points to the perceived limits of doctor availability, not only in terms of access, but also in relation to the time and attention that can be dedicated to listening to complex symptom narratives.

The same exchange also shows participants' awareness of the need to express subjective and embodied experiences in forms that remain meaningful within the practical constraints of consultation settings. The issue is therefore not only whether symptoms can be described, but how they can be communicated in ways that are concise, interpretable, and usable within clinical timeframes.

Using alternative forms to support communication

WS4 also includes an important reference to alternative forms of communication. One participant introduced a personal experience related to ectopic pregnancy, explaining: “I passed a very, very strong situation with the body because I had an ectopic pregnancy. Yeah, […] and in this moment I draw. I draw. In my body this is what is happening” (P; WS4). This account is significant because it presents drawing as a support for expressing what is happening in the body when verbal explanation alone is insufficient.

In this case, help-seeking is connected not only to reaching medical care, but also to finding a form through which the condition can be communicated meaningfully. The participant’s reference to drawing suggests that visual or material expression can help translate bodily experience into a form that can be shown, shared, and discussed.

Sharing experiences as informal support

A related issue appears in WS5, where one participant reflected on the relief produced by sharing symptom words with others, saying: “I found to write down the same clues and to share it I found it most, um, relieving because, um, to find out that we, like, all have, uh, made a thing that is somehow great to hear” (P; WS5). Although this does not refer directly to consultation, it shows that support also emerges through comparison with others who recognise similar experiences.

The same participant then added: “it gives me a bit more, like, Yeah, it’s, it’s, you have to carry less weight somehow” (P; WS5). This suggests that collective discussion can reduce the burden of carrying uncertainty alone. Help-seeking therefore extends beyond formal medical contact and includes the reassurance, recognition, and clarification that arise when symptoms are shared with others.

Taken together, WS4 and WS5 show that consultation and help-seeking are addressed primarily through the question of communication. Participants highlight the practical difficulty of fitting complex symptom accounts into limited consultation time, the value of alternative expressive supports such as drawing, and the relief that can emerge through sharing experiences with others. In this way, support is linked not only to access to care, but also to the availability of forms through which embodied experience becomes understandable to oneself and to others.

5.2.5 Treatment and self-management strategies

This section examines treatment and self-management as they emerge in WS4 and WS5. Compared with the UTI-focused sessions, participants discuss fewer specific

treatments, medications, or clinical decisions. Instead, they describe how conditions are managed through everyday adjustments, temporary withdrawal from routine, anticipation of symptoms, and coping with their wider effects. The focus therefore moves from treatment as a defined intervention to self-management as an ongoing practical response to embodied discomfort.

Managing illness through rest and interruption of routine

A first aspect concerns the ordinary management of common conditions through rest and temporary withdrawal from everyday activities. In WS4, the group working on flu framed the illness through a familiar experience, describing it as “the same symptoms that kept you from going to school when you were a kid” (G1; WS4). This formulation situates flu within a domestic and recognisable pattern of care, where the response is less about specialised treatment and more about stopping usual activities, staying home, and allowing recovery. The quote is relevant because it shows how participants associate management with the interruption of routine, rather than with a specific medical intervention.

Anticipating and adapting to bodily changes

A second aspect concerns how participants adapt to conditions by anticipating changes in how they feel. In WS4, the group discussing lactose intolerance explained that “sometimes it’s really bad, sometimes is not that bad. Sometimes is OK-ish” (G2; WS4). They also noted that the condition can begin more manageably and worsen as the day progresses. In this context, the relevance of the quote is not only that symptoms fluctuate, but that this fluctuation shapes how participants understand management. Living with the condition requires attention to bodily change, adjustment across the day, and practical awareness of when discomfort may become harder to manage.

A similar point emerges in WS5 in relation to shoulder pain, where one participant described the condition as “coming in stages” (P25; WS5). This description suggests that self-management involves recognising phases of discomfort and adjusting to them as they develop. The condition is not presented as something resolved through a single action, but as something that requires ongoing attention and adaptation.

Coping with wider bodily and social effects

The sessions also show that self-management becomes more complex when conditions affect the person’s broader capacity to act, relate, or remain present in daily life. In WS5, fatigue was described as “overwhelming and it’s all around” (G6;

WS5) and as something that “isolates you” (G6; WS5). In this case, the issue is related not only to the sensation of fatigue itself, but the way it limits participation and creates social withdrawal. Self-management therefore includes coping with reduced energy, isolation, and the difficulty of maintaining ordinary activities and relations.

Self-management as everyday accommodation

Taken together, WS4 and WS5 show that treatment and self-management are addressed mainly as everyday accommodation rather than as clearly defined medical intervention. The data does not produce substantial material on long-term treatment, medication, supplements, alternative therapies, or the distinction between side-effects and symptoms. Instead, it foregrounds how participants respond to conditions by pausing routines, anticipating bodily changes, and coping with the wider effects of discomfort. In this sense, these sessions contribute to understanding self-management as a practical and situated process through which people adjust their lives around embodied conditions.

5.2.6 Summary of findings on other health conditions

Table X summarises the key points and highlights emerging from the four themes discussed in this section. Together, these findings show that the workshop elicited forms of health-related knowledge that extend beyond the original focus on UTIs. In WS4 and WS5, participants addressed conditions such as flu-Covid, lactose intolerance, throat pain, stomach-ache, fever, fatigue, insomnia, neck pain, and shoulder pain, alongside one account centred on the healthy body as a contrast to illness. When applied to these embodied and experience-led conditions, the activity continued to support detailed accounts of symptoms, bodily perception, communication, and everyday management.

The first theme on “Symptoms and embodied descriptions” highlights how participants described conditions through internal sensation, bodily location, intensity, fluctuation, and progression over time. These accounts generated forms of embodied knowledge comparable in richness to those identified in the UTI-focused sessions. The second theme, which is on “Uncertainty and overlap between conditions”, shows that the broader range of conditions addressed in WS4 and WS5 made overlap and uncertainty particularly visible. Participants often recognised conditions through similarity, approximation, and comparison rather than through stable diagnostic categories, revealing ambiguity as part of how common embodied conditions are experienced and interpreted. The third and fourth themes indicate that the workshops supported reflection on communication and everyday coping. “Consultation and help-seeking”, and “Treatment and self-management

strategies" emerged mainly through concerns about how difficult experiences can be made understandable to others, while treatment and self-management appeared through recovery, fluctuation, and adaptation over time rather than through detailed medical pathways. Across these themes, the workshop supported the articulation of conditions that often remain diffuse, internal, or difficult to compare, such as fatigue, mental fog, insomnia, bloating, and nausea.

Taken together, the findings and the summary provided in Table 8 show that the method remained productive when extended beyond UTIs. While the specific conditions changed, the workshop continued to generate embodied, interpretive, and care-related knowledge grounded in lived experience. This broader application does not displace the centrality of UTIs within the thesis, but it clarifies that the methodological approach can also support reflection and communication across a wider range of intimate and embodied health conditions.

Theme (other conditions)	Key points	Higlights
T1: Symptoms and embodied descriptions (section 5.2.2)	Participants described conditions through differentiated, embodied, and changing sensations rather than through general labels alone.	Conditions were described through location, intensity, and change over time. Participants used comparison and discussion to make sense of fluid symptoms and communicate embodied experience. Management centred on rest, observation, and adaptation.
T2: Uncertainty and overlap between conditions (section 5.2.3)	Participants described uncertainty as part of symptom interpretation, especially where conditions shared similar sensations or evolved through overlapping signs.	Overlap between conditions such as flu and Covid, or between general bodily discomfort and other possible causes, made recognition difficult and highlighted the role of approximation and comparison in everyday health understanding. Body awareness, localisation, and discussion to support participants in making sense of conditions whose boundaries remained fluid.
T3: Consultation and help-seeking (section 5.2.4)	Help-seeking was discussed mainly in relation to communication, time, and the availability of forms through which symptoms can be expressed meaningfully.	Participants highlighted the difficulty of fitting rich and subjective symptom accounts into limited consultation time. Alternative modes of expression can be used to support communication. Sharing symptoms with others also appeared as a source of relief, reassurance, and clarification.
T4: Treatment and self-management strategies (section 5.2.5)	The sessions provided limited direct information on treatment, but they showed how participants understand conditions through recovery, fluctuation, and everyday coping.	Rather than focusing on detailed treatment pathways, participants described how conditions unfold, intensify, or improve over time. Management appeared through familiar practices of rest, observation, and adaptation to changing symptoms. These findings emphasise the experiential understanding of living with a condition rather than specific medical interventions.

Table 8: summary of key points and highlights from the four themes identified in the workshop analysis that provide insights related to health conditions others than UTIs.

5.3 Conclusion on results on UTIs and other health conditions

Findings on UTIs from WS1-3 and on the other health conditions addressed in WS4 and WS5 show that the workshop supported the generation of embodied and situated health-related knowledge across different topics. In both cases, participants articulated experiences that are often difficult to express within standard clinical language alone, bringing forward subtle sensations, uncertainties, and contextual factors that shape how conditions are recognised and managed. Across the two strands of analysis, the workshops supported forms of knowledge grounded in lived experience, bodily perception, and everyday practices of interpretation.

At the same time, the two sections reveal different emphases. The UTI-focused findings provide a more complete picture of the disease trajectory, spanning prevention, symptoms, diagnosis, consultation, and treatment. This reflects both the central focus of the thesis and the more specific workshop configuration through which women with lived experience of UTIs engaged directly with a shared condition. The analysis therefore offers detailed insights into preventive routines, intimate symptom expression, diagnostic uncertainty, consultation difficulties, and treatment-related confusion, showing how lived experience of UTIs extends well beyond biomedical descriptors.

The findings on other health conditions remain comparably rich in embodied description, yet they foreground different aspects. Because the conditions addressed in WS4 and WS5 were more diverse, the analysis highlights especially the articulation of symptoms, the overlap between conditions, the ambiguity of bodily interpretation, and the role of communication and everyday coping. Conditions such as flu-Covid, lactose intolerance, throat pain, stomach-ache, fever, fatigue, insomnia, neck pain, and shoulder pain were often described through internal sensations, progression over time, and partly invisible experiences. This broader range made overlap and uncertainty particularly visible, showing how participants often recognise conditions through approximation, similarity, and comparison rather than through stable diagnostic categories.

A clear similarity across both parts of the analysis lies in the importance of communication. Whether in relation to UTIs or to other health conditions, participants repeatedly showed that embodied experiences are difficult to reduce to standard labels alone. In both cases, the workshops supported the articulation of sensations that remain nuanced, layered, and context-dependent. Another shared aspect concerns uncertainty. In the UTI analysis, uncertainty emerged strongly in diagnosis, delayed clinical confirmation, and treatment interpretation. In the analysis of other

health conditions, uncertainty appeared more prominently in the overlap between conditions and in the difficulty of distinguishing one symptom cluster from another. Across both strands, uncertainty therefore appears not as a marginal issue, but as a constitutive part of how people experience and make sense of illness.

The comparison also clarifies an important difference in relation to care pathways. The UTI findings generated more detailed reflections on prevention, consultation, and treatment, because participants shared a condition closely tied to recurring healthcare interactions and antibiotic use. The broader health conditions discussed in WS4 and WS5 instead produced stronger insights into symptom articulation, overlap, and communication, while offering more limited information on specific treatment practices. This difference shows that the knowledge generated through the workshop is shaped by the conditions addressed, the participants' experiences, and the specific scope of each session.

Overall, the findings show that a specific focus, such as UTIs, is preferable when the aim is to generate detailed and disease-related insights. The UTI-focused sessions produced a richer empirical contribution because participants worked within a shared health topic and could compare experiences in greater depth. At the same time, WS4 and WS5 demonstrate that the method is not limited to UTIs. Other conditions with focus can also be addressed through the workshop format. This comparison therefore confirms the specificity of the UTI case while indicating the potential transferability of the method to other health contexts.

6. FINDINGS ON THE METHOD. “NO ACUTE PAIN IS A SPHERE”

This chapter examines the methodological findings emerging from the workshop activity. While the previous chapter focused on the health-related knowledge generated in relation to UTIs and other conditions, this chapter turns to the method itself. Drawing across all workshop sessions, it analyses how physicalization, physical variables, materials, Data-Probes, and workshop structure shaped participants’ engagement and supported the expression, interpretation, and communication of embodied experience.

In doing so, the chapter consolidates the methodological contribution of the thesis. It examines how the components of the workshop operated in practice, how they were refined across different settings, and what insights they offer for participatory data physicalization in health-related contexts.

6.1 Findings on physicalization and variables

As outlined in Section 3.4.1, the second aim of the data collection concerns the methodological knowledge generated through the workshop activity. This section examines how the method works in practice, focusing on the role of physical variables, materials, symptom-variable associations, Data-Probe representations, and workshop structure.

Table 9 presents the coding table for the thematic analysis of these methodological findings. The analysis is organised around five recurring dimensions, which are physical variables, materials, symptom-variable associations, modes of representation, and workshop structure. These themes correspond to the main components through which the workshop is developed, tested, and refined across sessions.

Theme 2.1	variables	Theme 2.2	materials	Theme	associations	Theme	representation	Theme	ws structure
Code	adding new variables	Sub-theme	**action towards the material**		* extracts re-organised into quantitative table of symptom-variable-material associations	Sub-theme	**overall structure**	Sub-theme	**role of the expert**
Code	description	Sub-theme	**difficulties**			Code	disease as a linear process		expert experience of disease
Code	explanation is needed	Code	limits of materials			Code	multiplicity of compositions representing multiple disease steps		expert feedback
Code	variable features inspiring symptom identification	Code	combination of units does not work			Code	unique symptom representation		expert providing info
Code	same value associated to different variables	Code	lack of alignment on material naming			Code	empty space for symptoms disappearing	Sub-theme	**participation**
Code	disease-material transposition	Code	material exploration			Sub-theme	**satisfaction/not**		confrontation
Code	identification by opposition	Sub-theme	**material selected to elicit a secondary perception**			Sub-theme	**naming**		sharing
Code	literal association	Code	sound			Sub-theme	**generalisation**	Sub-theme	**difficulties**
		Code	smell			Sub-theme	**normal conditions for comparison**		translation/vocabulary
		Code	haptic			Sub-theme	**notes for decoding**		lable limits
		Sub-theme	**missing**						understanding/approaching the activity
		Sub-theme	**methods of choice**					Sub-theme	**engagement**
		Code	material evoking the symptoms						
		Code	selection by exclusion						
		Code	transposition from disease to material						
		Sub-theme	**visual approaches**						
		Code	figurative shapes						
		Code	aesthetic						
		Code	metaphors						

Table 9: coding table for the thematic analysis of results on the method: use of materials and variables within the workshop activity.

This structure allows the chapter to examine how participants use physical variables to map symptoms, how materials support or constrain expression, how associations between symptoms and physical properties are negotiated, how artefacts are constructed through the Data-Probes, and how facilitation, timing, group composition, and modes of participation shape the activity. It also supports comparison across workshop sessions while preserving the specific conditions in which methodological adjustments are introduced.

As in the previous chapter, the thematic organisation is grounded in the coded analysis of multimodal workshop material, including narratives, discussions, label arrangements, artefact presentations, and the artefacts themselves. Each theme is introduced through a short framing that defines its analytical scope and supports a clear reading of the findings presented in the following sections.

6.1.1 Workshop sessions and participants included in the analysis

The methodological analysis presented in this chapter draws on all five workshop sessions conducted in the research. This broader scope reflects the way the method developed through the sequence of implementations rather than within a single session or condition alone. Accordingly, the chapter includes WS1, WS2, WS3, WS4, and WS5. Each session contributed to the refinement of the methodology in

a different way, whether by informing adjustments to the workshop structure, testing the material kit, clarifying the role of experts, or extending the range of conditions and forms of participation addressed. Considered together, these sessions make it possible to examine how the method operated across contexts and how it evolved through iterative refinement.

The participants included in this chapter therefore comprise all those involved in the five workshop sessions, including individuals with experience of UTIs and other conditions. Their contributions are analysed through the multimodal dataset generated during the activities, including written narratives, transcribed conversations, artefact presentations, label arrangements, and the material artefacts themselves.

6.1.2 Physical variables

As outlined in the methodology, the physical variables proposed by Hornecker et al. (2023) are used as a basis for designing the activity. However, not all variables suggested by the authors have been transformed into labels. Instead, a selection focusing on visual and tactile features is chosen, aligning with the availability of physical materials for the activity. Within the activity, it is essential to distinguish between variables and their values. Variables represent broad categories of physical or conceptual properties, such as “shape”. Values, on the other hand, refer to the specific manifestations within a given variable, such as “cube”, “sphere”, or “pyramid”. In this sense, variables function as overarching descriptors, while values provide the concrete options through which participants articulate and refine their representations. Understanding this distinction helps situate how participants move from general qualities to specific material choices when constructing their artefacts and associating them with symptoms.

This section shows that physical variables operate as a methodological bridge between embodied sensation and material representation. Rather than functioning only as predefined categories, variables help participants identify which qualities of a symptom matter and translate them into specific material choices. The distinction between variables and values is central to this process, as participants move from broad descriptors such as shape, texture, size, or weight to concrete options such as spheres, rough surfaces, larger components, or heavier materials. In this way, physical variables structure reflection and allow participants to compare experiences, justify choices, and develop more precise ways of expressing symptoms through the Data-Probe artefacts.

Emerging variables

Throughout the workshops, participants are invited to associate physical variables with symptoms using the materials provided. Their interactions reveal several gaps in the initial taxonomy. While the activity proposes a predefined set of qualities such as weight, texture, and flexibility, participants introduce additional dimensions grounded in their lived experience of illness. These emergent variables expand the expressive potential of the material system and show how participants reconceptualise the relation between body and material through sensory metaphors, bodily analogies, and subjective interpretation.

Because variables can be numerous and no exhaustive list exists, the analysis focuses on the emergence of new types. Specific values within each variable, such as hot, sharp, and dense, are described later in the analysis.

The variables that emerge explicitly during the workshops are:

- smell becomes immediately salient. One participant exclaimed, “It’s true! We did not put the smell” (P5, WS1), prompting a collective search for materials capable of producing or evoking odours. Items such as Vinavil glue, rubber bands, and Uniposca markers were tested for their olfactory qualities. Another participant added, “some people like it...” (P5, WS1), highlighting the subjectivity of smell. Here, smell appears not as an abstract concept but as a multi-step chain linking material to gesture to odour to symptom.

- temperature also emerges as a crucial property. Although included in Hornecker et al. (2023) under the haptic domain, temperature does not appear in the initial kit due to material limitations. Nevertheless, participants frequently referred to temperature sensations when describing their symptoms, as in the reflection that “something feels cold” (P17, WS3).

- elasticity is introduced to capture how bodily organs are perceived during infection. One participant explained, “When you’re in a normal state, you don’t feel your organs... but during an infection it’s like it’s bigger now” (P20, WS3). Elasticity here operates metaphorically, signalling inner tension, swelling, or distortion rather than literal stretchiness.

- sharpness emerges as another important dimension. Participants requested spiky or jagged materials to express irritation or pain, as when one noted, “I would add here sharpness (to express the pain when peeing)” (P18, WS3). The absence of sufficiently sharp pieces was also remarked upon: the existing units are not “very edgy” (G8).

- pressure is mentioned explicitly (P19), associated with cramps, urgency, and internal tension.

Other variables emerge indirectly through metaphors, analogies, or the observation of participant behaviour:

- permeability appears through an analogy involving nets: “If you have a net, drops fall; if you have a narrower net, fewer drops fall” (P5, WS1). Foam is repeatedly identified as permeable and becomes a useful representation of incontinence or leakage.

- durability captures how long a material form appears to “endure,” aligning with the temporal qualities of symptoms such as chronic discomfort or persistent cramps.

- hardness encompasses rigidity and resistance. Inflexible materials are chosen to represent symptoms that feel invasive or unyielding.

- density is linked to the compactness of materials and used metaphorically to represent tiredness or bodily heaviness.

- amount refers to the number of units selected. Participants often use repeated shapes to express frequency or recurrence, particularly for symptoms such as repeated vomiting.

- integrity concerns whether a material remains whole, breaks, or deforms. This becomes meaningful in representing breakdown, instability, or internal disintegration.

- sound emerges from both the material properties themselves and the gestures performed with them. Polystyrene squeaking, foam compression, or tapping wood produce sounds that participants use to describe sensations. Like smell, sound arises through interaction.

Together, these emergent variables demonstrate how participants dynamically extend the vocabulary available for symptom representation. Some variables, including temperature, smell, and sound, are present in the literature (Hornecker et al., 2023) but were not included in the kit because no clear connection were identified with available materials in the moment of designing the activity. Others, such as permeability or the sensation of burning, arise directly from participants’ embodied engagement with materials. These contributions indicate the need for a more nuanced and multimodal approach to variable design, one capable of capturing

static physical qualities as well as dynamic states, transitional sensations, and relational interactions.

Gestures further enrich this expressive vocabulary. Participants rub polystyrene to create sound, compress foam to simulate absorption, or mime burning to express the classic internal sensation described during UTIs (P2, WS1). Although gestures do not constitute material properties in themselves, they show how materials invite specific actions and how these actions become meaningful within the process of symptom interpretation.

Existing variables, alternative descriptions

Following the emergence of new variables proposed by participants, additional insights arise from the ways in which they reinterpret and refine the variables already included in the activity. In fact, participants also offered alternative and nuanced descriptions that deepen the understanding of certain properties. These contributions build directly on the previous section by showing how familiar variables can expand in meaning when grounded in lived experience and personal perception. The variable brightness, for instance, was described in three distinct ways by the same participant (P4, WS1): as saturation, referring to the intensity of colour and its vividness; as the black-and-white contrast, where brightness is detached from colour altogether; and as chiaroscuro, or the interplay of light and dark. These varying definitions highlight the need for flexibility in interpreting visual properties, particularly when linked to personal perception or metaphorical association. Similarly, viscosity was clarified through a comparison between water and maple syrup (P20, WS3), establishing a spectrum of fluid thickness that could be used to convey sensations such as ease or resistance in bodily processes.

Finally, the variable permeability was discussed through material comparisons. A participant (P5, WS1) described it using the metaphor of a net with different mesh sizes to indicate how easily liquid passes through, while another (P3, WS1) compared foam and wood to distinguish between absorbent and non-absorbent materials. Overall, these insights underline the participants' active role in contextualising variables, often grounding them in tangible analogies that connect material properties to bodily or experiential sensations.

Sensory, visual, and literal strategies for identification

Participants employed a wide range of strategies to identify and associate variables with symptoms, drawing on tactile exploration, metaphorical reasoning, and visual comparison. A frequent approach involved translating bodily sensations into material features. In these cases, specific qualities of the materials were interpreted as

analogues of physiological experiences. For example, friction encountered when manipulating a material was linked to the discomfort of urination, illustrating how tactile resistance became a metaphor for pain (P2, WS1). Similarly, the texture and permeability of certain materials were associated with difficulty in urination (P5, WS1), showing how sensory cues could evoke underlying physiological constraints.

Identification also emerged through strategies based on contrast. Participants rejected features such as smoothness (P9, WS2) or pronounced three dimensionality (P17, WS3) when these characteristics were perceived as incompatible with symptoms like itching or discomfort. These contrasts guided participants toward selecting variables that more closely aligned with their embodied experiences.

Literal associations formed another strategy, especially when variables such as temperature were used to represent fever. This direct correspondence was viewed by some as too explicit or didactic (P2, WS1), yet it nonetheless remained a meaningful way for participants to articulate internal sensations through material form. Aesthetic considerations also shaped variable selection. One participant, for example, explained how cutting polystyrene at an angle exposed three dimensional contours that could more effectively express certain symptoms than smoother finishes (P13, WS2). Colour proved especially influential because of its strong visual salience. Participants used it to represent symptoms that carry immediate visual markers, such as blood in urine, demonstrating how vividness and recognisability can guide material choice (P2, WS1).

Taken together, these strategies show how participants navigate between sensory transposition, contrast based reasoning, literal correspondence, and visual prominence in order to construct meaningful associations between symptoms and physical variables. Their approaches highlight the richness and complexity of symptom identification within the participatory environment and reveal how material engagement fosters interpretation.

Overlaps, mismatches, and uncertainty in variable association

Participants encountered several challenges when interpreting and applying the variables during the workshop activities. One recurring difficulty concerned uncertainty around the meaning of particular terms. Some participants explicitly asked for clarification, demonstrating that not all variable labels were immediately self-explanatory. For instance, the meaning of “three dimensional form” was questioned (P9, WS2), and similar confusion arose regarding “fuzziness”. These moments highlight the need for clearer terminology and the value of providing contextual examples to support shared understanding. Another source of complexity stemmed from the overlapping interpretation of values across different variables.

Participants occasionally associated a single descriptive element with multiple categories. One participant observed that both “a lot of balls” and “a lot of big ones” could correspond to quantity (P5, WS1), revealing how features such as size, number, or repetition might relate simultaneously to amount, density, or scale. In a similar way, colour was sometimes treated not as a standalone dimension but as a cue for another quality, such as temperature, with blue evoking a sensation of cold (P17, WS3). These examples show that variable values often operate fluidly across conceptual boundaries, making interpretation and representation less straightforward. Such ambiguity required participants to reason through their own associations when selecting variables, thereby adding an additional layer of cognitive work to the activity. The presence of these overlaps and mismatches indicates the importance of refining the structure of the activity, ensuring clearer boundaries between variables while preserving the openness that supports creative and embodied interpretation.

6.1.3 Materials

Materials play a central role in this research as expressive components of the workshop and as objects of analysis. Their qualities, including softness, hardness, weight, texture, and flexibility, support participants in recognising sensations, forming associations, and translating internal experiences into visible and shareable forms. In this sense, materials act as generative elements of the method, helping participants move from bodily perception to material expression and discussion.

The interpretation of the artefacts depends on their material composition. For this reason, visual documentation is essential to the analysis. Photographs make visible how participants combine components, relate symptoms to physical variables, and use material qualities to express embodied experience. They allow the analysis to consider not only what participants say about their artefacts, but also how those artefacts are physically constructed.

To examine these material choices more closely, the artefacts are reorganised into visualisations that function as analytical tools. These visual arrangements support comparison across participants and sessions, helping to identify recurring uses of specific shapes, materials, and combinations. They also serve two complementary analytical roles. The first traces how participants’ intended meanings are translated into material form, making visible how particular sensations or conditions are associated with specific components (Figure 6.1). The second supports comparison from the opposite direction by showing how the physical properties of the components recur across different artefacts and interpretations (Figure 6.2). A detailed description follows the figures.


feeling of discomfort (DP5)
headache (DP17)
pain (DP9)
something going wrong - messiness (DP19)
severity of pain - all around (DP13)
damaged shoulder (DP31)
combination of many factors: polystyrene for the permeability of not being sure to need to pee, and wire frame for burning (DP5)
different materials for the complex situation (DP9)
WORSENING OF THE SITUATION
PAIN
pain (DP17)
pain (DP23)
more discomfort - big units (DP15)
complex situation to consider individually (DP1)
the doctor is noticed (turning point) (DP5)
COMPLEX SITUATION
PAIN WHEN PEEING
initial/lighter symptoms (DP14)
burning and pain when urinating (DP7)
burning when peeing (DP19)
pain when peeing (DP10)
strong neck pain (DP29)
worst/serious symptoms - requiring medical attention (DP14)
"the word is not smooth" (DP1)
other eventual symptoms (DP24)
short time - between light and most severe symptoms (DP14)
LIGHTER SYMPTOMS
light neck pain (DP29)
burning and cramping when urinating (DP5)
pain when peeing (DP16)
temporal (and urine) flow as the representation of recurrent symptoms (DP2)
the cycle repeats (DP6)
"lighter solutions" as possible alternative remedies (DP1)
less discomfort - small units (DP15)
annoyance and pain when urinating, pee is spiky (DP4)
pain when peeing (DP20)
connection among different episodes part of the same disease (DP15)
RECURRENCY
urgency to go to the bathroom - incontinency (DP10)
INCONTINENCE
bloated - edges all around (DP11)
bloody urine(DP16)
units as episodes of the same disease. decoding strongly related to the relationship among the units. similar symptoms across the four initial episodes (DP3)
bellyache / stomachache (DP)
act of urinating repeated and getting worst (yellow) (DP2)
incontinence holding pee (DP4)
BLOATED STOMACH
STOMACH ACHE
anxiety (DP9)
anxiety especially towards sex and impact on life (DP3)
fullness, feeling full quickly (DP22)
bloating (DP22)
pain behind the bladder is the worst symptom (DP2)
anxiety (DP10)
1) knee-joint pain - twisted knee 2) constipation (DP21)
lower abdominal swelling (DP2)
LOWER ABDOMINAL
bellyache (DP24)
ANXIETY
anxiety (DP)
CRAMPING
cramping (DP10)
lower abdominal discomfort, roughness is for the difficulty in urinating (DP2)
anxiety increases and stability decreases" (DP3)
psychological discomfort/ consequence (DP6)
constriction - inability to flex (DP20)
lower abdominal cramps (DP10)
KIDNEY AND BLADDER
body cramps and the joint pains (DP24)
tiredness (DP19)
insomnia (DP29)
lower abdominal swelling increase (DP2)
metal spheres as discharges (DP4)
lower back pain (DP22)
DISCHARGES
fever (DP24)
FEVER
fatigue because of overwhelming (DP28)
foul smelling urine (DP16)
urine discharges (DP6)
fever (not sure) (DP3)
TIREDNESS
inertia because of tiredness - prisoner's ball (DP21)
instability and uncertainty (DP11)
perception of smelling bad - socially debilitating as looking for isolation (DP4)
swollen kidney and bladder (DP20)
UNCERTAINTY
SORE THROAT
mental fog - not sure (DP22)
symptoms invisible from outside - inside your body (DP12)
throat (DP23)
stuffy nose (DP)
empty cord = lack of symptoms thanks to antibiotics (DP5)
"NORMALITY"
itchy throat and loss of voice (DP21)
NOSE-RELATED COLD EFFECTS
normality (DP13)
follow-up (DP3)
swallowing in case of throat ache (DP23)
infection (not sure) (DP3)
running nose (DP21)
nausea (DP19)
nausea (DP17)
vomiting (DP)
INFECTION
shoulder ideal state (DP31)
health and full of energy (DP26)
NAUSEA
VOMITING
infection (DP1)
nausea - not sure (DP22)
vomiting (not sure) (DP3)

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Figure 6.1: decomposed Data-Probes regrouped according to the meanings assigned by participants to each component. The figure shows how materials were used to represent not only bodily symptoms, but also emotional states, temporal patterns, relational conditions, and broader interpretations of illness such as uncertainty, recurrence, or worsening.

Figure 6.1 groups the decomposed Data-Probes according to the meanings that participants attributed to each part. Rather than preserving the original artefacts as complete units, the figure separates them into individual components and repositions them under thematic labels such as pain, pain when peeing, lighter symptoms, tiredness, uncertainty, anxiety, recurrency, complex situation, follow-up, infection, lower abdominal, bloated stomach, cramping, urine conditions, discharges, sore throat, and nose-related cold effects. This arrangement makes visible the breadth of meanings attached to the material kit and shows that the same family of components could support both bodily sensations and more interpretive or relational categories, such as worsening, recurrence, or complex situations.

Several patterns emerge from this regrouping. First, the figure shows that participants often used materials not simply to name a symptom but to qualify its character. This suggests that participants did not approach pain as a single, uniform sensation. Rather, they used different material combinations to distinguish between its qualities, for example whether it was felt as sharp, spreading, localised, constraining, or intense. Pain therefore emerged as a differentiated experience with multiple internal variations, rather than as one generic category. A similar pattern appears in pain when peeing, where multiple components recur, but with stronger emphasis on more pointed, dense, or constraining forms. This suggests that participants treated pain as a differentiated experience rather than as a generic category. Second, the figure shows that materials were also used to express states that are difficult to stabilise in conventional medical vocabulary. Categories such as uncertainty, anxiety, complex situation, and worsening of the situation are especially significant in this regard. These groupings include mixed materials, connectors, unstable combinations, and irregular assemblages, indicating that participants relied on material contrasts, awkward joints, and composite structures to express situations that were layered, unresolved, or difficult to define. In this sense, the figure demonstrates that the Data-Probes did not only support the representation of bodily sensations, but also allowed participants to externalise ambiguity, instability, and emotional or interpretive dimensions of illness. Third, the visualization ighlights the role of recurrence and temporality. The categories recurrency and follow-up are particularly revealing because they are represented less through isolated solid units and more through repeated forms, connectors, arcs, and directional arrangements.

These components suggest movement, continuation, return, and interruption. Their presence indicates that participants often understood symptoms as unfolding processes rather than as single fixed events. Materials therefore helped represent not only what a symptom felt like, but also how it developed, returned, or persisted over time. The figure also makes visible how some meanings are strongly bodily and localised, while others are broader and systemic. Categories such as lower abdominal, kidney and bladder, bloated stomach, cramping, and infection remain closely tied to bodily regions or recognisable symptom clusters. By contrast, normality, lighter symptoms, and complex situation point towards comparative, relational, or reflective forms of interpretation. This suggests that participants used the same material kit to move across different levels of expression that goes from concrete bodily sensations to broader judgements about condition severity, progression, and quality of life.

If Figure 6.1 begins from meaning, Figure 6.2 (in the next page) reverses the perspective by reorganising the same decomposed artefacts according to their physical characteristics. Components are grouped first by material family, including foam, polystyrene, wood, plastic-PVC, rope, metal, and sandpaper, since the open materials used in WS1 are also included in the analysis. They are then grouped by geometric type, including triangular shapes, spheres, cubes, and connectors. This arrangement makes it possible to examine how specific material properties support recurring forms of expression across different workshop sessions.

Several tendencies become visible through this reordering. Foam elements appear frequently in relation to symptoms described as internal, diffuse, swollen, soft, or uncertain. Their porous texture, low density, and visual lightness seem to have supported meanings such as infection, nausea, shoulder discomfort, hidden symptoms, or states that were felt as present but difficult to delimit clearly. Polystyrene components, especially in spherical form, are often associated with lighter, vaguer, or more unstable sensations, including mental fog, initial symptoms, tiredness, and possible remedies. Their soft but synthetic consistency seems to have supported interpretations linked to instability, suspension, or reduced intensity.

Differently, wooden cubes and triangular units recur in relation to stronger, more structured, or more sharply bounded experiences, including pain, cramps, worsening symptoms, fullness, strong neck pain, and discomfort requiring medical attention.

[In the next page]

Figure 6.2: decomposed Data-Probes reorganised by material family and geometric type. Foam, polystyrene, wood, connectors, and other exploratory materials are grouped to show how recurring physical properties supported different kinds of symptom expression across the workshop sessions.


FOAM
POLYSTYRENE
WOOD
TRIANGULAR SHAPES
SPHERES
CUBES
connectors
bellyache (DP24)
headache (DP17)
swallowing in case of throat ache (DP23)
symptoms invisible from outside - inside your body (DP12)
nausea (DP19)
urine discharges (DP6)
shoulder ideal state (DP31)
infection (not sure) (DP3)
fatigue because of overwhelming (DP28)
nausea - not sure (DP22)
vomiting (DP)
instability and uncertainty (DP11)
running nose (DP21)
urgency to go to the bathroom - incontinency (DP10)
health and full of energy (DP26)
initial/lighter symptoms (DP14)
damaged shoulder (DP31)
bloody urine(DP16)
mental fog - not sure (DP22)
lower abdominal swelling increase (DP2)
swollen kidney and bladder (DP20)
follow-up (DP3)
foul smelling urine (DP16)
nausea (DP17)
bellyache / stomachache
symptoms invisible from outside - inside your body (DP12)
lower abdominal swelling (DP2)
combination of many factors: polystyrene for the permeability of not being sure to need to pee "feeling a perception that is not"; wire frame for burning (DP5)
incontinence - holding pee (DP4)
other eventual symptoms (DP24)
the cycle repeats (DP6)
the doctor is noticed (turning point) (DP5)
fever (DP24)
insomnia (DP29)
temporal (and urine) flow as the representation of recurrent symptoms (DP2)
throat (DP23)
constriction - inability to flex (DP20)
metal spheres as discharges (DP4)
connection among different episodes part of the same disease (DP15)
empty cord = lack of symptoms thanks to antibiotics (DP5)
anxiety especially towards sex and impact on life (DP3)
plastic - pvc
rope
metal
sandpaper
lower abdominal cramps (DP10)
lower back pain (DP22)
pain when peeing (DP20)
anxiety (DP)
different materials for the complex situation (DP9)
annoyance and pain when urinating, pee is spiky (DP4)
light neck pain (DP29)
anxiety (DP10)
burning and pain when urinating (DP7)
burning and cramping when urinating (DP5)
"lighter solutions" as possible alternative remedies (DP1)
tiredness (DP19)
more discomfort - big units (DP15)
act of urinating repeated and getting worst (yellow) (DP2)
lower abdominal discomfort, roughness is for the difficulty in urinating (DP2)
complex situation to consider individually (DP1)
perception of smelling bad - socially debilitating as looking for isolation (DP4)
fever (not sure) (DP3)
"the word is not smooth" (DP1)
feeling of discomfort (DP5)
less discomfort - small units (DP15)
strong neck pain (DP29)
pain (DP9)
anxiety (DP9)
bloated - edges all around (DP11)
severity of pain - all around (DP13)
something going wrong - messiness (DP19)
burning when peeing (DP19)
vomiting (not sure) (DP3)
worst/serious symptoms - requiring medical attention (DP14)
less discomfort - small units (DP15)
bloating (DP22)
pain (DP17)
pain (DP23)
inertia because of tiredness - prisoner's ball (DP21)
cramping (DP10)
psychological discomfort/ consequence (DP6)
itchy throat and loss of voice (DP21)
anxiety is the worst symptom (getting bigger because anxiety increases but stability decreases) (DP3)
more discomfort - big units (DP15)
normality (DP13)
fullness, feeling full quickly (DP22)
stuffy nose (DP21)
pain when peeing (DP10)
pain behind the bladder is the worst symptom (DP2)
knee-joint pain - twisted knee 2) constipation (DP21)
short time - between light and most severe symptoms (DP14)
infection (DP11)

Compared with foam and polystyrene, wood appears more often in representations of pressure, hardness, persistence, or localisation. Its solidity and resistance seem to have made it particularly effective for expressing symptoms experienced as fixed, obstructive, or strongly present in the body.

The distinction by shape further strengthens this reading. Triangular forms recur in relation to sharper, more directional, or more penetrating sensations, such as pain, itching, or cramping. Spheres often support meanings related to swelling, fullness, instability, fatigue, or rounded internal sensations. Cubes appear more frequently where participants expressed obstruction, structure, containment, or bodily boundedness, for example in representations of stomach-ache, infection, bloody urine, or strong discomfort. Connectors form a separate but crucial category, as they reveal that participants frequently represented symptoms through relations between units rather than through isolated objects. These elements were used to express recurrence, continuity, constriction, links between body parts, temporal development, or the coexistence of multiple symptoms.

The presence of rope, metal, sandpaper, and plastic-PVC at the bottom of Figure 6.2 belong mainly to the earlier exploratory sessions before the final Data-Probe kit was fully stabilised. Analytically, their inclusion helps clarify the methodological development of the workshop. Compared with the later standardised kit based on foam, polystyrene, and wood, these earlier materials supported highly expressive but less comparable interpretations. Their position in the figure therefore documents the transition from an open exploratory palette to a more controlled set of components that still preserved interpretive richness while improving comparability across sessions.

Taken together, these visualizations show that materials are not neutral supports for representation. Figure 6.1 demonstrates how participants used the same components to express a wide range of bodily, emotional, temporal, and interpretive meanings. Figure 6.2 shows that these meanings are not random, as recurring patterns can be observed in how particular materials and shapes were selected for particular kinds of symptoms or conditions. Read together, the figures strengthen the argument that materials actively shaped the workshop process by guiding how symptoms were externalised, differentiated, and discussed. Their analytical value lies precisely in making visible the mutual relation between material affordances and participant interpretation, showing that meaning emerges through the encounter between bodily experience and the physical qualities of the Data-Probes.

Based on these higlights, the next sections focus on the main material categories identified through thematic analysis, showing how specific materials and physical properties support the expression and interpretation of embodied experience.

Personal experience, exclusion, and transposition as methods of selection

Participants employed a wide range of strategies when selecting materials for their artefacts, often guided by personal associations linked to the symptom they aimed to represent. Material choices were rarely based on formal qualities alone. Instead, they were shaped by affective memories, sensory resonance, and embodied interpretation. One participant expressed this directly: “I hate this kind of material,” referring to polystyrene, which she selected precisely because it triggered a negative physical memory and therefore reinforced the unpleasantness of her symptom (P18, WS3). Another chose foam “because it is an absorbent material,” associating its softness and capacity to hold liquid with the sensation of incontinence (P4, WS1). These examples illustrate a form of direct translation in which material properties serve as proxies for bodily states.

Metaphorical reasoning also guided the use of sharpness, texture, and weight. One participant associated the pain of urination with “something sharp and very rough” moving through the body and constructed a mobile artefact to capture that sensation (P7, WS1). Another highlighted solidity by saying, “You feel something solid passing through you” (P4, WS1), demonstrating how tactile responses were intentionally used to simulate internal pain through physical form.

Several participants relied on exclusion as a method of selection. They rejected specific shapes or materials when these conflicted with the sensations they wished to express. One remarked, “Triangles and no… balls” (G8, WS5), favouring angular forms that better communicated pain. Another explained, “I’m trying to avoid any sphere. I feel like when it’s smooth surface, it doesn’t quite explain the pain” (P9, WS2). Wood was also dismissed for its comforting connotations: “I didn’t add wood here because for me, wood is something cozy” (P18, WS3). These cases highlight how avoidance can be as meaningful as selection, allowing participants to refine their representations through contrast.

Colour, whether physically present or imagined, also influenced material choices. One participant associated lighter shades with calm or peaceful states and therefore rejected them, noting, “So I would prefer something darker, or grey, or black” (General). Even when the materials did not include specific colours, participants verbalised what they would have chosen, indicating the expressive power of chromatic associations for conveying emotional tone.

Transposition represented another common strategy, in which symptoms were projected onto the material through reenactment or analogy. One participant wrapped foam with rope to represent internal pressure and residual urine: “this sort of chain around… creates these bubbles that become sore” (P4, WS1).

Another linked the brightness and shape of white material to images of leakage and discomfort (P6, WS1). A participant from another session twisted material to reflect joint pain during the flu, referring to it as a “twisted knee” (G1, WS5).

Overall, participants choose, exclude, or transform materials based on affective resonance, sensory analogy, and embodied knowledge. Whether through metaphor, rejection, or transposition, materials become active mediators of narrative, allowing participants to articulate the lived experience of illness in expressive, multidimensional ways.

Materials as gesture elicitators

Participants often used physical gestures not only as construction techniques but as expressive actions intended to embody their symptom experiences. These actions, such as pressing, pushing, destroying, or even (ideally) burning the material, played a central role in externalising discomfort. One participant proposed that “you could set fire” to the material, using the imagined act of burning as a way to evoke the sensory association of a bad smell. This symbolic gesture expanded the meaning of the artefact beyond its visible qualities (P5, WS1).

Another participant intentionally designed her artefact to be unstable. During her presentation, she narrated, “and then also like unstable because if you touch it will no boy come on,” before nudging the object and allowing it to fall, concluding with “Yeah, it destroys” (P18, WS3). The performative collapse became a metaphor for the body’s fragility under illness. Similarly, one participant selected polystyrene because “it’s something that you can destroy with your hand. So it’s kind of something that you could spread, but it’s not going away,” linking the material’s partial destructibility to the recurring and persistent nature of cystitis (P11, WS2).

Even when gestures were not enacted, the impulse to manipulate or damage materials remained noticeable. One participant admitted, “I wanted to press your materials together. Okay. I hesitated because I thought I cannot mess up your kit” (G8, WS5). This hesitation suggests that the instinct to deform, compress, or otherwise act upon materials functioned as an expressive drive, even when suppressed out of respect for the toolkit.

These contributions indicate that action upon the material served as a fundamental semiotic resource. Through gesture, manipulation, and transformation, participants expressed the unpredictability, recurrence, and emotional intensity of illness in ways that extended beyond static representation.

Materials evoking secondary perceptions

Some participants selected materials based on their ability to elicit sensory responses beyond visual or tactile qualities, drawing on smell, sound, and thermal associations to intensify the representation of symptoms. Smell emerged as one of the most prominent dimensions. One participant expressed the need for materials capable of reproducing unpleasant odours, saying, “I want something for the stench” (P4, WS1). To address this, she used glue, noting, “I take a Vinavil thingy, which stinks,” intentionally leveraging its odour as part of the expressive vocabulary (P4, WS1). She later reinforced this preference by adding, “Perfect. Plastic. Rubber,” confirming her deliberate use of materials chosen for their particular scent (P4, WS1). Another participant proposed using a permanent marker, asking, “Use a single-point marker, do we have one? But some people like it,” recognising that even strong chemical smells can carry expressive potential, despite differing personal preferences (P5, WS1).

Auditory responses also played a role in how participants interpreted and selected materials. One participant observed that “when (polystyrene) touched to each other it makes a noise which like make a painful inside,” linking the abrasive sound of the material to an internal sensation of discomfort (P18, WS3). This association demonstrates how sound was mobilised as a metaphorical extension of physical pain, enabling multisensory expression within the artefact.

Temperature and weight, though less immediately perceptible, were likewise used to express bodily conditions. One participant asked, “a heavy material (to represent fever)? A material that makes, that gives heat,” explicitly connecting mass and perceived warmth to the sensation of fever (P4, WS1). This choice illustrates how thermal associations, even when indirectly represented, contributed to conveying states of overheating or internal pressure.

Overall, these examples show how participants relied on smell, sound, and thermal associations as secondary perceptions to enhance the expressive accuracy of their artefacts. By engaging multiple senses, participants expanded the representational scope of the materials and strengthened the emotional and experiential resonance of their interpretations.

Plugs to connect components, and concepts

Connectors played a critical role in the construction of the artefacts, serving not only as structural elements but also as expressive components that supported narrative and symbolic meaning. Initially introduced to simplify the assembly process, connectors quickly became central to how participants articulated relationships between parts of their artefacts and, by extension, between different aspects

of their symptoms. One participant noted the need “for a connection from two different sides,” explaining that a more flexible connector was required “to connect different situations” (P10, WS2). This reflects how connectors were not just tools for mechanical aggregation but were also used to build conceptual or temporal bridges within the representation of illness. Several participants emphasised the expressive value of connectors. One participant stated, “I think the connecting material were important. In case to even express, yeah, the pain” (G8, WS5), suggesting that the act of linking materials could itself convey symptom intensity or interaction. Another added that the meaning of her artefact became clear only during the process of connection: “That became only clear to us when we connected it, and then we’re like, oh my God these tubes are really cool” (G8, WS5). Here, connectors functioned not only to complete the artefact’s form but to reveal latent meaning through spatial and symbolic alignment. The technical qualities of the connectors were also subject to critique. Some participants found them too short or rigid to accommodate the complexity of their ideas. One participant remarked, “Maybe (the connector) longer so I can decide how long it is” (P3, WS1), while another expressed dissatisfaction with the material: “I missed longer connectors I wasn’t happy with the material to be honest with you” (P3, WS1). These reflections suggest that connectors constrained design choices when insufficient in length or adaptability. Others simply requested more of them, highlighting their importance to the overall process: “Maybe something more connections” (G1, WS4). Overall, connectors operated on multiple levels: functionally, they enabled the construction of stable and articulated forms; conceptually, they allowed participants to express relational or causal dynamics between symptoms; and materially, they became symbolic elements in their own right. Their success or failure to perform these roles had a visible impact on both the visual outcomes and the interpretative clarity of the artefacts.

These approaches show that participants did not only build to show what illness looks like, but to communicate how it feels, moves, and limits. The visual strategies employed ranged from playful figuration to stark metaphor, reflecting diverse understandings of illness and different ways of translating it into form.

Glass and plasticine among the missing materials

Participants identified a wide range of materials they considered missing from the kit, revealing both practical needs for construction and symbolic gaps in symptom expression. One recurring category concerned sharp or fragile materials. Glass was mentioned several times, valued not for its transparency but for its fragility and cutting quality. As one participant noted, “That is why I wouldn’t use the wood, but I will probably use the glass because it’s something sharp” (P18, WS3).

The absence of glass was perceived as a limitation, with the same participant emphasising, “One part is missing. It’s a piece of glass because it’s something sharp” (P18, WS3). Metal was similarly requested, particularly for its weight and tactile resistance. “It’s heavy also and that’s what I needed,” explained a participant, who associated heaviness with sensations such as pressure or discomfort (P17, WS3). Others added that metal could effectively represent pain due to its density and hardness (P14, WS2). Metal wire was also mentioned as desirable for its shaping and connecting possibilities (P4, WS1).

Participants frequently pointed out the absence of mouldable materials, such as Play Doh, clay, or plasticine. These substances were appreciated for their familiarity, flexibility, and low threshold for engagement. One participant suggested, “Play Doh might be very interesting because it’s something very mouldable,” highlighting its potential for creating diverse or irregular forms (P14, WS2). Another clarified that “it doesn’t have to be sculpture or not sort of designers do it, but something that can again show the different symptoms” (P14, WS2). The capacity to represent transformation, complexity, or fluidity made such materials particularly appealing.

Colour also emerged as a critical missing component. Since the original kit consisted entirely of neutral tones, several participants felt constrained by the lack of chromatic expression. “These neutral colours don’t describe like the pain for me,” one explained, adding that red or flesh-like tones would have been more appropriate (P20, WS3). Another stated, “I would need colours! Yellow...” (P2, WS1), while a third emphasised, “For me, the colours were very important” (P14, WS2). Participants also linked colour to temperature and mood, with one noting that “brighter colours could have probably meant something for people as well” (P14, WS2). Although some appreciated the focus enabled by a neutral palette, colour clearly represented a missing expressive layer.

Requests also extended to structural forms and supports. A flatter base was needed in one case: “It would be better if it was a cube but not a cube but a parallelogram, so flatter” (P17). Others proposed 3D printing as a way to overcome shape limitations. Preferences for specific textures were also evident. Foam spheres, for example, were criticised for being too rigid compared to foam cubes and prisms: “The foam sphere is not made of the same material as the other foam components,” a participant observed, noting that this inconsistency influenced representational coherence (G2, WS4). Participants also expressed interest in rubbery textures that could simulate skin or muscle, with one suggesting, “Maybe like a rubbery if it was like proper flexible rubber” (G1, WS4). Textiles were requested for their ability to simulate thin bodily layers: “Either textiles and scissors to have something, because I was related to the body, the very thin layers” (General).

In addition to these more symbolic materials, common building aids were also requested: pins (P4, P6, WS1), toothpicks (P2, WS1), twine (P4, WS1), and scissors (General). These items would have supported both the construction of more elaborate structures and the expressive richness of the artefacts.

Taken together, these requests demonstrate that the missing materials were not simply logistical gaps. They reflected the ways participants actively sought tools to extend their symbolic vocabulary and engage more deeply with the physical expression of symptoms. These observations offer concrete guidance for refining future iterations of the material kit and ensuring that material choices fully support embodied representation and narrative expression.

Sharpness and amorphousness: the missing features

In addition to requesting new materials, participants identified limitations in the qualities of the materials that were already available. These missing features concerned not the substance of the kit but the absence of specific properties such as sharpness, amorphousness, texture, and flexibility, which were needed to fulfil expressive intentions or support construction.

One of the most frequently mentioned gaps related to sharpness. Participants noted that the existing components were not sufficiently edgy or spiky to represent sensations such as stabbing, cutting, or burning. As one remarked, “I thought I should have something that’s more spiky than what was available” (G7, WS5). Another added, “They’re not representative of the pain that I have here” (G8, WS5). These observations underline the need for components with sharper geometries to convey acute discomfort in physical form.

At the same time, participants expressed the opposite need for materials that could capture organic or irregular forms. One participant explained, “I wanted to change this to more like organic shape and rather than something rigid with sharp edges” (P20, WS3). Another emphasised the desire for “something more amorphous, like a clay or something, that I can give a shape to” (G8, WS5). These comments indicate that geometric and regular shapes were often too limited to represent fluid, diffused, or irregular sensations.

Textural qualities were also a source of concern. Some participants wished for materials with a more fluid texture: “I was hoping for fluid texture” (P16, WS3). Others asked for elasticity or rubberiness, as in the request that “a rubbery material will be nice” (G1, WS4). These preferences suggest that flexibility and stretch are important symbolic dimensions for representing sensations such as tension, fullness, or internal movement. Inconsistencies within the existing kit further contributed to this issue. One participant observed that the foam sphere was harder than the other

foam components, which interfered with representational consistency (G2, WS4).

Transparency was also identified as a missing feature. One participant referred to the absence of “material that is completely not transparent” (P11, WS2), suggesting that this property could symbolise clarity, visibility, or transformation depending on context.

The analysis highlights that the limitations of the kit were not only material but also qualitative. Missing features affected how participants could manipulate form, gesture, and structure to construct meaning. While missing materials reveal gaps in the substance of the kit, missing features point to constraints in its expressive flexibility. Both sets of concerns offer valuable guidance for future refinement of the material system, suggesting the importance of a more diverse, adaptable, and responsive palette to support embodied interpretation in participatory settings.

Lack of cohesion

Participants encountered a range of difficulties while interacting with the material kit, particularly during the construction phase. Several comments pointed to physical limitations in the properties of the units. One participant explained that “its shapes does not work, so I took something heavy that’s on top,” indicating that the shape alone was insufficient to convey the intended meaning and required compensation through added weight (P17, WS3). Another expressed uncertainty about the structural integrity of her artefact, stating, “mine will never hold,” and later adding, “I made this it was to hold together but they don’t hold,” illustrating how fragility and instability hindered her ability to build a coherent form (P6, WS1).

Difficulties combining units were a recurring issue. One participant noted, “I was needed to connect these two pieces, but it was difficult,” referring to mechanical challenges in linking components (P10, WS2). Glue was also problematic; participants reported long drying times (“you have to wait for all the scaffolding to dry,” P4, WS2) and lack of adhesion, especially with metal spheres (“it is a nightmare to glue the balls, they do not fit,” P4, WS1). These obstacles often forced participants to intervene manually to ensure stability, interrupting the flow of the activity and limiting expressive freedom.

Thermal properties introduced another layer of complexity. One participant observed that “some (units) are cold and some others are not,” suggesting that the variable temperature of the materials influenced how they were matched to symptoms (P12, WS2). These differences affected the emotional and sensory associations participants sought to express through material choice.

Conceptual challenges also emerged. A participant reflected on the cultural specificity of symbolic cues, particularly colour, noting that “in our society or

country, but not, they are not universal" (WS5). This remark highlighted the risk of miscommunication when symbolic associations are not shared among participants from different backgrounds.

Further confusion arose from difficulty identifying materials. Participants struggled to name or classify components, asking, "How do we call? Is this and foam, foam plastic, you know?" (P17, WS3) or simply, "This is foam?" (P13, WS2). Others referred to it informally as "spongy thing" (P11, WS2), "SpongeBob" (participant), or "memory foam" (P20, WS3). These inconsistencies, though minor, generated hesitation and uncertainty when selecting materials and articulating their intended meaning.

These challenges appear multifaceted, involving structural limitations, unfamiliarity with certain materials, mismatches between intended and available features, and various forms of symbolic ambiguity. Although the kit is designed to support expressive engagement, these barriers at times reduced the ease with which participants could construct coherent and meaningful representations. They also prompted reflection on what additional elements might have been beneficial and on the point at which the available materials can be considered sufficient for the activity.

Just enough to reveal what is missing

Participant feedback on the material kit revealed a mix of appreciation and critique, showing how even a limited set of tools can provoke both creative engagement and moments of frustration. Several participants offered positive observations, highlighting aspects of the kit that supported their process. One participant valued the neutral colour palette, stating, "I really enjoyed that it was neutral. Yeah, exactly. It was not distracting." The absence of strong colours was perceived as enabling focus rather than diverting attention away from the task.

This view was reinforced by another participant, who noted that the materials on hand, although limited, actually helped clarify what was missing: "What was available was helping to form this… to form this idea what it should look like" (G7, WS5). Here, constraint encouraged reflection, prompting participants to imagine alternatives and refine their interpretive strategies.

Some participants also expressed satisfaction with the geometric forms provided. As one stated, "I think the shapes are good I didn't think of like, oh, I need another shape" (G1, WS4). Although this participant later suggested adding rubbery materials to enhance texture, the core set of shapes was considered sufficient for constructing meaningful artefacts.

At the same time, several concerns emerged regarding quantity and expressive range. Material scarcity was a recurring issue. One participant remarked, "I was

running out of material, to be honest" (P3, WS1), indicating that the limited number of units constrained the construction of more complex forms. Others commented on the expressive limitations of the kit. One participant noted, "I really missed some more expressive materials, to be fair" (G8, WS5), while another pointed out that the materials felt "a little bit lighter, neutral, compared with pain when peeing" (P18, WS3). This mismatch between the emotional intensity of symptoms and the polished, generic appearance of the materials was felt throughout the sessions.

In one case, a participant deliberately selected a slightly damaged sphere because its imperfect condition aligned with the sensation she wished to express. She explained, "It was kind of already, like, marred so this is what I feel my shoulder is coming in stages, to be fair" (G8, WS5). This comment implicitly critiques the overly pristine, idealised quality of the rest of the kit.

These responses show that while the kit was broadly appreciated for its neutrality, clarity, and simplicity, participants also perceived its limitations in terms of variety, tactile intensity, and visual nuance. These tensions highlight a core challenge in designing for open-ended expression which corresponds to providing a material palette that is limited enough to be manageable but diverse enough to support rich and embodied representation.

6.1.4 Symptom-physical variable associations

The associations between symptoms and physical variables reveal a situated and materially grounded process of representation. Their relevance does not depend on producing fully consistent or universal mappings between symptoms and material properties. Instead, they show how participants reason through symptoms materially and collectively. Some associations remain personal and context-dependent, reflecting the subjective nature of embodied experience, while others recur across participants and sessions, suggesting shared tendencies in how certain sensations are translated into material qualities.

Figure 6.3 shows a moment from the discussion in WS1, in which participants worked together to combine symptom and physical-variable labels. The combined results is visible in Figure 6.4. Participants relied not only on the physical properties of the available units but also on their embodied experiences to construct meaning. This collective association phase is methodologically important because it helps participants negotiate meanings before moving into individual artefact construction. Physical variables therefore do not function as a fixed vocabulary, but as a flexible structure for interpretation, comparison, and discussion.



Figure 6.3: the image illustrates a moment from the WS1 discussion in which participants collaboratively associated symptom and physical-variable labels.

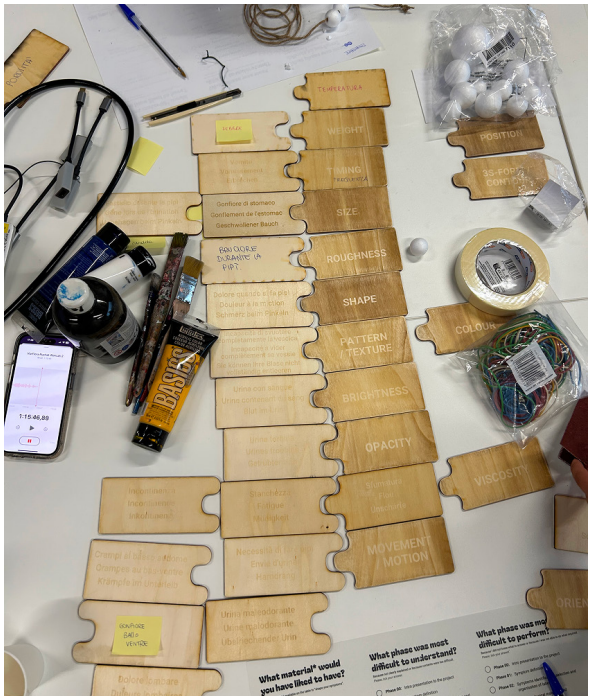


Figure 6.4: the resulting set of associations that participants later carried into the shaping activity.

In the UTI-focused sessions, some recurring associations emerge. Pain, particularly in relation to urinary tract symptoms, is often represented through rough textures, sharp edges, and heavy materials. Triangular prisms, wood, and metal elements are selected for this purpose, supported by verbal reflections such as “associated with angles sharp or tuned” (P18, WS3). When expressing discomfort during urination, participants frequently manipulate polystyrene units to produce friction and sound, transforming tactile gestures into representations of internal irritation.

Ambiguous sensations, described through blurriness or uncertainty, are conveyed through opaque or visually diffuse materials, reflecting the difficulty of understanding a symptom while still perceiving its presence (P18, WS3). Colour also plays an important role in anchoring certain symptoms. Yellow is selected to signify cystitis, while red is used to represent blood in urine, showing how visual cues contribute to diagnostic clarity. Psychological symptoms are sometimes represented through composite or unstable structures, as participants create asymmetrical or precarious arrangements to evoke anxiety, imbalance, or mental strain. Temporal aspects of the illness are also explored. Symptoms such as urgency and incontinence are represented using rolling spheres or compressed spatial configurations to suggest speed, frequency, or loss of control.

These associations are further detailed in Figure 6.5, which presents the symptom, variable, value, and material relations identified in WS1, WS2, and WS3. The size of the text indicates the frequency with which each variable is cited, with the smallest text corresponding to a single mention and the largest indicating the highest recurrence, up to a maximum frequency of 17. The associations presented below refer specifically to the UTI-focused analysis. Associations related to other health conditions are discussed later in the chapter, where the method is examined across a broader range of embodied experiences.

[In the next page]

Figure 6.5: The image illustrates a moment from the WS1 discussion in which participants collaboratively associated symptom and physical-variable labels.

Symptom	Variable	Value	Material	Shape	Dimension
Challenges associated with the disease (2)	Weight (2)	Heaviness (2)	Wood (2)		
Pain (17)	Weight (6) Shape (5) Dimension (3) Texture (2) Temperature	Heaviness (6) Sharpness (5) Increasing dimension (3) Roughness (2) Warmness	Wood (5) Metal	Sphere Triangular prism (2) Pegs	
Painful areas	Size	Increasing dimension	Foam		
Condition worsening (7)	Weight (4) Shape Spatial disposition Colour	Heaviness (4) Sharpness Instability Red	Wood (3) Metal Wood Sandpaper	Cube (2) Sphere Triangular prism Cube	 Medium/Small
Aching	Shape			Sphere	
Lighter symptoms	Weight	Lightness	Polystyrene	Sphere	Small
Annoyance	Sound	Noise	Polystyrene		
General symptoms of cystitis (2)	Texture Colour	Rough Yellow			
Discomfort when urinating	Blurriness				
Burning when urinating (6)	Texture (4) Shape Temperature	Roughness (4) Sharpness Warmness	Metal pins pierced around a polystyrene unit		
Discomfort and pain when urinating (3)	Movement (3)	Friction + Sound (3)	Polystyrene (3)		
Pain when urinating (5)	Shape (3) Weight (2)	Sharpness (3) Heaviness (2)	Polystyrene (2) Wood (2)	Triangular prism (2) Cube (2)	
Swollen bladder and kidney	Movement	Friction			
Swollen stomach	Shape	Round and regular			
Pain in the swollow behind the bladder	Texture	Roughness	Small metal spheres and pins of metal embedded in a unit of polystyrene		
Inability to fully empty the bladder	Pattern and texture				
Cramping (2)	Durability	Resistance	Wood	Cube Triangular prism	

Symptom	Variable	Value	Material	Shape	Dimension
Need to urinate / incontinence (9)	Timing (5)	Fastness (5)		Sphere	Big
	Permeability (2)	Absorbent (2)	Foam (2)		
	Force	Pressure			
	Constraint	Bounding	Rope tightly wrapped around foam		
Bloody urine (5)	Light (3)	Brightness (3)			
	Colour (2)	Red (2)			
Cloudy urine (2)	Opacity (2)				
Fever (5)	Temperature (3)	Warmness (3)	Wood (3)		
	Material - fabric (2)	Warmness (2)	Wool Fur		
Nausea (3)	Light Weight Spatial disposition	Brightness Lightness Floating / Suspension	Polystyrene	Sphere	Small Bigger units on top of smaller ones
Vomiting (4)	Frequency (2) Light (2)	Rhythm (2) Brightness (2)	Wood (2)	Sphere (2)	Small (2)
Tiredness (2)	Colour Density	Gradient Compactness	Wood		
Need to lie down	Orientation	Horizontal			
Inability to move	Hardness	Rigidity			Short connectors between units of material
Recurrency (8)	Amount (3)	Many (3)		Sphere (2)	Small (2) Several compositions
	Spatial disposition (3)	Linear (3)	Rope (3)		
	Hardness	Resistance / Spreadability	Polystyrene		
	Sound	Rhythm	Polystyrene		
Complexity of the disease (2)	Material Texture	Diversification Net	Wood, polystyrene, foam Metal pins crossing each other in a sort of net woven on a polystyrene unit		
Unusual health conditions	Spatial disposition	Messiness			
Psychological discomfort (6)	Texture	Roughness			
	Shape	Sharpness		Triangular prism	
	Hardness	Rigidity	Wood	Cube	
	Spatial disposition	Asymmetry			
	Permeability	Absorbent			
	Dimension / Spatial disposition	Increasing dimension / Instability			
Anxiety (2)	Weight	Heaviness	Metal Polystyrene	Sphere Triangular prism	
Uncertainty (2)	Spatial disposition (2)	Instability (2)	Metal Polystyrene	Sphere Triangular prism	
Doctor intervention	Unity	Fork	Knot on the rope		
Treatment efficacy	Spatial disposition	Emptiness	Segment of (empty) rope placed among other threaded units		

The associations between physical variables and symptoms of UTIs and related intimate infections are described in the order in which they appear in the Figure 6.5, from top to bottom, and are supported by the motivations provided by participants during the workshop discussions:

- The difficulties of the disease are associated with the variable of weight and more specifically the value of heaviness, represented by wood.
- The general pain is associated with:
  - texture ("suffering is rough");
  - sharpness made of edges and spikes recurrent in the triangular prisms. These pointy peaks not only symbolise the severity of pain but also contribute to creating an irregular, rough surface. This reinforces the earlier association of pain with roughness, merging the sharpness and irregularity into a cohesive representation of the symptom;
  - temperature (warmness/high temperature);
  - weight (heaviness).
- The increasing pain is associated with elasticity referring to the ability to stretch. Rather than simply representing pain, one participant suggested using the material to exemplify how her body feels when affected by the disease. She imagines her body stretched, expanding in size and volume. She also emphasises, "it's not something that's just like transparent or like something that you can go through it" (P20), combining the sensation of pain with the idea of bigger bodies that resist and contrast.
- The worsening of the conditions is associated with:
  - weight (heaviness) and represented by wood;
  - sharpness and the edges of the triangular shapes. To increase the peaks, edges are also adopted, even if originally available to combine the units together.
  - the red colour represented by sandpaper, which was available only during the first workshop session in its default red colour.
- Aching, which is continuous and unpleasant but not very strong, is represented by the sphere: "The first symptoms that I usually have are these ones, so discomfort and pain when peeing, and I represent them with a sphere because I see the sphere or something that is still. Since it doesn't have so many edges, so I think like something that is still feasible to

manage." Edges are perceived as difficulties and are associated with pain. The more the edges the more the pain. Because of this reason, the sphere is chosen to represent initial symptoms or the discomfort generated by the disease (P5). Sphere as sign of discomfort because no edges involved, pointing to a general situation which can improve instead of getting worse.

- Lighter symptoms are associated with weight (lightness) and represented by polystyrene.
- The general symptoms of cystitis are represented by yellow and represented colouring with acrylics some units related to the pain caused by urinating.
- Discomfort when urinating is associated with blurriness, "you feel something but you don't understand what is that." (P18).
- The imaginary friction caused by the discomfort and pain when urinating has been transformed into an active gesture performed on polystyrene to produce sound, and noise more specifically. The pain when urinating is associated with friction that is transformed into a gesture that produces noise. This association is not straightforward, but the variable is selected through different steps that involve senses differently. The sound produced by the units of polystyrene is also recognised as similarly irritating, reinforcing the association of this material with discomfort. The pain during urination is also associated with sharpness, represented by the edges of polystyrene units. Triangular shapes of polystyrene are identified as symbolic of this sort of pain. One of the participants clearly stated this association: "It's when usually the doctor asks me what kind of pain you have. It's usually like associated with angles. It might be sharp or tuned" (P18).
- The burning sensation experienced during urination is associated with:
  - roughness (a value referring to the surface texture identified by Hornecker and colleagues in their classification) and represented by metal wire pins pierced around a polystyrene unit. The participant assembled the material while imagining the object moving through her body, evoking the same intense pain caused by the disease.
  - temperature.
- Swollen bladder and kidney are associated with the variable of friction and represented by small cubes in foam considered "rubbery and stretchy" by the participant. This representation is linked to the idea of organs and body parts

that increase in size and volume when affected by the disease.

- The pain behind the bladder is associated with roughness and represented by small spheres and pins of metal embedded in a unit of polystyrene.
- The inability to fully empty the bladder is associated with pattern and texture. While no further explanation was provided for this association, it may be conceptually linked to the earlier association with roughness.
- The swollen stomach is round and regular. (How much do the words to describe the symptoms influence the perception and the representation of the symptom itself? “Swollen”).
- The need to urinate and incontinence are associated with:
  - the variable of time due to their urgency, frequency, and duration. Urgency compresses the time to act, while frequent episodes emphasise recurrence. Incontinence varies from brief to prolonged, disrupting daily routines and creating temporal distress, making time central to understanding and representing these symptoms. Timing is represented by a big wooden sphere because of the inertia of the rounded shape which naturally tend to roll and move.
  - pressure, because of the physical perception and urgency.
  - permeability, and represented by foam which has been considered, compared to the other materials available, the one that can keep the liquids the most.
  - boundness. To recreate this feeling, the rope was wrapped tightly around a unit of foam, creating some growth standing for the urine constipated in the body.
- The presence of blood in the urine is associated with:
  - brightness, primarily due to its visual representation. This association provided an opportunity for a participant to introduce an important diagnostic insight, emphasizing the distinction between menstrual blood and the blood associated with cystitis. This differentiation, previously mentioned during the discussion of symptoms, highlights the diagnostic relevance of colour and brightness in understanding the condition.
  - red colour. Participants recognised colour, particularly red, as one of the most significant visual variables, confirming its suitability for symbolising blood. In healthcare, blood is universally regarded as an indicator of

urgency, and this urgency is mirrored in the prominence of the colour variable within visual representations. The use of red effectively conveys the critical nature of this symptom, aligning with its diagnostic and communicative importance.

- The cloudy urine is associated with opacity, based on the same interpretative principle.

- Fever was initially associated with the variable of temperature and represented by wood, reflecting the perception of warmness commonly linked to this material. Some participants recognise this association as literal and for this reason try to move forward suggesting alternative associations. In one case, to represent different temperatures, and warm temperatures specific to fever, participants suggest working on the nature of the material instead of their direct degree surface, such as fur and wool. This idea opens to different methods of representing the same variable, instead of changing the variable to represent that specific symptom.

- Nausea is associated with:
  - brightness.
  - lightness, and represented by small polystyrene spheres.
  - the concept of floating and suspension, linking it to the variable of position. This interpretation considers not only the location of individual units but also their relationship to one another, emphasising the interconnected dynamics that contribute to the sensation.

- Vomiting is associated with:
  - shape, size, quantity, and frequency of material units, represented by small wooden spheres. These units symbolise the symptom's recurrence, typically observed during the worsening of an infection. Their selection allowed the expert to highlight the diagnostic significance of quantity and frequency, as these details provide critical insights into the patient's condition. The variable of amount not only visually conveys rhythm but also introduces a sound component, further enriching the representation of vomiting.
  - brightness, symbolising a clear and unmistakable sign that something is wrong. Unlike the previous approach, which leans toward a literal representation of the symptom, this association situates vomiting within the broader context of the disease. Here, it is used as a lens to interpret

and understand the overall condition rather than focusing solely on the symptom itself.

- Tiredness is associated with:
  - colour gradient, which might be considered a value that combines the variable of hue, saturation or brightness.
  - body mass and density, represented by wood. The unit is described by the participant as “full”.
- The need to lie down when sick, which is not a symptom, but a behaviour driven by the disease, is associated with orientation and is represented by the artefact extending horizontally.
- Inability to move and restricted flexibility are associated with rigidity and associated with short connectors between units of material.
- Recurrency is associated with:
  - amount and represented by several composition. Each composition stands for one of the episodes that the participant attributes to one proper event of illness.
  - endurance and spreading of polystyrene, which crumbles yet remains difficult to eliminate, representing the persistent and challenging nature of eradicating the infection.
  - spatial disposition is represented through a linear arrangement, symbolised by the rope. This also allow participants to correlated causes and effects of the disease. One participant makes sure that the rope can close suggesting the repetitiveness of the episodes.
- The complexity of the disease, due to many aspects and factors involved, is associated with:
  - texture, created with metal pins crossing each other in a sort of net woven on a polystyrene unit.
  - multitude and variety of materials used. Each material represents a distinct facet of the condition. Rather than establishing a one-to-one correlation between symptoms and the variable, the overall experience is expressed through the perception of contrasts and differences that emerge when comparing the various physical elements. This approach represents a different method of association and interpretation

compared to the more direct ones discussed earlier. In this case, a broader perspective takes precedence over detailed analysis, allowing the meaning conveyed by the objects to emerge through an overarching view. Even though variety is not considered in this context as a proper variable as it can be breakdown by associating specific materials to punctual causes of the disease complexity.

- Unusual health conditions are associated with the spatial disposition of elements, represented through disorder or mess, reflecting the disruption caused by these conditions.

- Psychological discomfort is associated with:
  - roughness.
  - rigidity, and represented by wooden cubes.
  - dimensions and stability inversely related: the greater the discomfort, the larger the dimensions and the less stable the overall artefact. While most associations among symptoms, variables, and materials focus on individual material units, this participant took a holistic approach by referring directly to the final artefact. This allowed her to incorporate the concept of instability, which arises from how she selected and combined the individual units, into the representation of the symptom. To recreate this perception, bigger cubes have been mounted on top of smaller wooden cubes that serve as bases. In a different occasion, the same result is perceived with small metal spheres.

- Anxiety caused by the disease, persisting in daily life even after treatment, is associated with:
  - weight (heaviness) and represented multiple metal spheres resting on a soft foam surface.
  - triangular shapes made in polystyrene.

- The uncertainty related to the next step of the disease (if improving or worsening) is associated with the physical instability of the units.

- An important step within the progress of the disease considers the intervention of the doctor which is associated with a turning point and represented by a knot on the rope.

- The efficacy of the treatment, reflected in the disappearance of symptoms,

is associated with emptiness, represented by a segment of (empty) rope placed among other threaded units. In this case, the value is assigned to the absence of materiality. This association gains significance within the broader context of other symptoms being represented by tangible materials.

Associations that emerged during WS4 and WS5 are presented separately below because these sessions focused on conditions other than UTIs. They are included in this section to show how participants use physical variables and materials to represent embodied experiences across a broader range of health conditions.

- The itchy throat is associated with friction (G1, WS5).
- Throat ache and swallowing are represented by a linear transparent connector with some metal wire inside (G3, WS5). The wire is "something moving. Yeah, something disrupting the throat. Mm hmm. It's making one cough" (G3, WS5). In this case, the association is possible by comparison. The wire would not have the same meaning if not passing through the flexible and transparent connector.
- Linearity is also used to symbolising the progression of the tonsillitis and transparent elements are incorporated to reflect fluidity (G3, WS5.
- The loss of voice is associated with sound enveloping (G1, WS4).
- The knee-joint pain is associated with kinesthetic friction and represented by a small wooden cube positioned opposite to larger cubes at the base and top. "This is like a twisted knee" (G1, WS4). This representation is part of a composition intentionally compared to the shape of a human figure. The cubes symbolise the legs, even though the structure consists of a single stack rather than a pair, as might typically represent human legs.
- Constipation is associated with compactness. The cube in wood is selected because of the density of the material that reminds the fullness caused by the difficulty in emptying the bowels (G1, WS4).
- The feeling of fullness caused by food in the case of lactose intolerance is similarly represented by the density of the material and the angles of the shape (G2, WS4).
- Bloating (following the constipation) is represented by a sphere (G2, WS4).
- Stomach-ache is associated with compression and represented by a "squishy triangle" of foam (G4, WS5).

- The nausea is a small wooden sphere which participants refers to as “marble” moving inside the body (G2, WS4).
- The lower back pain is associated with the sharpness and the triangular prism (G2, WS4).
- Neck pain is associated with spikiness and the possibility/impossibility of moving represented by triangular prisms (G7, WS5). The fact that this condition is not always present is depicted by the multiplicity of materials, for this purpose, wood, polystyrene, and foam were adopted.
- For opposition, the ideal condition of the shoulder is associated with softness and represented by foam.
- Mental fog is differently represented with small polystyrene spheres (G2, WS4).
- Fatigue is associated with sound enveloping and blurriness.
- Insomnia is embodied in a sense of constant motion and restlessness represented by a flexible connector that should have been longer, as from the participant’s request, not to stop like this condition.
- The worsening of the conditions with weight and size and for this reason represented by wood (G2, WS4).
- Feeling overwhelmed is associated with being surrounded and recreated positioning one small sphere at the centre of triangular prisms recreating a square.

6.1.5 Data-Probes representation

This section examines how participants use Data-Probes to construct material representations of symptoms and health conditions. The findings show that the artefacts support rich forms of interpretation by helping participants organise sensations, relationships, intensity, temporality, and emotional dimensions of experience. Through the combination of components, participants translate embodied perceptions into tangible forms that can be explained, compared, and discussed with others. Data-Probes therefore operate as expressive and analytical objects, showing how symptom–variable associations develop into situated material representations.

Artefact structures between abstraction and figuration

Participants adopted a wide range of visual, spatial, and material strategies to externalise their healthcare experiences. These strategies move between abstraction and figuration, integrating metaphor, symbolism, and aesthetics to communicate symptoms, emotions, and broader illness narratives. One of the most recurrent approaches involved structuring the illness as a linear process. Several artefacts took the form of timelines or journeys, in which participants arranged components to express the recurrence of discomfort, the progression of symptoms, or the cyclic nature of the condition (P2, P5, P11, P15 – WS1, 2, 3). These linear constructions also conveyed emotional states such as anxiety or uncertainty at critical turning points, visually expressing the illness's fluctuating trajectory (P3, P5 – WS1).

Alongside these temporal representations, many participants embraced figuration, building recognisable or suggestive shapes. Some constructed house-like forms, as in the case of a participant who announced, "I am making a beautiful house. A tree house" (P19, WS3), or another who recognised in a peer's structure, "Oh cute, it looks like a house" (P18, WS3). Others leaned into more metaphorical interpretations: "It's like a boat" (P15, WS3), or "a cherry on the top of my cake to make it more unstable" (P18), adding layers of associative meaning to otherwise abstract compositions. In more anthropomorphic forms, artefacts were shaped to resemble the human body to facilitate symptom localisation, sometimes evoking imagery such as a voodoo doll (P1, P6 – WS1). This supported a relational mapping of pain across body parts, allowing for embodied storytelling.

Aesthetic considerations were also central. Participants used materials to evoke emotional textures or subjective discomforts. One explicitly stated, "I'm trying to build something disgusting" (P18), selecting elements that visually communicated fragility or repulsion. The final artefact, described as "pathetic and weak made with disgusting materials" (P18, WS3), visualised vulnerability through deliberate material choices. By contrast, another participant rejected an artefact for being "too cozy," arguing that its polished wooden form was misaligned with the painful experience it was meant to express (P18, WS3). This aesthetic mismatch, where beauty or softness undermined the communicative intent, which was also noted by another participant who preferred "rough textures" over those that appeared "too cute" (P15, WS3).

Several participants adopted a more intuitive process, shaping without a predetermined concept. "I would say first created and then I thought about what it could be," explained one participant (P2, WS1), highlighting how meaning emerged through material engagement rather than conceptual planning. This process-oriented method often allowed metaphor to surface retroactively, shaped by the properties of the materials and the associations they triggered.

Multiplicity and fragmentation also played key roles in how participants structured their artefacts. Some chose to construct modular, discontinuous forms, using separated elements to reflect episodic flare-ups or instability (P3, P9, WS1; P14, WS2). Different materials were often used to represent emotional contrasts or symptom variation, such as soft foams for transience, harsh textures for pain, metal for stiffness. In several cases, empty spaces or voids indicated phases of remission or the absence of symptoms, such as the effect of antibiotics (P5, WS1).

Generative metaphors for narrations

Metaphors emerged as a powerful mechanism for expressing complex, subjective experiences of illness through tangible form. Rather than functioning merely as illustrative language, they acted as interpretative method enabling participants to bridge the gap between bodily sensation and physical representation.

Painful urination, for instance, was not simply described but externalised through expressions like “fire drops” (P2, WS1), “wood chips” (P6, WS1), and “hot pins stuck in the urethra” (P2, WS1). These vivid formulations anchored abstract discomforts in specific physical images, directly informing the choice of sharp, rough, or pointed materials. The difficulty in urinating was metaphorically framed as “a spiky object covered in metal pins passing through the body,” a conceptualisation that later guided the construction of a material artefact featuring embedded metal elements (P4, WS1).

Beyond isolated symptoms, some metaphors reflected broader narratives. One participant described her artefact as “something disgusting” to embody the repulsion caused by the disease (P18, WS3), while another likened the illness to “a monster” (P5, WS4), projecting its emotional impact onto the final object. These ontological metaphors provided concrete identities to abstract conditions, helping participants externalise what might otherwise remain internal and inexpressible. Similarly, references to figurative shapes such as “a house” (P19, WS3), “a boat” (P15, WS3), or “a doll” (G1, WS4) endowed the artefacts with recognisable form, transforming symptom representations into objects with character, place, or symbolic meaning.

Other metaphors served structural purposes, guiding the overall organisation of the artefacts. The use of a linear configuration, for instance, was described as “a flow... both temporal and metaphorical” of urination (P2, WS1), or as a “journey” (P11, WS2), turning the artefact into a narrative space. Connectors were described as “bridges” between mild and severe states (P14, WS2), reflecting both the speed and reversibility of symptom escalation. These structural metaphors shaped not only the logic of the composition but also the sequencing and physical linking of components.

Affective responses were equally central. One participant described their construction as “pathetic and weak”, assembled with materials they found “disgusting” (P18, WS3), while another disqualified a peer’s artefact for looking “too cosy” to represent disease (P18, WS3). These affective metaphors conveyed emotional resonance, translating feelings such as discomfort, fragility, or denial into material and aesthetic choices.

These metaphorical strategies show that participants use figurative thinking to give shape to experiences that are difficult to describe directly. In this sense, metaphors become practical tools that help them understand and communicate their symptoms. Their frequent use in the workshop highlights the importance of interpretative flexibility in participatory data physicalization, enabling forms of expression that go beyond what physical variables alone can represent.

Participants attitude towards the artefact

Participants expressed a wide range of emotional responses regarding the outcome of their artefacts, revealing how satisfaction was closely tied to both material execution and emotional investment. Some participants demonstrated a strong sense of care and attachment to their creations. One described their artefact as “my beautiful, beautiful [artefact]” (P1, WS1), while another expressed frustration when a structural element failed, stating that a malfunction “ruined my whole structure” (P4, WS1). These reactions suggest that the act of shaping was not merely functional but deeply affective, with success or failure in execution impacting personal satisfaction.

Conversely, some participants expressed disappointment or insecurity about their results, particularly when the artefact did not physically behave as intended. A lack of confidence in material stability (P6, WS1) or an inability to balance the structure due to limited technical knowledge (P16, WS3) led to visible dissatisfaction.
Despite these challenges, several participants described the experience in positive and emotionally resonant terms. One participant described the transformation of symptoms into shapes as “very poetic” (P16, WS3), while others responded with spontaneous expressions of delight, referring to the artefacts as “cute” or evoking nostalgic feelings of childlike wonder (P17 and P18, WS3). These responses highlight how, beyond technical outcomes, the participatory process generated affective responses that blended pride, frustration, amusement, and emotional reflection. Satisfaction was not solely dependent on the physical success of the artefact, but also on the participant’s personal engagement and the meanings embedded in the creative process.

Naming for positioning

Participants occasionally reflected on how to name or categorise their creations, highlighting how terminology shaped both the artefact and the experience it conveyed. In one instance, a participant hesitated between calling the outcome an "artefact" or an "installation," expressing uncertainty about its classification but also allowing room for multiple interpretations (P18, WS3). In another case, a participant referred to their piece as a "model," explaining that it represented the presence of symptoms within the body (P12, WS2). Some artefacts were referred to more abstractly as a "thing," pointing to a general sense of material assemblage without specific classification. In more expressive terms, one participant described their final object as a "monster," revealing how the artefact came to embody the disease itself through its form and symbolic weight (P5, WS1). Similarly, another participant framed her artefact as "something disgusting," projecting the emotional discomfort of the illness into the overall composition (P18, W3). In contrast, the use of the term "doll" suggested identification with a human figure, allowing symptoms to be mapped onto the body and transforming the object into a visualised stand-in for personal experience (G1, WS4). Another participant described the whole artefact as a "journey," referring to the linear arrangement of components as a metaphor for the illness's temporal unfolding (P11, WS2). These naming choices reveal how participants navigated the ambiguity of their creations, adopting terms that reflected symbolic, emotional, or functional interpretations.

Describing the representation

Some participants engaged in describing or framing how their artefacts should be read, often by clarifying what the representation was intended, or not intended, to convey. P1 (WS1) specified that the iron wire wrapped around a ball was not meant to suggest constraint, but rather to indicate the complexity of each situation, which must be considered individually. Similarly, the same participant used rough paper to state that "the world is not smooth" referring to the inevitable presence of imperfections or interruptions (P1, WS1). In other cases, artefacts were described as representing general symptoms, such as the repeated experience of cystitis, where cloudy yellow acrylic was used to evoke associations with urine (P2, WS1).

Some participants chose to depict normal or healthy bodily states to create contrast with illness. Examples included describing softness as an "ideal state" of the body (G8, WS5), arranging materials in structured forms to express being "full of energy" (P2, WS1), and using foam shapes to signify the absence of discomfort (P13, WS2). Others designed artefacts that represented alternating or cyclical conditions, such as the back-and-forth experience of a blocked and running nose

(G1, WS4). Finally, one participant used handwritten notes to accompany and explain the artefact during presentation (P11, WS2), demonstrating how verbal or written annotations were incorporated to clarify meaning when material forms alone were insufficient.

6.1.6 Workshop structure

This section examines how the workshop structure supports participants in moving progressively from reflection to shared interpretation and material construction. The findings show that the sequence of activities helps participants build confidence, develop a common vocabulary, compare experiences, and translate symptoms into Data-Probe artefacts. The structure also supports different modes of participation, including writing, selecting, discussing, associating, shaping, and presenting. Overall, the workshop operates as a guided process that enables embodied experience to become progressively articulated, materialised, and shared.

United by a common condition

The participatory nature of the workshops played a central role in facilitating interaction, exchange, and emotional engagement. Participants often reflected on their symptoms in response to what others shared, creating moments of comparison, confirmation, or questioning. One participant remarked, “For me, I don’t experience all of this,” while reviewing symptom labels (P20, WS3), whereas another asked, “Are these symptoms related only to UTIs or just general symptoms?” (P20, WS3). These comments show how group dialogue encouraged self-reflection and highlighted differences in experience. Others confirmed alignment with the collective discussion: “Yes, an experience of UTI. These seem correct” (P15, WS3). Some participants expressed uncertainty about their own experiences, as in the admission, “I feel like I’m the one that’s not normal” (P17, WS3).

Alongside these exchanges, participants also shared personal narratives more openly. One asked, “Like according to my experience, can I share it or not?” (P18), while another described writing down symptoms as “relieving,” explaining that sharing them made the burden feel lighter by realising others had experienced similar conditions. The group format thus fostered a safe, responsive environment. Recruiting participants based on shared experiences of illness enabled spontaneous conversation and peer support, particularly around anxiety and the impact of UTIs on daily life. Working in groups also elicited detailed symptom descriptions, often offered by participants directly to one another. In contrast, a one-to-one format with a facilitator might not have produced equivalent detail, as participants may have

assumed shared understanding or omitted explanations. In the workshop setting, expressions were more instinctive and less shaped by expectations of correctness, and the experimental character of the tasks encouraged spontaneous insights that might not have emerged otherwise.

Language differences did not hinder communication. Instead, they prompted participants to clarify meanings through paraphrasing, examples, or collaborative interpretation. When unfamiliar with terms such as groin or incontinence (P12, WS2; P17 and P19, WS3), participants actively worked together to resolve misunderstandings. This process not only improved communication but also encouraged deeper reflection on sensations and interpretations, generating rich, situated descriptions of the illness.

Although the group setting generally supported interaction, there were exceptions. Of the approximately thirty participants involved in the final two workshops, only two (P25, P26, WS5) chose to work independently. One ultimately did not present their work, likely due to the private nature of the condition explored. The other reported that aesthetic pleasure guided their design choices more than meaning. These cases suggest that while group activities promote social exchange and collective meaning-making, individual work may be more suitable for deeply personal or sensitive content. This structure proves beneficial, as it encourages mutual understanding and shared reflection at the beginning, while still offering participants the space to explore and represent their personal experiences through material engagement. This balance emerges as one of the strengths of the format, supporting both communal learning and individual insight.

Participation across different phases of the workshop

A relevant methodological finding concerns the different moments in which participation unfolded across the workshop sessions. Participation did not operate in a single way throughout the activity. Instead, the sessions showed that it could be activated at different stages of the process, with direct consequences for how meaning was generated, expressed, and shared.

In WS1, WS2, and WS3, participation was concentrated mainly in the collective phases that preceded the shaping of the artefacts. Participants worked together to identify symptoms, discuss their relevance, explore the meaning of physical variables, and define associations between symptom labels and material qualities. These stages created a shared interpretative ground through discussion, comparison, and negotiation. The shaping of the Data-Probes then took place individually, before returning to the group through presentation and discussion. This configuration proved especially suited to the topic addressed in the research.

Because UTIs and related intimate conditions involve personal, embodied, and often sensitive experiences, the collective phases of association offered an appropriate space for participants to discuss symptoms together and build a shared vocabulary. At the same time, the individual shaping phase provided a more focused moment of reflection in which each participant could develop a personal representation of her own experience. This sequence enriched both the workshop process and the results it generated. Participants benefited from the shared discussion before moving into their own material interpretation, and the workshop produced artefacts that preserved the specificity of individual experience while remaining grounded in collectively discussed meanings.

A different configuration emerged in WS4 and WS5, where participation extended more directly into the shaping phase itself. In these sessions, participants not only discussed symptoms and variables together, but also constructed the artefacts collaboratively. Meaning was therefore negotiated both through label association and through the shared selection, combination, and arrangement of materials. This produced a more explicitly collective form of representation, in which the artefact expressed a negotiated understanding developed by the group.

Comparing these configurations shows that participation can support the methodology in different ways depending on when it is activated. In the earlier sessions, participation structured the discussion and prepared the ground for individual expression. In the later sessions, it also shaped the material construction of the artefacts themselves. The first configuration remained especially appropriate for intimate health conditions, where personal reflection and individual representation contribute directly to the richness of the accounts produced. The second configuration proved more suitable for settings in which broader or shared issues were explored collectively.

Medical experts to clarify and contextualise symptoms

Medical experts involved in the workshops contributed by clarifying symptoms, contextualising bodily experiences, and reflecting on the diagnostic process. One expert stated explicitly that, although she had no personal experience of UTIs, her understanding derived from treating many patients (P1, WS1). Drawing on this clinical perspective, she distinguished between overlapping conditions, such as the difference between UTIs and genital infections (P1, WS1), and explained how *Escherichia coli* can be a normal bacterial presence that becomes pathogenic, causing cystitis or even pyelonephritis when immune defences are low (P1, WS1).

Experts also provided broader biomedical explanations, including the definition of the urinary tract system and how infections in this system differ from vaginal

infections (P1, WS1). They described typical diagnostic procedures, noting that physicians usually begin by assessing general indicators such as fever, temperature, and shivering before moving on to more specific signs, including bloody urine (P14, WS2). These symptoms, they noted, are often shared with other conditions, which complicates clinical reasoning and contributes to diagnostic uncertainty (P14, WS2).

Beyond clinical clarification, experts reflected on the workshop itself. One expert emphasised that, despite attempts to establish shared definitions, each individual case remains unique and difficult to reconcile with standardisation practices in healthcare (P1, WS1). Another highlighted the value of the workshop for helping participants recognise their symptoms, increase their awareness, and improve the way they communicate their experience to medical professionals (P14, WS1).

These contributions position medical experts not only as providers of clinical information but also as interpreters of the workshop's educational and communicative value, underscoring the role of medical presence in supporting participants' understanding and in enriching the overall process of symptom articulation.

Misalignments in understanding

Participants encountered several types of difficulties during the workshop, particularly concerning language, materials, and understanding the structure of the activities. A common issue related to translation and vocabulary. Some participants did not recognise key medical terms and explicitly asked for clarification. "What is this for?" asked one participant, pointing to the term groin (P17, WS3), while another added, "You know when you guys say the kick in the groin... that's the groin. It is there basically" (P16, WS3), attempting to explain the word to others. Similarly, the term incontinence caused confusion: "What incontinence mean?" (P12, WS2), "This is incontinence? What is it?" (P19, WS3), followed by an explanation: "When you cannot keep your keep it inside" (P18, WS3). In some cases, language barriers required additional support: "I need a translator" (P18, WS3), and "I don't know how to say in Italian when you feel like... full" (P11, WS2).

Difficulties also emerged around the use of symptom labels. One participant noted, "I cannot read them..." when referring to the tags (Unidentified). Another hesitated to write on the wooden labels: "It is not making it dirty" (P18, WS3), expressing concern about damaging the polished surface. Additionally, some participants found the number of available labels limiting: "I feel like what I notice is we need multiple of these" (P20, WS3), referring to the need for duplicate labels to make multiple associations.

Regarding activity structure, participants often expressed uncertainty about how

to proceed. “What do you want us to do?” (Indistinct), “Together?” (Participants), and “Are we linking with this or are we” (P13, WS2) illustrate recurring confusion. One participant asked, “So we need to link those to their materials?” (P17), while another wondered, “Do we start from symptoms or from a variable?” (P2, WS1). When asked whether label associations were mandatory, a participant asked, “And I do not have to follow this, or do I?” (P2, WS1). Representational challenges were also raised: “It was difficult to represent all the symptoms in one” (P11, WS2), and one participant noted, “For me, it was very difficult to express pain” (G8, WS4).

These difficulties spanned both linguistic and structural aspects of the workshop, highlighting the need for clearer guidance, flexible tools, and accessible language throughout the process.

Was it useful in the end?

Participants offered a range of responses to the workshop activities, combining positive reactions, reflective insights, and critical observations. Several expressed direct appreciations for the experience, with comments such as “It was really funny” (G1, WS4) and “It was really interesting” (G1, WS4). The materials themselves also received positive remarks, as one participant noted, “I think this was quite cute” (G2, WS4), referring to the physical components used during the shaping process.

Many participants highlighted the novelty of the method. One remarked, “I have never thought of associating symptoms with materials and their characteristics” (G1, WS4), and later reflected, “I’m gonna think of it (symptom communication) differently from now on” (G1, WS4). These comments suggest that the workshop introduced an unfamiliar yet stimulating approach to expressing bodily experience. Some participants also wondered about the broader lineage of such methods, asking, “Do you think that these shapes, the material and these textures, that you use in your workshop, was it already, like, was it done somewhere here?” (General). This curiosity indicates an interest in situating the activity within a wider context of design or health-related practices.

Participants also proposed potential extensions or alternative formats. One suggested that resembling a human shape might enhance communication, asking, “I’m wondering if it could help to resemble a human shape in this way because we [are] working this way” (G1, WS4). Others connected the experience to personal practices of body awareness. One participant recalled using drawing to process her ectopic pregnancy, explaining, “In this moment I draw. I draw. In my body this is what is happening” (G1, WS4), demonstrating how the workshop resonated with pre-existing embodied methods of expression. Not all feedback was positive.

One participant questioned the relevance of materialising symptoms for their

own case: “Materializing it, um, for me, there, I did not have a benefit from that, so I was wondering in what ways does the materialising help people like me” (General). This reflection underscores individual differences in the perceived usefulness of the method and points to variation in how participants relate to embodied forms of representation.

Overall, the feedback reveals a diverse spectrum of responses. While many participants expressed enjoyment, curiosity, and reflective engagement, others remained more critical or uncertain about the value of materialising symptoms. Together, these reactions point to the method’s potential while also highlighting areas for further adaptation and exploration.

6.1.7 Summary of the findings on the method

The findings presented in this chapter highlight how the method operates through participants’ engagement with physical variables, materials, and the process of externalising sensations into artefacts. Across Section 6.1.2, participants identified physical variables using sensory, visual, and literal strategies, revealing both the generative potential and the inherent ambiguity of these categories. New variables emerged, familiar ones were reinterpreted, and overlaps exposed the interpretive flexibility needed to represent complex sensations. Section 6.1.3 shows how material selection further shaped interpretation, with participants drawing on personal experience, transposition, and exclusion to judge suitability. Materials elicited gestures, evoked secondary perceptions, and occasionally exposed gaps in the kit, demonstrating that the material palette was “just enough to reveal what is missing”. Together, these insights indicate that variables and materials co-produce meaning, structuring the expressive space without predetermining the outcome.

The analysis also shows how participants established connections between sensations and material properties, forming consistent yet situated symptom–variable associations (Section 6.1.4). Through the creation of Data-Probe artefacts, participants navigated between abstraction and figuration (Section 6.1.5), generating results that operated both as metaphors and as grounded representations of lived experience. Naming, positioning, and describing these artefacts became part of the interpretive process, revealing how making supports reflection and narrative construction. Finally, Section 6.1.6 discusses the workshop structure as a methodological contributor. Shared conditions fostered a sense of proximity, experts enabled clarification while also revealing misalignments in understanding, and participants ultimately valued the activity for the communicative and reflective space it created.

Table 10 provides a list of key points and related highlights for every theme identified within the analysis. Overall, the findings from Chapter 6 show how participatory data physicalization supports the translation of tacit and embodied knowledge, particularly in relation to UTIs and other intimate conditions, into forms that can be collectively interpreted through material engagement, collaborative meaning making, and structured variability.

Theme (on WS method)	Key points	Higlights
T1: Physical variables (section 6.1.2)	Physical variables support the translation of sensations into structured material expressions. Participants consistently associate specific variables with particular symptom qualities (e.g. sharpness with pain, softness with relief). Variables enable articulation of nuances that are often difficult to capture verbally.	Establish physical variables as the core interpretive system of the method, providing shared dimensions for comparing experiences and generating collective understanding.
T2: Materials (section 6.1.3)	The material kit influences how sensations are explored and expressed, with some materials prompting clearer associations than others. Participants rely on tactile affordances (temperature, rigidity, texture) to externalise sensations. Material diversity shapes imagination, expressiveness, and precision.	Confirms the need for curated material sets that balance openness with analytical coherence, ensuring that materials support rather than limit interpretive clarity.
T3: Symptom-physical variable associations (section 6.1.4)	Participants form systematic and repeatable links between symptoms and physical properties. Associations reveal both sensory dimensions (pain, pressure, rhythm) and emotional or experiential layers (anxiety, urgency). These patterns show how participants understand and compare symptoms.	Demonstrates the generative role of variables as mediators between sensation and representation, enabling symptom mapping that is both subjective and comparable.
T4: Data-Probes representations (section 6.1.5)	Artefacts embody participants' reasoning and act as tangible records of interpretation rather than fixed representations of the body. The form of the artefact reveals perception patterns: aggregation, contrast, sequencing, or fragmentation. Data-probes facilitate dialogue and collective interpretation.	Positions data-probes as analytic artefacts and communicative anchors, supporting multimodal analysis across material, verbal, and gestural data.
T5: Workshop structure (section 6.1.6)	Sequential tasks scaffold perception, interpretation, and comparison, enabling participants to move from narrative description to material translation. Group discussions enrich interpretation and validate associations across participants. Structure influences depth of reflection and consistency of outputs.	Shows how the workshop protocol itself contributes to meaning-making, providing a reproducible flow through which embodied knowledge emerges and is collectively elaborated.

Table 10: summary of key points and highlights from the five themes identified in the workshop analysis that provide insights on the workshop method.

6.2 Conclusion from the methodology

This section draws together the main insights emerging from the analysis and situates them within the aims and structure of the workshop format and the methodology of this research. By consolidating these findings, this section prepares the ground for the following Chapter, where the results are presented to medical experts to support their contextualisation and understanding within the healthcare setting.

6.2.1 Opening and building the conversation

The thematic analysis focused on the methodology of this research shown that participants engaged meaningfully with the unconventional method of representing symptoms through physical variables. The introductory activity, focused on exploring the concept of symptom, proved effective in initiating engagement. It allowed participants to situate themselves within the topic, either by offering general interpretations or by sharing personal and intimate accounts. Several concerns first raised during this ice-breaking phase resurfaced in later exercises, indicating a strong thematic continuity throughout the workshop.

The participatory format plays a central role in supporting open dialogue. This is particularly evident when participants share lived experience of UTIs, as this common ground fosters mutual understanding and creates a safer space for discussing sensitive topics. Similar dynamics also appear in other sessions, where group interaction encourages peer support and richer descriptions of symptoms. Compared with one-to-one exchanges with facilitators, the group setting supports more spontaneous and detailed accounts because participants respond to each other's experiences, recognise similarities and differences, and build on shared reflections. Speaking with peers therefore encourages more direct expression and generates insights that may be less likely to emerge in a more formal or hierarchical setting.

Language barriers, initially perceived as potential obstacles, proved instead to be productive. The need to find alternative words led to creative formulations and deeper reflection. This linguistic negotiation enriched the descriptions and opened new paths to understanding symptoms not just as medical facts but as experiences of every day. At the same time, the workshop made visible that experience with illness does not always guarantee clarity about one's own condition. One participant realised only during the activity that her recurring symptoms were caused by candidiasis rather than cystitis. Another, with no prior experience of UTIs, became an active listener, asking questions that prompted collective reflection on disease origins, interpretations, and treatments. These exchanges highlight how informal

knowledge sharing operates within group settings and reveal how misunderstandings can shape personal narratives of disease, reinforcing the value of collaborative interpretation. The inclusion of medical professionals in the workshops aimed to maintain focus, clarify medical ambiguities, and counter potential misinformation. Experts also gained valuable insights into the patient's perspective. Their active participation blurred traditional hierarchies, especially when experts matched the demographic profile of participants and adopted informal attitudes. One expert recognised the workshop's relevance to her own research on antibiotic resistance. Her feedback highlighted how the activity helped participants recognise early symptoms, enhancing self-management and potentially reducing inappropriate antibiotic use. Notably, the absence of a medical expert during the third session negatively impacted both the accuracy of information and the clarity of symptom differentiation. While the session proceeded, a lack of guidance led to broader and less grounded conversations.

6.2.2 Beyond material for body expression

Materials played a primary role in enabling participants to communicate sensitive or difficult topics. Physical components provided both a symbolic and functional medium for expression. Participants often translated bodily sensations into physical forms, referring to materials instead of body parts. This distancing allowed greater freedom of expression while prompting detailed reflection on symptom characteristics. Exploring material features, such as texture, temperature, and shape, stimulated nuanced dialogue around symptomatology. The material encouraged instinctive and metaphorical connections. Participants assigned meaning to physical variables like sharpness, smoothness, and weight, sometimes drawing from personal memories or embodied experiences. Although the same symptom was represented by different materials across participants, the reasoning often converged, suggesting that the meaning resided more in the explanation than the material itself.

While some participants embraced improvisation and reinterpretation of materials, for example, using pegs as spikes or reappropriating sandpaper, others were hindered by constraints such as limited material choices or unclear instructions. The availability and presentation of materials strongly shaped how smoothly participants could engage in the activity. Glass, for example, was often mentioned as a desirable addition because of its dual symbolic value: broken fragments were associated with pain, while its translucent quality evoked uncertainty or blurred perception. These symbolic associations further support the hypothesis that materials function both literally and metaphorically in the communication of symptoms.

Beyond materials, gestures also emerged as communicative strategies.

For instance, one participant simulated a creaking sound by mimicking the action of rubbing polyether foam, evoking the discomfort of friction without producing an actual sound. This observation raises questions about gesture sonification and the extent to which communicative variables are defined by actions rather than by the intrinsic properties of materials. To further investigate how physicalization can trigger sound within data representation, the workshop format was adapted and conducted at the EKSIG conference (Budapest, 2025) in collaboration with sonification expert Sara Lenzi. This experience, described at the end of Chapter 9, broadened the scope of the research to include related themes and yielded promising results, which are intend to pursue in future research.

6.2.3 Presentation of the representation

The artefact presentations revealed different relationships to the physical output. Some participants offered purely descriptive accounts, while others used the artefact as a platform to narrate their lived experiences. Naming conventions also varied, going from technical terms like “artefact” to colloquial ones like “this” or “mine”, and further reflecting the spectrum of attachment and interpretation.

Notably, those with recurrent or chronic symptoms tended to represent their condition through timelines, reconstructing sequences of events to make sense of their illness. In contrast, experts often produced simplified or symbolic artefacts with fewer components, emphasizing clarity over detail. This divergence points to differing communicative goals and levels of familiarity with the embodied aspects of illness.

Communication strategies varied across sessions, with participants drawing on vocal negation, metaphor, and comparison to clarify the intent behind their representations or to differentiate their work from group tendencies. At times, participants described states of well-being to contrast with dysfunction, using oppositional reasoning to highlight what the body should feel like in order to emphasise what it does feel like during illness. These contrasting formulations reveal an elaborated approach, showing how participants negotiated meaning by moving between what is present and what is absent, what is ordinary and what is altered.

Despite episodes of confusion or ambiguity, the workshop format encouraged meaningful engagement, fostered reflection, and supported participants in articulating their experiences of illness. The use of material as a communicative medium proved particularly valuable, revealing forms of insight that often remain inaccessible through verbal description alone. At the same time, the challenges participants faced in manipulating and interpreting materials highlighted a general need for cultivating tactile literacy, a capacity that remains far less developed and discussed than visual communication.

6.2.4 Generative physical variables to map symptoms

Finally, the analysis demonstrates that physical variables are central to participants' capacity to externalise and communicate bodily experiences, serving both as conceptual and expressive tools. Throughout the workshops, a set of recurring associations emerged with notable consistency. Weight was commonly used to express severity or burden. Sharpness developed from general roughness into pointed, peak-like forms that marked pain. Spherical shapes often represented general, ambiguous, or early symptoms, whereas irregular or unstable structures conveyed uncertainty, diagnostic ambiguity, or emotional instability. In one particularly striking example, a participant constructed an artefact designed to collapse on touch, using its intentional destructibility to embody the fragile nature of her condition. However, these associations were neither systematic nor prescriptive. Variables functioned not as fixed indicators but as negotiated affordances, shaped by context, interpretation, and material availability. Participants adapted the same variable to different ends, sometimes proceeding by metaphors (e.g., permeability to suggest body leakage or disease lack of control) and at other times by indexes (e.g., red to signal the presence of blood or temperature for fever). This dual possibility underscores the interpretive potential of variables and their embeddedness in personal narratives.

As participants interacted with the materials, variables emerged as situated constructs rather than fixed categories, shaped by expressive intentions and by what each component afforded. Participants did not treat variables as stable qualities. Instead, properties shifted as part of the interaction and became performative rather than inherent. A feature such as softness or sharpness could carry different meanings depending on how it was manipulated. Gestures such as rubbing a surface to create sound, layering components to produce instability, or arranging pieces to suggest growth expanded the communicative role of variables beyond their initial encoding function. These observations show that variables emerge through process, interaction, and temporality rather than from intrinsic material qualities, reinforcing the thesis's initial framing of materiality in physicalization as an active and situated form of engagement.

The analysis revealed that participants not only associated specific physical variables with symptoms but also began to organise these associations into layered and interrelated structures. This indicates that variables are not perceived as isolated elements. Instead, they are understood as part of a system of meaning, where some variables take on foundational roles and others provide nuance or further specification. A clear example emerged in the way roughness was described not as an independent variable, but as a refinement of discomfort, which itself was

embodied through shape. In this structure, shape operates as a broader container of meaning (for instance, denoting pain or tension), while roughness narrows the expression to a specific quality of that discomfort, such as how it feels on the surface or how intense it is. This kind of nested association suggests that participants were intuitively building semantic hierarchies, even without formal instruction. Similar to the role of grammar in language, some variables functioned as primary descriptors in participants' use of physical materials, while others operated as modifiers that added depth, context, or specificity to the representation. By distinguishing between what could be called primary and secondary variables, participants were engaging in an expressive logic. This logic enabled them to build internal coherence across the elements they selected, even when the materials and instructions were open-ended. Rather than treating all variables as equal, they prioritised some as central to the message and others as supporting elements. This reflects an emergent grammar or syntax of physical expression as a set of unspoken rules or preferences that governed how meaning is constructed within the physicalization process.

However, this process also revealed the limits of the predefined variable set. Certain terms, such as "three-dimensional form" or "fuzziness", were either misunderstood or resisted. Variables like colour were repeatedly appropriated across categories, used not only for visual qualities but also as carriers for temperature, urgency, or psychological state. This blurring of boundaries indicates that participants did not treat variables as discrete, isolated dimensions, but rather as multifunctional communicative devices.

Together, these findings suggest that the act of variable selection and use is not a process of classification, but a form of situated reasoning and a negotiation between personal experience, social context, and material constraint. Variables provided a structure for expression, but one that remained open-ended and generative rather than prescriptive. Their value lay not in standardisation, but in their capacity to accommodate plurality, ambiguity, and affect within a physical language of symptoms.

From a design perspective, this positions variables not merely as descriptors but as epistemic tools that help participants make sense of, and give form to, experiences that are otherwise difficult to articulate. The vocabulary that emerges from this work is a living lexicon, grounded in practice and responsive to context. This orientation shifts the focus from designing communication tools about illness to designing with illness as it is contextualised, narrated, and reshaped within participatory settings. In this view, illness becomes something understood through interaction, reflection, and collective interpretation, rather than a static object to be represented.

As such, this research contributes to the broader field of data physicalization by proposing an expanded view of variables as relational, performative, and open to appropriation. Future applications could embrace this complexity by incorporating gesture-driven elements, supporting multi-modal associations, and allowing participants to articulate new variables on their own terms. Rather than offering a fixed set of options, the aim becomes to design approaches and materials that evolve alongside the interpretive practices they support.

In this chapter, I showed through analysis how participants externalised, compared, and interpreted their embodied experiences through physical variables and material engagement. The following chapter situates these participant-generated insights in relation to clinical knowledge and professional practice. It therefore presents the dialogue developed with medical experts around the workshop findings on UTIs and related conditions, examining how these expressions resonate with, expand, or challenge established healthcare understandings. The discussion Chapter 8 then reflects on these contributions in relation to the broader research questions, before the Chapter 9 which consolidates them within the Physical-Variable Apparatus.

7. MEDICAL EXPERTS' PERSPECTIVES ON WORKSHOP FINDINGS

This chapter presents medical experts' perspectives on the workshop findings, placing participant-generated knowledge in relation to clinical expertise and professional practice. Medical experts hold an important role in this research because their contributions help contextualise how participants' accounts of UTIs, symptoms, diagnosis, treatment, and communication relate to healthcare practice.

The chapter focuses mainly on the health-related findings connected to UTIs, in line with aim [A] defined in Section 3.4.1. Medical professionals with relevant expertise were invited to engage with selected workshop outputs and to reflect on their clarity, relevance, and clinical significance. Their perspectives help situate the workshop outcomes in relation to existing clinical understandings, patient communication, and the practical conditions of diagnosis and care.

Although the interviews centred mainly on the topical findings, methodological reflections also emerged. This connection is expected because the physicalization process shapes how participants describe, interpret, and communicate their symptoms. The chapter therefore considers both clinical and methodological observations, showing how expert perspectives contribute to a richer understanding of the knowledge generated through the workshops.

7.1 Aims and methods to collect medical experts' perspectives

This section presents the process through which medical experts engage with the workshop findings related to aim [A], which concerns the contribution of the research to the understanding of UTIs. To support this aim, I developed a structured process of expert engagement. Medical professionals with expertise in UTIs, infectious diseases, antibiotic resistance, patient communication, or narrative approaches to

care were invited to review a curated selection of workshop outputs. These included written narratives, artefact descriptions, and excerpts from conversation transcripts. Experts were asked to reflect on the clarity, relevance, and clinical significance of participants' accounts, to consider whether the material brought forward tacit or under-recognised aspects of UTI experience, and to comment on the expressive forms through which participants communicated their symptoms.

For this purpose, each expert received an individual document containing the selected material and was invited to annotate it before the interview. This allowed their reflections to develop through direct engagement with the workshop outcomes. I then conducted an online semi-structured interview of approximately forty-five minutes with each expert. The interviews explored how the findings relate to established clinical understandings of UTIs, whether participants' terminology and metaphors add nuance to symptom description, and how these insights might inform more patient-centred communication in healthcare settings.

Ethics approval for this process was granted by Brunel University's Research Ethics Committee, and the interview guide is included in the Appendix.

7.2 Interview modalities and interviewees

A total of twelve healthcare professionals were interviewed. They were selected for their expertise in infectious diseases, UTIs, antibiotic resistance, clinical research, pharmacy, patient communication, or narrative approaches to care. Some experts work directly with UTI patients, while others contribute through research, antibiotic stewardship, ethics, anthropology, pharmacy, or narrative medicine. Several interviewees are professionals I met during the research or members of the SPEARHEAD consortium.

Female experts were prioritised because the workshop findings concern women's embodied and intimate health experiences, and this choice supports a more situated interpretation of data related to women's physical and mental conditions. Male experts were also included when their clinical, methodological, or research expertise was directly relevant to the study. In total, the interviews involved nine female and three male experts. Medical expert interviewees are identified with the abbreviation ME, to distinguish them from workshop participants, identified as P.

The expert profiles are listed below, with gender specified because of the sampling rationale described above:

* ME1: senior researcher and lecturer in Biomedical Ethics at the master's in medicine in the Faculty of Biomedical Sciences of the Università della Svizzera Italiana. Previously at the Oncology Institute of the Italian

Switzerland (IOSI), focusing on ethics, communication, and technology in health contexts (female);

- ME2: project manager at the University Hospital in Basel. She holds a PhD in clinical research and currently works on antibiotic stewardship. Works closely with patients and doctors in hospitals (female);
- ME3: head of Clinic in the Infectious Diseases Department at CHUV and University of Lausanne (UNIL). She holds specialist titles in Internal Medicine (2021) and Infectious Diseases (2022). Previously worked in Hospital Hygiene, Prevention, and Infection Control at CHUV (female);
- ME4: pharmacist with a PhD at the Swiss Centre for Antibiotic Resistance. She performs epidemiological analyses, works at the University Hospital of Basel and the geriatric hospital in Basel, and supports physicians and nurses in optimizing treatments as a clinical pharmacist (female);
- ME5: intern in clinical research medicine in infectious diseases at Geneva Hospital, graduated from Geneva Medical School in 2022, focusing on epidemiology and supporting ME12 in the UTI clinic (female);
- ME6: infectious disease physician with experience in infectious diseases for 7 years and in UTIs specifically for 1 year, assisting with the opening of a UTI clinic (female);
- ME7: senior researcher at the University of Basel and professor in pediatric infectious diseases at City St. Georges, UK. Trained as a pediatrician (female);
- ME8: medical anthropologist and senior research fellow at the Bern University of Applied Sciences, deputy head of the “Psychosocial Health” research unit. Her research focuses on organ transplants, palliative care, gender medicine, and expertise in healthcare, with a growing emphasis on interdisciplinary and participatory approaches (female);
- ME9: head of the hospital pharmacy at University Hospital in Basel. He leads a research group in Pharmacoepidemiology. Pharmacist by training, with extensive experience in community pharmacy, drug safety research, and patient-related pharmacy services (male);
- ME10: MD-PhD candidate at the Institute of Microbiology, Lausanne University Hospital. Specialises in antimicrobial resistance research (male);

- ME11: professor of Surgery at USI and Chief of the Hepatobiliary Center in Lugano and specialises in liver, pancreas, and bile duct surgery, with research in surgical techniques and outcomes, and an interest in narrative medicine (male);

- ME12: infectious disease specialist and professor at the University Hospital of Geneva. She works on general infectious diseases with a subspecialty in UTIs. She manages an outpatient UTI clinic and provides inpatient consultations for complex UTI cases (female).

Interviews were conducted online via Microsoft Teams and lasted approximately forty-five minutes. The semi-structured questions examined how experts interpreted the findings, whether they identified inaccuracies or ambiguities, and whether the analysis revealed insights that extend or challenge existing clinical knowledge on UTIs and women's intimate infections. The interviews also explored experts' perceptions of participants' vocabulary, including whether unconventional or unexpected descriptions offered greater clarity or added value in understanding symptoms.

A complete list of the interview questions is available in the Appendix. Six experts also provided written comments directly on the Word document shared with them. These comments were reviewed during the interviews and incorporated into the preliminary analysis. Two experts had not read the document before the interview, so I provided a short summary of the activity and an overview of the main findings at the beginning of the conversation to guide the discussion.

7.3 Analysis of medical expert interviews

The interviews were transcribed and coded to examine how medical experts interpret the workshop findings. The analysis highlights a gap between clinical diagnostic routines and the ways patients experience and communicate illness. Experts describe this gap as relevant to diagnosis, care, and patient communication, especially when symptoms are ambiguous, recurrent, or difficult to express. At the same time, their reflections indicate the potential of design-led, narrative, and material-based approaches to support more nuanced understanding between patients and healthcare professionals.

The findings are organised around four main themes (Table 11). The first theme, "The diagnostic challenge", details the core clinical ambiguities in symptom identification, progression, and the profound lack of a shared language between

patients and clinicians. The second theme, “The lived experience”, moves beyond physical symptoms to explore the significant psycho-emotional burden of UTIs and the patient’s journey from confusion toward self-management and empowerment. The third theme, “Bridging the gap”, examines how the design-led methods used in this research, specifically narrative practices and the use of physical artefacts, were assessed by experts as powerful tools for facilitating richer communication and shared meaning-making. Finally, the fourth theme, “Methodological reflections”, offers a critical evaluation of this novel approach, considering its practical limitations, risks of misinterpretation, and its future potential within clinical and research contexts.

Theme 1	**The diagnostic challenge: ambiguity in symptom identification and expression**
Sub-theme 1.1	**Misunderstandings, misattributions, and unclear symptoms**
	Misconceptions and misattributions
	Experience-dependent understanding
	Confusion and uncertainty
	Knowledge gaps on infection types
	Language and terminology issues
	Narrative framing and expression
	Unusual / atypical symptoms
Sub-theme 1.2	**Symptom variability, specificity, and progression**
	Severity and progression
	Variability in manifestation
	Pain characteristics
	Infection type differentiation
	Systemic symptom indicators
	Pain/symptom characteristics
	Common symptom profiles
	Differential diagnosis issues
	Hematuria as severity marker
	Combined symptom value
	Lived vs textbook patterns
	Lived vs textbook patterns
Sub-theme 1.3	**The vocabulary gap: the struggle for a shared language**
	Symptom subjectivity and variability
	Diagnostic frameworks and priorities
	Perceived communication sufficiency
	Relational and narrative practices
	Language and communication gaps

Theme 2	**The lived experience: the psycho-emotional and relational burden of UTIs**
Sub-theme 2.1	**Anxiety, fear, and shame: the unspoken symptoms**
	Preventive practices
	Psychological and emotional dimensions
	Early recognition (pre-symptoms)
	Anxiety as symptom and consequence
	Stigma and shame
	Overlooked impact in medical discourse
	Burden differences
Sub-theme 2.2	**The journey to literacy: from confusion to competence**
	Foundational knowledge for symptom
	Tools to support awareness
	Relational learning for self-awareness
	Misattributed external factors
	Conditions for self-management
	Role of proper diagnosis
	Reconstructing disease timeline
	Learning through recurrence
	Learning from body signals
	Learning to qualify symptoms
Sub-theme 2.3	**Empowerment through education and relational care**
	Awareness through introspection
	Data-driven awareness
	Communication of personal experience
	Precision in symptom description
	Awareness through introspection
	Validation through participation
	Importance of conversation
	Patient empowerment
	Antibiotic stewardship
	Patient empowerment
	Educational practices
	Safe dialogue
	Relational support
	Narrative medicine

Table 11: coding table for the thematic analysis of the medical expert interviews on UTIs.

Theme 3	**Bridging the gap: facilitating meaning-making through narrative and physicalisation**
Sub-theme 3.1	**Materials as communicative tools: eliciting nuanced vocabularies**
	Need for explanation with materials
	Vocabulary enrichment
	Role of materials
	Material qualities and sensations
	Method and openness
	Subjectivity in material associations
	Mixed communication modes
	Use of metaphorical materials
	Need for explanation with materials
	Pain quality vs intensity
	Precision in symptom description
	Limits of material kit
	Use of metaphorical materials
Sub-theme 3.2	**Metaphors and analogies as bridges to**
	Metaphors for pain
	Use of analogies in male patients
	Use of metaphors by patients
	Child's metaphorical description
	Abstract metaphors – ongoing threat
Sub-theme 3.3	**Collective sense-making and validation in peer dialogue**
	Collective sense-making
	Risk of mutual influence
	Pain descriptions

Theme 4	**Methodological reflections: potential, pitfalls, and pathways to practice**
Sub-theme 4.1	**Interpretation, limits, and risks**
	Need for clear explanation and contextualisation
	Risk of abstraction without context
	Interpretation dependent on context
	Risk of abstraction without context
	Subjectivity and variability in interpretation
	Subjective, interpretive value in practice
	Value and limits of visual/material outcomes
	Debated educational value
	Debated necessity of material methods
	Limited diagnostic relevance
	Preference for traditional (written) documentation
	Subjectivity and qualitative limits
Sub-theme 4.2	**Clinical applicability and transferability**
	Transferability to medical practice
	Suggested tools/kits for clinical use
	Practical constraints in clinical settings
	Reliance on direct questioning in practice
	Simplified tools as alternative
	Potential but limited transferability
	Limitations in clinical applicability
	Design suggestions for clinical adaptation
Sub-theme 4.3	**Representativeness and generalisability**
	Inclusion/Exclusion in recruitment criteria
	Recruitment and population differences
	Delayed recognition of severe cases
Sub-theme 4.4	**The value for patients and future research potential**
	Medical presence as supportive factor
	Safe and supportive environment
	Reflective and empowering value
	Validation through material engagement
	Positive reception of material methods
	Methodological novelty
	Potential for diagnostic insights
	Requirement for empirical validation

7.3.1 The diagnostic challenge: ambiguity in symptom identification and expression

This section examines how medical experts respond to the workshop findings on symptom description and diagnostic uncertainty. Their reflections confirm that the difficulties participants described, including unclear sensations, overlapping symptoms, recurrence, and uncertainty about when to seek care, are also recognised as diagnostic challenges in clinical practice. Experts highlight that patients' accounts can contain valuable experiential detail, but that this detail can be difficult to translate into clinically actionable information. This theme therefore connects the workshop findings to the broader problem of how embodied symptoms are identified, expressed, and interpreted within healthcare encounters.

Misunderstandings, misattributions, and unclear symptoms

Across the interviews, at least four experts noted that patients often struggle to correctly identify and differentiate UTIs from other conditions, especially during first episodes or when symptoms overlap with other intimate or lower genital infections (ME2, ME3, ME5, ME9). This difficulty appeared even in basic terminology, as one expert recalled a participant who "described incontinence as urge" (ME10), and extended to broader diagnostic uncertainty, where experts observed "[how] confused patients are about their own symptoms… a kind of collective thinking that helps them identify" (ME5). First-time episodes were described as particularly challenging, since "if a woman has experienced the first time UTI, she doesn't really know what to expect. If somebody had a second or third, she probably will react much quicker" (ME9). Overall, three experts stressed the importance of distinguishing first-time from recurrent UTI experiences, noting that recurrent patients tend to recognise patterns earlier and describe symptoms with greater precision, while first-time cases are marked by greater uncertainty (ME3, ME6, ME9).

Cultural explanations frequently contributed to misattributions. Patients often linked UTIs to cold exposure, reporting beliefs such as "when you are sitting on the cold place, that is this factor for developing UTI" (ME3) or "cystitis can come after sitting on a cold chair we often hear that from patients as well" (ME6). Although three of the interviewed clinicians dismissed these explanations as unscientific, they acknowledged how persistent and widespread such beliefs remain.

Experts also described ambiguous or unusual symptom expressions that blurred clinical categories. Examples included references to "the swollen, the swelling not often with UTIs" (ME5) or "swollen stomach not something I learned" (ME10), which were considered diagnostically unclear: "swollen stomach not clear if feeling

or physical examination" (ME10). Reliance on sensory cues could also mislead, as seen in comments about "urines that have a false smell studies show you get better without antibiotics" (ME6). Misattributions further extended to overlaps with other infections, especially mycosis, where "symptoms can overlap need lab work to distinguish" (ME6).

These examples illustrate how subjective framings, cultural beliefs, and imprecise terminology complicate diagnostic clarity. Even when harmless, such narratives can delay or obscure accurate medical assessment.

Symptom variability, specificity, and progression

Clinicians emphasised that UTIs do not follow a uniform pattern of symptoms but instead present wide variability. Burning during urination was described as the most common complaint: "most of the time it was a burning sensation when going to the toilet" (ME9). However, experts stressed that this is not universal: "Not everyone has the burning some people have different manifestations" (ME12).

Patients also expressed pain in diverse ways, referring to "punching pain, pulsing pain burning pain, stinging pain" (ME10), underscoring the importance of recognising qualitative differences rather than relying on generic descriptors.

Indicators of severity and progression were considered especially meaningful. Clinicians noted how certain patterns signal escalation, such as "radiation into the kidneys, back pain speaks for ascending infection" (ME9), or "vomiting probably when you have pyelonephritis not the same as cystitis" (ME3). Haematuria, or blood in the urine, was consistently identified as a red flag (ME6). Clinicians also distinguished clearly between "two kinds simple cystitis pyelonephritis very different disease" (ME12), highlighting the importance of differentiating lower from upper urinary tract infections.

Despite these distinctions, symptoms frequently overlapped with those of other intimate conditions. Vaginal infections, for example, were contrasted through discharge and odour (ME5), yet patients rarely recognised these cues as distinct. Experts also pointed out that variability extends to individual interpretation: "manifestation can be quite individual some interpreted it this way, others that way" (ME9). This variability reinforced the need for clinicians to assess combinations of symptoms and how they develop over time, rather than relying on isolated indicators.

The struggle for a shared language

Experts consistently identified communication as a central challenge in diagnosing UTIs. While some clinicians argued that most women "really know their symptoms" and that "there's very rarely problems in the communication" (ME6), others pointed

to substantial gaps between medical terminology and the language used by patients. As one expert observed, there is a "discrepancy between medical terms and terms [from people]" (ME4), and another described expressions such as "intimate infections" as "not precise scientifically you would have to be precise" (ME2). These misalignments create confusion not only during clinical encounters but also within research activities, where ensuring that "participants really understand what a symptom means" was considered essential (ME4).

The lack of a shared vocabulary extended across linguistic and cultural contexts. ME8 emphasised that word choice carries different connotations across languages: "what kind of words are used for what and what are the connotations and what are the connotations in the different languages?" (ME8). ME7 further questioned whether shared words reliably convey shared sensory experiences: "do you have a stinging sensation what I mean by that in terms of quality is the same as the patient? I just don't know that that's always the case we're very bad at finding a shared language" (ME7). These vocabulary gaps had concrete implications for diagnosis. Several clinicians stressed that accurate assessment depends on eliciting precise descriptions: "the doctor really needs to understand if the pain is like a burning sensation or more like an electric shock materials gave space to describe more precisely" (ME1). Other experts noted that verbal accounts alone may be insufficient, particularly in vulnerable groups such as elderly patients with dementia who "can't really talk" (ME12). Some clinicians used structured questioning, such as "do you have burning pain? do you have to wake up at night to urinate" (ME6), while others preferred open-ended conversation that allowed patients to elaborate freely (ME12). These practices are typical of UTI-specific clinical settings where both doctors and patients are familiar with the condition and its recurrent nature.

Overall, the interviews reveal that language is not a neutral medium but an active site where meaning can be lost, negotiated, or co-constructed. Without efforts to bridge linguistic and cultural gaps, diagnostic processes risk remaining ambiguous and inconsistent. Experts therefore stressed the importance of integrating precise yet accessible vocabularies, fostering shared understanding of symptom-related terms, and complementing verbal reports with contextual cues such as timelines, patterns, or material tools to improve diagnostic reliability.

7.3.2 The lived experience of the psycho-emotional and relational burden of UTIs

This section examines expert comments on workshop findings that extend beyond the physical symptoms of UTIs. Experts recognise that participants' accounts make visible anxiety, fear, shame, uncertainty, relational discomfort, and the everyday

burden of recurrence, even when these dimensions are not always treated as diagnostically central in clinical practice. Their reflections also show how the workshop supports a movement from confusion towards greater symptom literacy, as participants externalise sensations, compare experiences, and develop more precise ways of describing what happens in their bodies. Finally, experts connect this growing awareness to education, relational care, and antibiotic stewardship, suggesting that better communication can support patients as active partners in care while helping clinicians make more targeted decisions. Overall, this theme shows that the workshop findings are valuable because they reveal UTIs as lived, emotional, and relational experiences as well as biomedical events.

Anxiety, fear, and shame: the unspoken symptoms

Through my analysis, I found that experts consistently described psycho-emotional aspects as central to patient experience, even when these remain largely unacknowledged in clinical practice. Psychological and emotional aspects emerged as integral to how patients perceive and manage UTIs, even though they are often excluded from clinical frameworks. Four experts addressed anxiety or panic directly, and three of them framed it primarily as a psychological reaction or secondary impact of the infection rather than as a core biomedical symptom (ME2, ME3, ME5, ME6). They described how anxiety, fear, and shame shape patient experiences. ME5 remarked that “people don’t talk about the anxiety and the fear behind having infections enough” (ME5), while ME12 illustrated the sense of vulnerability through a metaphor: “there’s a sword hanging over me symptoms could start anytime” (ME12).

Emotions were also linked to recognition of early cues, as ME5 observed: “very early patients know even though there isn’t a pain something’s wrong” (ME5). However, shame could obstruct awareness, as in the case of a patient who “thought it was because she was having too much sex she didn’t know it was something that can occur” (ME10).

Four experts addressed anxiety, panic, or fear directly, and three of them framed these responses primarily as secondary effects of the infection rather than as core biomedical symptoms, while still recognising their importance in patients’ lived experience (ME2, ME3, ME5, ME6). ME6 described anxiety as “secondary to the infection”, and ME3 commented that such psychological reactions “will never be found in a book” yet still have “a huge impact”. Panic and incontinence were likewise acknowledged as psychological reactions (ME2). Despite this medical framing, many experts acknowledged that the emotional burden of UTIs remains underestimated in practice. Two experts explicitly stressed that recurrent UTIs can have a major impact on daily life and remain insufficiently recognised as such in medical settings (ME3,

ME5). Recurrent infections, often dismissed as minor, are for patients “a real big thing” (ME3), and the burden varies significantly across individuals (ME10).

The journey to literacy: from confusion to competence

Participants’ engagement in workshops revealed a transformative journey from uncertainty to informed self-recognition. The creative process of externalising symptoms provided the occasion to reflect and straight bodily awareness. As one expert observed, the setting itself “was functioning as an intervention I believe it also happened through the participants’ own awareness” (ME1). By expressing symptoms through materials and sharing them with others, participants deepened their understanding: “Reporting it to others and having to explain it through these materials it was possible to collect data” (ME1). Over time, this reflective practice led to “a more sophisticated elaboration to describe their symptoms more precisely” (ME1).

This evolution in self-knowledge directly supported clinical interactions. Participants began to “understand better what happens which is a good step also to explain it to the doctor” (ME10). Recognition and validation were crucial in this process, counteracting experiences of dismissal: “Very validating already these are women who often are told you don’t have anything” (ME12). Such acknowledgement fostered confidence and empowered individuals to take an active role in their care.

Initially, however, many participants lacked basic symptom literacy. Discomfort was frequently dismissed as insignificant: “This itching, this pain you don’t necessarily put it on something medical or disease” (ME2). For first-time patients, this uncertainty was particularly pronounced, especially in contexts like pregnancy, where “there is so much you don’t understand about your body symptoms of infection is new” (ME2).

Developing literacy required the ability to interpret bodily signals: “You need a sort of like basic knowledge to recognise symptoms some others are maybe just a normal and not normal condition, but something that you do not recognise as symptoms” (ME8). This learning process was relational and iterative. External aids, such as thermometers or self-monitoring devices, supported recognition (ME8), while peer exchanges and expert input played a central role: “Diagnosing knowledge is always relational” (ME8). Repeated exposure helped participants refine their descriptions and build timeline awareness, which experts described as diagnostically significant: “Some patients reported this timeline of the symptomatic one clue often that the person has recurrent infections” (ME10).

Recurrent episodes served as powerful teachers. Initial confusion gave way to rapid recognition: “If a woman has experienced the first time UTI, she doesn’t really know what to expect. If had a second or third, she probably will react much,

much quicker" (ME9). Repeated cycles of diagnosis and treatment reinforced experiential expertise: "Learning, diagnosing, treating, learning. Having it again after the second, third or fourth time, you're probably specific" (ME9). Accurate early diagnosis was crucial, enabling participants to build a reliable knowledge base for future management: "Doctor makes a proper diagnosis this happens two or three times, then it will most likely just be the right thing in the future" (ME9). Over time, some progressed toward semi-autonomous care, supported by immediate access to medication (ME9). Preventive practices, such as post-coital hygiene, were also adopted: "Cleanliness after sexual intercourse recommended to avoid UTIs and it works quite well" (ME10).

Altogether, these insights describe a progression from confusion to competence, where experiential learning, validation, and relational support converge to strengthen participants' ability to recognise, articulate, and manage their symptoms with increasing clarity and confidence.

Empowerment through education and relational care

Education emerged as a central driver of patient empowerment, enabling individuals to participate actively in their care while supporting responsible antibiotic use. Experts stressed that informed patients complement, rather than replace, clinical expertise: "the idea is not to cut the doctor out but rather enable the patient-citizen to support the doctor" (ME1). Through enhanced understanding, patients could communicate more effectively, allowing clinicians to "intervene with treatment in a more targeted and effective way" (ME1).

Antibiotic stewardship was a consistent objective across interviews. Improving awareness was seen as key to reducing unnecessary prescriptions: "Help decrease the antibiotic prescription clearly we need that" (ME3). Better comprehension of disease mechanisms altered patient expectations, reducing demands for antibiotics: "Improving and understanding about the disease has an effect on antibiotic use. Patient don't think, oh, I need an antibiotic" (ME4). Patients echoed this sentiment, recognising the value of reconsidering automatic requests for medication: "I shouldn't just ask for an antibiotic it could be something completely different" (ME9). For many clinicians, simple information-sharing proved transformative: "A lot of what I do is just informing, and it's actually hugely impactful. So it helps to save antibiotics" (ME12). Beyond information transfer, relational practices created the conditions necessary for this transformation to take place. Safe spaces for dialogue allowed patients to express uncertainties, seek clarification, and develop confidence: "provided space to share their feelings methods to talk about insecurities and feelings and clarify some doubts a space where you can ask your questions and a space

where you have time" (ME4). Narrative approaches were particularly effective in reinforcing individuality and trust: "The narrative approach is indispensable to build a relationship in which he feels safe. The biography is nothing else than the validation of the individuality of a patient" (ME11). Recognising patients as people, rather than cases, fostered engagement: "If you are interested in knowing who he is, beyond his illness, ah, another relationship is established" (ME11).

Such relational and educational practices are fundamental as they sustained awareness, encouraged responsible self-management, and positioned patients as informed partners in care, supporting both personal wellbeing and public health goals.

7.3.3 Facilitating meaning-making through narrative and physicalization

This section examines expert comments on how the workshop supports meaning-making through narrative, material expression, and data physicalization. Experts recognise that participants' accounts and artefacts help translate sensations that are often difficult to verbalise into more concrete, visible, and discussable forms. Their reflections highlight the value of metaphor, storytelling, and physical representation in expanding symptom vocabulary, supporting self-awareness, and creating shared points of reference between patients and clinicians. At the same time, experts raise concerns about how these expressive forms can be interpreted, standardised, and integrated into time-constrained clinical encounters. Some comments point to the risk that rich personal narratives may remain difficult to translate into actionable diagnostic information unless they are clearly contextualised and communicated in accessible ways. Overall, this theme shows that narrative and physicalization can mediate between embodied experience and clinical communication, while also requiring careful attention to clarity, usability, and clinical feasibility.

Materials as communicative tools: eliciting nuanced vocabularies

In examining how experts responded to the workshop artefacts, I identified a series of reflections on materials as communicative tools and on the role of metaphor in supporting shared understanding. Across the interviews, medical experts consistently described physical materials as powerful facilitators of communication, capable of eliciting richer and more precise accounts of symptoms. ME1 emphasised that the very act of explaining material choices produced meaningful insight: "even just to justify why they were putting a ball on top of a polystyrene triangle it was possible,

through the material that requires explanation, to collect data" (ME1).
Materials encouraged participants to extend their vocabularies, sometimes beyond medical terminology, since "the material greatly helped bring out or find new vocabularies, non-scientific vocabularies" (ME1). Three experts linked the workshop process to increased patient awareness or self-recognition, describing it as a setting that helped participants reflect on their bodies, identify symptoms, and articulate what they were experiencing more clearly (ME1, ME2, ME8). They highlighted how objects supported layered forms of expression that combined physical, emotional, and psychological dimensions. ME2 explained that patients often needed "different materials to express herself because it was different feelings and different they could not be presented by one material" (ME2). Artefacts frequently acquired symbolic meaning: upward shapes represented relief, while necklace-like forms suggested heaviness (ME2). Such combinations made abstract sensations tangible and helped participants articulate nuances that might remain inaccessible through words alone.

Sensory and affective qualities reinforced this expressivity. ME8 described how polystyrene's tactile and auditory properties resonated with embodied discomfort: "some people, really, get like a big feeling when you touch it or when you even like connect it thinking about how I recall the sensation of a UTI like this. It's just like this is discomfort" (ME8). These observations suggest that material properties can bridge internal sensations and communicable forms, allowing patients to externalise experiences that are otherwise difficult to express.

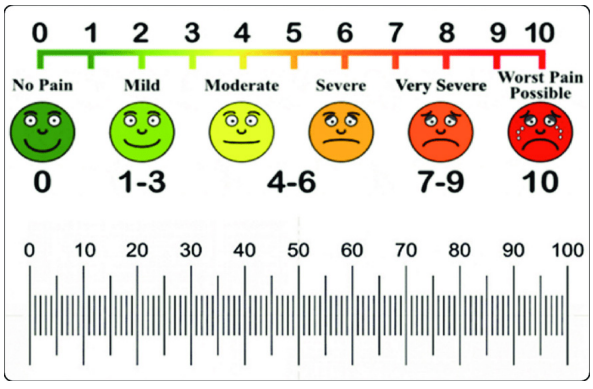
Materials also supported communication of both qualitative and quantitative aspects of symptoms. ME10 noted that participants conveyed intensity and magnitude through the size and number of elements they selected: "the different persons found how to qualify qualitatively the symptoms, but also quantitatively because the size of the forms or the numbers of the different forms they used had a meaning" (ME10). ME7 further observed that objects have the capacity to describe not only intensity, as in conventional visual analogue scales, but also quality: "if you had 9 objects, you could capture intensity, but you could also capture quality" (ME7).

This extended expressive capacity suggests that workshop materials functioned as communicative tools rather than simple modelling elements. As ME1 noted, they enabled "a more sophisticated elaboration to describe their symptoms more precisely" (ME1). Experts suggested that expanding the material palette, such as introducing metallic or temperature-sensitive elements, could enhance this potential. ME1, ME4, and ME7 explicitly pointed to a gap between medical vocabulary and the language patients use to describe symptoms, suggesting that symptom interpretation depends in part on creating more accessible and shared terms. In this direction, four experts recognised that the use of materials, metaphors, or physical prompts could support more precise or more layered descriptions of symptoms than standard verbal

reporting alone (ME1, ME2, ME7, ME9).
Despite these strengths, experts raised concerns about subjectivity and interpretation. ME8 emphasised that "the use of materials is very subjective what happens in the workshop where people then discuss these very subjective interpretations of their sensations" (ME8), highlighting the need for facilitation that mediates divergent readings. ME10 warned of "interpretation bias" when objects lack contextual explanation: "if you do not have this person that explains you what exactly it means then you have the risk of interpretation bias" (ME10). Their surprise at fur being used to express fever underscored the risk of intuitive mismatch: "fur is for me something smooth, comfortable not very intuitive to use something comfortable to qualify something disagreeable, like fever" (ME10).

Some experts questioned whether materials were always necessary. ME4 acknowledged the value of the discussion space they created but doubted their indispensability: "I could imagine that's good to have a room to discuss such questions and feelings but I'm not sure if it's needed that work with material" (ME4). Nonetheless, several experts contrasted material-based communication favourably with conventional scales, pointing out that objects support more nuanced expression than purely numeric or verbal measures (Figure 7.1–7.3).

Overall, these expert insights portray materials as communicative tools that broaden expressive possibilities and help participants articulate embodied experiences with greater nuance. At the same time, they underscore the need for contextual explanation and critical facilitation to mitigate subjective interpretation. Materials enrich communication by enabling non-scientific vocabularies, sensory associations, and multimodal representation, ultimately expanding the repertoire available to patients for describing intimate health experiences.



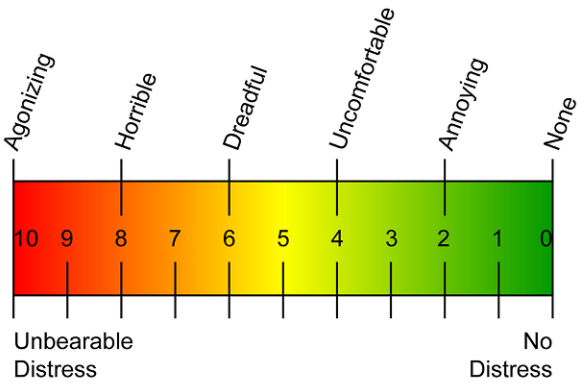


Figure 7.1 and 7.2: the images represent two scales adopted by doctors during consultations to ask patients about the level of their pain (images provided by ME7 of during the interview).

Task _____

Date _____ Start _____ End _____

SOCRATES[1][2]

Letter	Aspect	Example Questions
S	Site	Where is the pain? Or the maximal site of the pain.
O	Onset	When did the pain start, and was it sudden or gradual? Include also whether it is progressive or regressive.
C	Character	What is the pain like? An ache? Stabbing?
R	Radiation	Does the pain radiate anywhere?
A	Associations	Any other signs or symptoms associated with the pain?
T	Time course	Does the pain follow any pattern?
E	Exacerbating / relieving factors	Does anything change the pain?
S	Severity	How bad is the pain?

Figure 7.3: the image represents the SOCRATES scale of pain, which is another tool used to investigate pain. Screenshot taken from the Wikipedia page on the SOCRATES scale.

Metaphors and analogies to understanding

Metaphors and analogies emerge as indispensable tools for articulating sensations that defy straightforward description. ME5 described how metaphors make subjective pain intelligible: “In the case of urinary tract infections, it will often be urinating needles like you’re feeling. And so these are things that you give them examples just because it is hard to describe it. It also in a way that will make medical professionals understand” (ME5). For men with prostate infections, analogies helped overcome discomfort and inexperience: “does it feel like a hot potato in your pelvis? oh yeah, kind of it just helps them” (ME5).

Patients themselves generated potent imagery. ME12 recounted how one woman described “an elephant sitting on her bladder a lot of pressure, this sense of this heaviness” (ME12), while a child compared their symptoms to “the moment before sneezing” (ME12). Metaphors also captured the emotional weight of illness, as with the “sword hanging over me” to describe fear of recurrence (ME12).

These figurative expressions provide common ground between subjective experience and medical interpretation. They translate sensations into recognisable referents, bridging the gap between bodily feeling and shared understanding.

Collective sense-making and validation in peer dialogue

The workshop provided an opportunity for collective reflection, where participants compared and refined their descriptions through shared dialogue. ME5 noted how such exchanges enabled patients to clarify and own their experiences: “how

confused patients are about their own symptoms it's a kind of collective thinking that helps them identify what the symptoms are exactly. And to put words on them better, you know" (ME5). This dynamic validates individual sensations while offering shared reference points. As ME5 explained, "it's very helpful to have somebody say something and then you can say if yes or no, that is the same it's easier especially like to describe it in a way that people will understand it" (ME5). Yet, collective processes also introduced risks. ME5 warned that patients might inadvertently adopt each other's terms, even when clinically inappropriate: "two people are talking about pain, but it's not pain in the same place and it's not the same type of pain" (ME5).

7.3.4 Methodological reflections on potential, pitfalls, and pathways to practice

This section examines expert comments on the methodological potential and practical limitations of the workshop approach. Experts recognise that the method can support reflection, patient awareness, richer symptom communication, and dialogue between experiential and clinical knowledge. At the same time, they raise concerns about feasibility, including the time required, the need for facilitation, the risk of overinterpretation, and the difficulty of integrating material and narrative outputs into existing clinical workflows. Their reflections suggest that the approach may be most useful as a preparatory, educational, or complementary tool rather than as a direct diagnostic instrument. Overall, this theme shows that the workshop has potential to enrich healthcare communication, while its translation into practice requires careful adaptation to clinical contexts, professional roles, and patient needs.

Interpretation, limits, and risks

In the fourth theme, I analyse expert reflections on the methodological potential and limitations of the approach, including concerns about interpretation and clinical applicability. While experts acknowledged the expressive value of materials, they repeatedly cautioned against the risks of misinterpretation. Artefacts were seen as highly dependent on participants' explanations, functioning less as stand-alone representations and more as prompts that required verbal contextualisation. As ME1 emphasised, "something that absolutely needed an explanation, otherwise it could not be understood" (ME1), and ME10 warned that "you really need the presentation of the one that did the artefact because if you do not have it you are going to misinterpret you give free room to interpretation, then you have the risk of interpretation bias." (ME10). Concerns also emerged regarding clinical translation. ME5 questioned whether metaphorical objects could be reliably mapped onto

medical categories: “if a patient’s like oh, it feels it reminds me very much of this and they take out a wooden sphere then like the doctors may not know what [it] that means” (ME5). ME8 highlighted both subjectivity and intersubjectivity in this interpretive process: “how you connect and associate with the sensations of your symptoms is very subjective and also then the intersubjectivity in between, like what happens in the workshop where people then discuss these very subjective interpretations” (ME8). Some experts doubted whether the approach aligned with clinical priorities or helped address unmet needs. ME11 stated, “the character of the pain has not helped me. So, since your approach is the materialisation of this character, I would not necessarily have chosen that direction to respond to an unmet need.” (ME11). ME6 and ME8 also expressed reservations about its necessity and clarity. However, several experts recognised value beyond clinical diagnosis. ME2 pointed to the method’s potential in public engagement: “the output, at least in forms of the material and the pictures of what the participant did could be very funny to use for a discussion or campaign posters or postcards” (ME2). ME10 linked the interpretive nature of artefact reading to familiar clinical practices, noting that “it’s a challenge but it’s more or less the same in clinical life when you see the body language it’s also interpretation you need both.” (ME10).

Collectively, these reflections show that while material artefacts can deepen expression and enrich communication, they must be carefully contextualised, accompanied by explanation, and aligned with intended use to minimise misinterpretation and maximise their value.

Clinical applicability and transferability

Expert opinions diverged on whether material-based methods could be integrated into routine clinical practice. Four experts raised concerns from different angles, all nonetheless converging on the relevance of materials as a communicative resource. ME1 raised the central issue of transferability, asking, “I asked myself how then to transfer somewhere all that you have learned regarding the use of materials” (ME1). They imagined possible adaptations, such as compact kits or labelled tools, but also acknowledged the difficulty of translation into clinical settings: “maybe it could be moved into the doctor’s office, where the doctor has a tool in hand, whether your labels or a material” (ME1).

Other experts were more sceptical about feasibility. ME5 pointed to structural constraints that limit expressive methods in clinical encounters, noting that “consultations usually last maximum 15 minutes patients are not asked to describe it they’ll be asked to answer questions” (ME5). ME9 similarly regarded the method as primarily reflective rather than clinically actionable: “I wouldn’t say this is something

that you can really apply maybe in a doctor's office or in a pharmacy It's more like again reflecting the individual sensation" (ME9).

Despite these reservations, several experts recognised potential value in specific contexts. ME12 suggested integrating textures into anatomical models to support communication in chronic or recurrent conditions: "it might be useful to create a material using your different textures in the shape of a bladder so that they can say, yeah, this is how my bladder feels like" (ME12). Such applications indicate that while direct implementation in general practice is unlikely, adapted material-based approaches may serve as useful tools in targeted areas such as chronic pain management, patient education, or awareness campaigns.

Representativeness and generalisability

Experts reflected critically on the representativeness of workshop participants, raising concerns about inclusivity and generalisability. ME1 explicitly questioned: "I always ask myself the question, who are we leaving out in the research?", pointing to the methodological challenge of ensuring findings do not disproportionately reflect certain groups.

From a clinical perspective, ME2 noted discrepancies between participants and typical patient populations: "My worries would be as a clinician I don't recognise those I know from the clinic or from the literature necessarily in your participants mostly women around pregnancy elderly women" (ME2). ME6 similarly emphasised that most participants seemed to be first-time patients, contrasting with recurrent or complex cases often encountered in practice: "Usually it's people who don't have regular infections maybe who experience their first UTIs and elderly also have" (ME6).

Three experts expressed concern that broadening the focus beyond UTIs risked reducing diagnostic precision, especially when vulvovaginal infections or other conditions were discussed together with UTIs (ME2, ME3, ME5). The same experts questioned the precision of the term "intimate infection", suggesting that it grouped together clinically different conditions and could create ambiguity in the interpretation of symptoms.

The value for patients and future research potential

Experts consistently highlighted the value of material-based methods for patients, particularly in providing validation and encouraging reflection. The simple act of dedicating time to explore symptoms through tangible means was described as profoundly positive: "just the act of taking the time of thinking about this with them, of creating, you know, making available these materials, it's very validating already these are women who often are told you don't have anything" (ME12).

Transforming often-dismissed sensations into concrete, shareable artefacts legitimised patient experiences and offers a basis for dialogue. The participatory setting also creates a safe and constructive environment for discussion. As one expert noted, it "provided space to share their feelings to talk about insecurities and feelings and symptoms and I read also that the participant like that there's an expert, so they could clarify some doubts" (ME4). Clinician presence helped to ensure that discussions remained accurate and supportive, "to actually clarify and add medical insights in the discussion" (ME3). Beyond validation, the process actively strengthened patients' ability to articulate their experiences: "maybe if patients think about it more as well to be able to say no, it's this or not this" (ME5). Engagement extended beyond cognitive benefits, fostering positive emotional involvement: "they really like it I could take these things out and they can open them" (ME12).

Alongside these immediate benefits, experts recognised the broader research and diagnostic potential of material-based methods (Figure 7.4). ME4 identified the approach as "a really new method I could imagine that would be a good method also for children to learn about to describe symptoms" (ME4), while ME9 characterised it as "very special women try to conceptualise and to symbolise their symptoms which is I think quite a creative way to do it" (ME9). Some experts saw opportunities for systematic investigation of symptom expression, where recurring patterns in materials might indicate meaningful clusters: "if you basically find that certain groups of signs or symptoms ever tend to result in them using similar images or textures then that would be really something very interesting as an observation" (ME7). This would require empirical validation to establish clinical relevance: "if you can really validate that say you know this is eighty percent correct whenever people combine this and this then you could really have a sort of a set for these situations" (ME9).

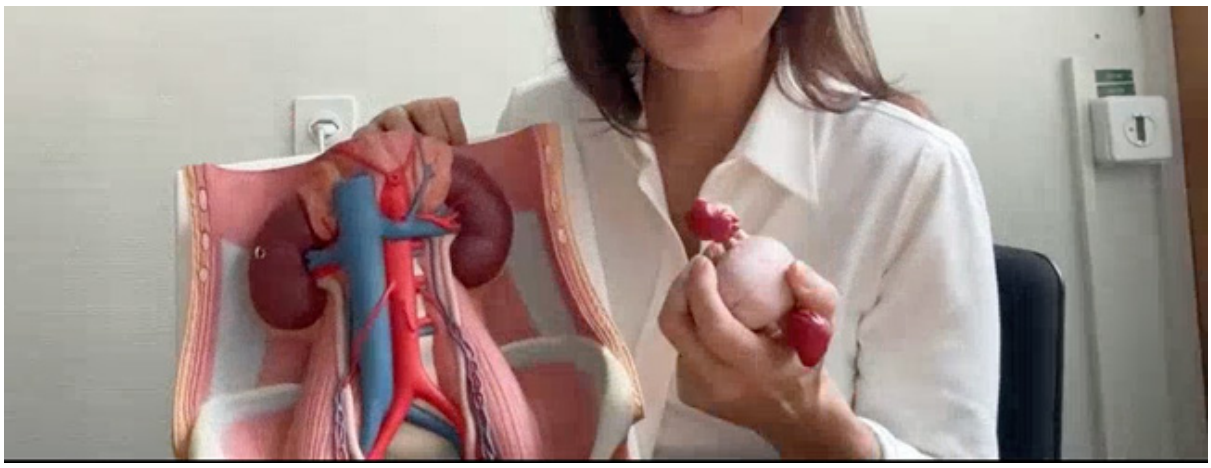


Figure 7.4: screenshot from the interview's recording. The expert displays the model that she uses to engage UTI patients at the first appointment to explain causes and effects of the disease on their bodies.

7.4 Methodological limitations of the interviews with medical experts

The expert sample, primarily drawn from my professional network and the SPEARHEAD consortium, carries a risk of partiality and reduces exposure to more critical, external perspectives. Feedback from the panel further indicated that the workshop participants, often first-time or particularly patients, do not fully represent the complexity of recurrent UTI populations. This reflects both the methodological evolution of the study, which expanded from an initial narrow focus on UTIs to include women's intimate infections, and the inherent challenges of recruiting participants for sensitive topics.

The dialogue with experts was based on a curated written document presenting selected findings from the workshops. This format supported focused engagement with the material and helped maintain consistency across interviews, yet it also shaped the form of interpretation available to the experts. The selected excerpts provided a mediated account of the workshop outcomes rather than direct immersion in the full multimodal dataset. The artefacts, gestures, interactions, and practical dynamics of the sessions were therefore encountered mainly through description rather than through direct experience.

Furthermore, the structure of short, remote interviews constrained deep engagement with the artefacts themselves, and the physical and practical nature of the workshops proved difficult to capture in written form alone. Future developments of this line of enquiry would benefit from formats in which experts can interact directly with the artefacts and with the workshop process itself, allowing a closer dialogue between clinical interpretation, material expression, and participatory practice. Considering the participatory environment of the methodology, a promising next step would be to involve both patients and medical experts not only in data collection and assessment but also in the interpretation of results, fostering a more collaborative and integrated evaluative process.

7.5 Conclusions from medical experts' perspectives on the findings

The dialogue with medical experts helps situate the workshop findings in relation to clinical knowledge while also clarifying their methodological relevance. Across the interviews, several shared positions emerged. At least four experts recognised the variability of symptom expression, and the difficulty patients may have in identifying

or differentiating UTIs from other conditions, especially when symptoms overlap with other intimate or lower genital infections (ME2, ME3, ME5, ME9). Three experts also stressed the importance of distinguishing recurrent from first-time experiences, noting that recurrent patients tend to recognise patterns earlier and describe symptoms with greater precision (ME3, ME6, ME9).

The experts reaffirmed the central role of laboratory testing and clinical questioning in diagnosis, while also recognising that richer patient descriptions can add relevant nuance to how symptoms are understood and communicated. In this sense, the workshop findings were seen as helpful in bringing forward dimensions of symptom experience that often remain less visible within biomedical language alone, including differences in intensity, quality, progression, and everyday impact. At least four experts recognised that materials, metaphors, or physical prompts could support more precise or more layered descriptions of symptoms than standard verbal reporting alone (ME1, ME2, ME7, ME9).

The interviews also highlighted differences in how emotional and relational aspects of UTIs are framed. Four experts addressed anxiety, panic, or fear directly, and three of them described these mainly as secondary effects of the infection rather than as core biomedical symptoms, while still acknowledging their relevance to patients' lived experience (ME2, ME3, ME5, ME6). This distinction is significant because it shows how the workshop findings extend beyond a narrow symptom list and bring attention to the wider consequences of recurrent infection for daily life, anticipation, and self-management.

A further contribution of the interviews lies in the way they clarified the importance of communication and awareness. Several experts described uncertainty in symptom recognition as a recurring issue and recognised that participants do not always immediately connect bodily sensations to a possible UTI. In this regard, the workshop findings show how patients compare sensations, build familiarity with recurring patterns, and develop a more articulated language for describing what is happening in their bodies. Three experts linked this kind of process to increased patient awareness or self-recognition, describing the activity as a setting that could help participants identify symptoms and reflect more clearly on their experience (ME1, ME2, ME8).

On the other hand, the interviews surfaced relevant tensions. Three experts raised concerns about widening the focus beyond UTIs, noting that combining UTIs with other intimate or vulvovaginal conditions risks reducing clinical precision and blurring symptom interpretation (ME2, ME3, ME5). Related to this, at least three experts considered the term "intimate infection" too broad or imprecise for clinical use because it groups together conditions that differ in cause, treatment, and symptom profile (ME2, ME3, ME5). These reflections are especially useful for

the thesis because they help define more clearly the scope within which the topical findings can contribute to healthcare understanding.

Taken together, these perspectives strengthen the two main contributions of the thesis. They show that the workshops generated health-related insights capable of enriching how UTIs are understood through lived experience, and they show that participatory data physicalization can support forms of symptom articulation and communication that are meaningful in relation to healthcare practice. The interviews also suggest a clearer direction for refinement, particularly through a stronger focus on recurrent UTIs and through greater attention to the quality, intensity, and progression of symptoms over time.

The next chapter builds on these conclusions by returning to the broader theoretical and conceptual framework of the thesis. It situates the empirical findings in relation to situated knowledge, participatory design, and data as a relational and interpretive practice, and reflects on how physical variables and material engagement contribute to the communication of embodied experience within and beyond clinical contexts.

8. DISCUSSION. FROM EMBODIED EXPERIENCE TO COLLECTIVE KNOWLEDGE

This chapter brings together the theoretical, methodological, and empirical developments of the thesis to clarify its main contribution. Chapter 2 introduced physical variables through existing classifications in data physicalization, where material and perceptual qualities are generally understood as resources for encoding information into physical form. Chapter 3 then defined physical variables and Data-Probes as methodological components of the Shape Your Symptoms workshop. Through the workshop analysis and expert feedback, these components are now discussed as contributions to participatory data physicalization, showing how embodied health experiences can be articulated, interpreted, and communicated through material enquiry.

The thesis situates this contribution within the difficulty of communicating women's experiences of UTIs. Symptoms such as burning, pressure, discomfort, urgency, and pain are felt through the body, shaped by context, and often challenging to describe with precision. Biomedical indicators and standard descriptors remain essential to diagnosis and treatment, while lived experience adds affective, situated, and relational dimensions that can enrich healthcare communication.

The workshop results show how physical variables supported participants in recognising sensations, selecting material associations, explaining choices, and comparing experiences with others. Texture, shape, weight, size, density, sharpness, resistance, and related qualities extended data physicalization from the representation of information towards the generation and interpretation of embodied data. Data-Probes provided the material means for this process. Through touch, gesture, arrangement, and assembly, participants explored physical variables and shaped artefacts that made symptoms tangible, communicable, and open to shared interpretation.

Physical variables and Data-Probes therefore work together as a methodological contribution to participatory data physicalization as a form of enquiry. Physical variables provide the interpretive structure through which embodied sensations are related to material qualities. Data-Probes constitute the practical system through which these relations are explored, shaped, and discussed. Together, they support a process in which personal sensations become comparable while preserving their situated and individual specificity.

The discussion first examines physical variables as interpretive and generative resources within participatory data physicalization. It then considers Data-Probes as the material system through which physical variables become usable in practice. Participation is discussed as the social condition that enables individual experiences to become collective knowledge, followed by material engagement as the embodied process through which making, gesture, material specificity, unfamiliarity, metaphor, and allegory shape interpretation. The chapter then turns to measurement, validity, and clinical knowledge before preparing the transition to the Physical-Variable Apparatus.

8.1 Reframing physical variables in participatory data physicalization

Physical variables operate in this thesis as an interpretive infrastructure for participatory data physicalization. They connect bodily sensation, material exploration, group discussion, artefact-making, and analysis. Their contribution lies in extending physical variables beyond encoding and positioning them as resources for generating embodied data.

In the Shape Your Symptoms workshops, participants used physical variables to recognise sensations, associate them with material qualities, explain their choices, and compare their interpretations with others. Qualities such as shape, texture, weight, density, resistance, permeability, timing, instability, and blurriness supported the articulation of symptoms that are often intimate, layered, and difficult to describe through words alone. Through these variables, pain, burning, discomfort, pressure, urgency, incontinence, cloudy urine, foul smell, and anxiety became perceptible and communicable without being reduced to fixed categories.

This reframing directly addresses the second and third research questions, which respectively ask how material engagement supports the communication of embodied experience and how physical variables transform individual interpretations into collective knowledge. In relation to the second question, the workshops show that material engagement gives participants tangible resources through which to

express sensations that are difficult to verbalise. In relation to the third question, they show that physical variables create shared material references that make experiences comparable while preserving their situated and personal specificity. Physical variables therefore support enquiry as well as representation, generating the conditions through which embodied health experiences become articulated, shared, and collectively interpreted.

Drawing on Barad's agential realism, this role can be understood as onto-epistemological because physical variables participate in the material-discursive arrangements through which symptoms become knowable (Barad, 2007). In the workshops, bodies, materials, labels, gestures, concepts, and conversations worked together to shape what participants noticed, how they selected components, and how their interpretations became available to others.

The following subsections develop this contribution by showing how physical variables operate across the research process. They extend mapping beyond the encoding of predefined data, supporting the interpretation of embodied experience as data in formation. At the same time, they structure the methodological movement from symptom discussion to association, artefact-making, presentation, and analysis. Through this process, they create shared references that allow individual interpretations to become comparable and open to collective discussion.

8.1.1 From encoding to interpretation

As discussed in Chapter 2, data physicalization commonly relies on mapping processes in which data is associated with physical form. Shape, size, position, and orientation support spatial and visual mappings that make values, categories, and relations perceptible (MacEachren, 1995). Texture, weight, resistance, density, and other material qualities expand this association through touch and embodied perception, showing that data physicalization operates through multisensory physical properties rather than visual form alone (Dragicevic et al., 2021). Hornecker and colleagues further clarify that these properties can function explicitly, when they encode information directly, implicitly, when they shape perception without carrying a defined value, and consequentially, when meaning emerges through material production and use (Hornecker et al., 2023).

In this thesis, mapping extends from representing predefined data to interpreting embodied experience. During the workshops, participants associated symptoms with physical variables while clarifying what those symptoms meant for them. The relation between symptom and variable therefore became part of the interpretive process. Participants used material qualities to define the character of a sensation, distinguish between related symptoms, and communicate bodily states that were not defined yet.

Shape supported distinctions between different qualities of pain and discomfort. Pain during urination was associated with angular and sharp qualities, described as “angles” and “sharp or tuned” (P18, WS3). A more manageable discomfort was instead expressed through a sphere, which “doesn’t have so many edges” and still felt “feasible to manage” (P5, WS2). Through these choices, participants used shape to separate acute pain from discomfort that remained present but bearable.

Fuzziness and blurriness supported the description of sensations that were present but difficult to identify. One participant described this unclear bodily state as “you feel something but you don’t understand what is that” (P18, WS3). The variable made ambiguity part of the symptom description, allowing uncertainty to be expressed as a quality of experience rather than treated as a lack of explanation.

Permeability supported the interpretation of incontinence through degrees of passage and restriction. One participant explained this relation through the image of a net, saying, “If you have a net, drops fall; if you have a narrower net, fewer drops fall” (P5, WS1). The association between permeability and incontinence made bodily control expressible as a relation between openness, containment, and leakage.

Similar processes appeared in the later workshops on other health conditions. Neck pain was described as “something that would be moving” and as a condition that “has its spikes” (G7, WS5). Shoulder pain was represented through a damaged component because “this is what I feel my shoulder is coming in stages” (P25, WS5). These examples show how physical variables supported the expression of movement, recurrence, progression, and instability.

Through these associations, symptom labels became richer in meaning. Pain, discomfort, burning, urgency, and incontinence were articulated through sharpness, roundness, blurriness, permeability, movement, damage, and instability. Physical variables therefore expand mapping from the encoding of known information towards the interpretation of embodied experience as emerging data.

8.1.2 Physical variables as methodological instruments for knowledge generation

Physical variables also function as methodological instruments because they organise the workshop process. They guide the activity from symptom discussion to material exploration, from material exploration to symptom–variable association, and from association to artefact-making and presentation. Their role is practical because they structure the sequence of the workshop, and conceptual because they turn symptoms into qualities that can be explored, explained, and analysed.

The use of labels, group discussion, artefact-making, and presentation encouraged participants to attend to qualities such as roughness, sharpness,

heaviness, softness, instability, and permeability. These qualities created a practical vocabulary for working with symptoms that were intimate, layered, and difficult to describe through words alone. Rather than asking participants to define symptoms only verbally, the workshop invited them to consider how a sensation felt, which material qualities could express it, and how those choices could be explained to others.

The association phase was central to this process. It created a structured moment of interpretation in which participants compared meanings, adjusted terms, and clarified relations between symptoms and physical qualities before moving into artefact-making. In this context, physical-variable labels acted as prompts for thinking and discussion rather than as fixed categories. They slowed down symptom description and opened space for participants to reflect on the sensory, emotional, and relational qualities of their experience.

This methodological structure also supported the analysis. Because participants worked through identifiable variables, their artefacts could be interpreted in relation to the discussions that informed them during the workshop. The variables made it possible to trace how embodied sensations moved across formats: from spoken accounts, to shared associations, to material artefacts, and then back into verbal explanation. Physical variables therefore position data physicalization as a method of enquiry, supporting the production of embodied data through participation, material engagement, and discussion.

This structure also creates the conditions for collective knowledge, because the same variables become shared references through which participants can compare and discuss their interpretations.

8.1.3 From situated interpretation to collective knowledge

In the direction outlined above, physical variables supported the movement from situated interpretation to collective knowledge by creating shared references for comparison. Participants began from personal sensations, but related them to qualities that others could see, touch, question, and interpret. This made embodied experience available to the group without forcing it into a single description.

A symptom such as pain was associated with sharpness, roughness, density, pressure, or heaviness, depending on how it was felt and by who. These differences expanded collective interpretation because they showed how the same symptom could be experienced from different embodied positions. Recurring associations made patterns perceptible across participants, while variations showed how symptoms changed across bodies, contexts, and personal histories. This was especially important for symptoms such as discomfort, pressure, urgency, and pain, which often

overlapped, shifted, or remained difficult to locate.

Collective knowledge therefore emerged through the relation between resonance and situated difference. Participants could recognise similarities across experiences, while also preserving the specific ways in which each person understood and communicated their symptoms. The value of physical variables lies in the balance between providing enough structure to support comparison, and remaining open enough to accommodate different interpretations.

This process aligns with feminist epistemologies that value partial, embodied, and contextual perspectives as sources of knowledge (Haraway, 1988). Barad's concepts of intra-action and diffraction further clarify how meaning emerged relationally (2007). Physical variables gained significance through the interaction among body, material, gesture, label, explanation, and group response. Based on this, difference became productive because it revealed how experiences mattered in distinct but comparable ways.

This also contributes to debates on vocabulary in data physicalization, mentioned in the literature review (Chapter 2). A clearer vocabulary of physical variables can support analysis, comparison, methodological rigour, and communication across studies (Hornecker et al., 2023). At the same time, openness allows physicalization to remain responsive to multiple material and interpretive possibilities (Offenhuber, 2024). The findings of this thesis support a context-dependent vocabulary that emerges through participation and discussion. Physical variables provide a shared structure for comparison, while their meanings remain responsive to bodily experience, material encounter, memory, metaphor, affect, and situated interpretation.

This point directly addresses the third research question, which asks how physical variables transform individual interpretations of embodied experience into collective knowledge. In the workshops, physical variables made personal sensations materially available for discussion and comparison, allowing embodied data to become collective while preserving the specificity of lived experience.

8.2 Data-Probes as a methodological contribution

While physical variables provide the interpretive structure of the method, Data-Probes make this structure usable through a material kit, a making process, and analysable artefacts. They translate symptom–variable associations into components that participants can touch, compare, assemble, modify, and explain.

Data-Probes are developed in this thesis from the intersection of cultural probes and data physicalization. Cultural probes support open, situated, and reflective

responses through designed artefacts (Gaver et al., 1999). Data physicalization supports the communication and interpretation of information through physical form (Jansen et al., 2015). In this research, these two traditions are brought together to support embodied health enquiry. In the workshops, the probes elicited personal interpretation while also giving that interpretation material form.

Their contribution lies in operationalising physical variables within a participatory process. The variables define the qualities through which symptoms can be interpreted, while Data-Probes provide the components through which those qualities can be enacted. The kit therefore transforms physical variables from an abstract reference into a practical tool for engaging with symptoms.

This role responds to the second research question, which asks how material engagement supports the interpretation and communication of intimate and embodied experiences. Data-Probes addressed this question by offering material components through which participants could handle, assemble, and explain sensations that were difficult to express verbally. They also support the third research question, which asks how physical variables transform individual interpretations of embodied experience into collective knowledge. By producing artefacts that could be compared and discussed, Data-Probes made personal interpretations available to others while preserving their situated specificity. They therefore enact the thesis' wider argument that embodied data can be generated through participation, material engagement, and situated interpretation.

8.2.1 From physical variables to material enquiry

The Data-Probes kit turns the vocabulary of physical variables into a material activity. After discussing symptoms and associating them with physical variables, participants selected and assembled components that expressed those associations through form, material, size, weight, texture, position, and connection. The kit therefore creates a passage from bodily sensation to material enquiry, allowing participants to investigate symptoms through handling and making.

This passage depends on a balance between openness and structure. The components give participants enough freedom to create personal artefacts, while their repeated forms and materials support comparison across participants and sessions. Cubes, spheres, prisms, and connectors establish a shared material vocabulary, while keeping symptom representation open to situated interpretation. Participants could therefore work in different ways while still using a limited and recognisable set of components.

This modular structure supports both expression and analysis. It reflects constructive approaches to physicalization, where meaning emerges through

selecting, arranging, grouping, and assembling physical units (Huron et al., 2014). In the workshops, participants used this modularity to test relations between sensations, variables, and material qualities while making. The simplicity of the components also supported accessibility. Basic shapes and familiar materials allowed participants to focus on interpretation rather than technical skill. This accessibility reflects the participatory orientation of the method, where participants contribute as experts of their own embodied experience rather than as trained makers or designers. In this sense, the components did not simply represent prior decisions, but helped participants explore and refine how symptoms could be expressed.

Alongside the shapes, connectors proved especially important because they allowed participants to express relations among symptoms. Pain, burning, pressure, urgency, discomfort, uncertainty, and emotional tension could be positioned together, layered, extended, or made unstable. This relational capacity reflects how participants perceived UTI symptoms, which were rarely described as isolated sensations and more often as combinations that changed over time, interacted with one another, or accumulated in daily life.

Data-Probes therefore move the method from conceptual association to material enquiry. Physical variables structure interpretation, while Data-Probes make that structure tangible, workable, and shareable. The artefacts produced through this process are not only final workshop outputs, but traces of how participants moved from symptom experience to material expression, as explained in the next section.

8.2.2 Artefacts as traces for expression, analysis, and communication

The artefacts produced with Data-Probes are not only the final outputs of the workshop activity. They are traces of the interpretive process through which participants moved from symptom experience, to physical-variable association, to material selection, and finally to verbal explanation. Their value lies in the relations they preserve among symptoms, variables, components, gestures, and narratives.

As expressive devices, the artefacts gave participants a way to communicate sensations that were difficult to describe through words alone. A participant could point to a heavy component, an unstable arrangement, a sharp edge, or a layered configuration while explaining pain, discomfort, anxiety, urgency, or loss of control. The artefact created an external focus for speaking about intimate experience, allowing participants to discuss sensitive symptoms through material form while keeping the account grounded in their own interpretation.

As analytical devices, the artefacts make the workshop process traceable.

Each object can be examined in relation to the symptom labels selected by participants, the physical variables associated with those symptoms, the material components used, and the verbal explanations given during presentation. This makes each artefact a process-based record of interpretation rather than an isolated object. Its analysis therefore requires attention to multiple formats, including labels, images, transcripts, material choices, and participant accounts.

This process-oriented value connects Data-Probes to broader work in participatory and reflective physicalization, where meaning emerges through making, handling, and discussion, as well as through the finished artefact (Lockton et al., 2020; Freeman et al., 2023). In this thesis, the artefacts carry evidence of how participants interpreted their symptoms during the activity. They show which material qualities participants selected, how they combined them, and how those combinations were explained to others.

Data-Probes also mediated communication among participants. The artefacts allowed others to see, ask about, recognise, or compare an experience, supporting the movement from personal expression to shared understanding. This was particularly relevant for UTI symptoms, where embarrassment, uncertainty, and difficulty in describing sensations can limit communication. By creating a shared point of reference, the artefacts allowed private sensations to enter collective discussion without requiring participants to rely only on verbal description.

This communicative role also extends towards clinical interpretation. The medical experts' feedback in Chapter 5 shows that material and narrative expressions can reveal dimensions of symptoms that may remain implicit in consultation, including uncertainty, emotional burden, intensity, rhythm, and relations among symptoms. Data-Probes therefore offer complementary support for health communication. They enrich dialogue by making lived experience more explicit, situated, and discussable alongside clinical indicators.

Data-Probes contribute methodologically by connecting elicitation, making, communication, and analysis within one process. They allow embodied data to be generated through material engagement and then examined through the traces of that engagement. In doing so, they extend participatory data physicalization as a method for working with experiences that are intimate, situated, and difficult to articulate through conventional forms of data collection.

Further insights also emerged from the use of Data-Probes, particularly in relation to the broader role of materials in supporting discussion, interpretation, and collective meaning-making. For this reason, these insights are addressed separately in the following section.

8.3 Material engagement in knowledge generation

The following section builds on the components discussed above by examining how they operated through material engagement. The roles of physical variables and Data-Probes became visible through the ways participants handled, interpreted, and discussed materials. This section therefore focuses on specific aspects that emerged from this process: the gestures participants used while working with components, the role of unfamiliar materials in encouraging exploration, and the use of metaphor to connect bodily sensations with material form. Together, these aspects clarify how the method moved from its structural components to the practical conditions through which symptoms became tangible, discussable, and open to shared interpretation.

8.3.1 Gestures and making as ways of thinking

Gestures actively contributed to shaping interpretation during the making process. Pressing, stacking, connecting, balancing, rotating, repositioning, and altering components allowed participants to examine sensations through action. These movements supported reflection because the artefact developed in response to what participants felt in the materials and remembered from their bodies. Schön's account of a "conversation with materials" helps clarify this process, as reflection develops through the feedback that materials provide during manipulation (1983). In the workshops, participants responded to how components resisted, balanced, connected, changed, or failed to hold a stable relation.

P9's artefact illustrates how gesture could give form to emotional and anticipatory aspects of symptom experience. She described the wish to create "something asymmetric" and "not safe or stable" to express feeling "anxious" and "scared every time you go to the bathroom" (P9, WS2). The gesture of arranging instability gave form to the anticipatory fear attached to urination. Gestures further enriched this expressive vocabulary by extending interpretation beyond the visual and tactile qualities of the components. Participants rubbed polystyrene to create sound, compressed foam to simulate absorption, or mimed burning to express the classic internal burning sensation associated with UTIs (P2, WS1). These actions show that meaning did not emerge only from the selected materials, but also from the bodily operations performed with and around them. Through gesture, participants activated sound, pressure, movement, and imagined transformation as additional registers for expressing sensations that were difficult to materialise directly.

Comparable findings emerged from the extension of the workshop protocol conducted at the EKSIG conference on sonification, described in Chapter 7, where gestures again shaped how participants explored relations between materials, sound, and meaning. A similar role of gesture also appears in the Shape-Shifter method, where repositioning, recomposing, and adjusting elements supported reflection and made tacit assumptions visible (Gobbo et al., 2026). In this thesis, gestures worked both to externalise reasoning through movement and allow participants to refine interpretation through the physical possibilities of the Data-Probes.

8.3.2 Material specificity and productive unfamiliarity

Material availability was important for eliciting perception and interpretation, but the limits of the kit and participants' varying familiarity with the materials also slowed interpretation in productive ways. Participants paused to compare components, tested their tactile qualities, and decided whether a material could carry a sensation. This pause made the act of choosing part of the enquiry itself. Rather than applying a familiar symbolic vocabulary, participants developed meanings through contact, comparison, and discussion, negotiating what each material could express and where its expressive capacity became insufficient.

The limits of the kit also generated interpretation. Some sensations exceeded the available physical qualities, prompting participants to extend meaning verbally or through combination. P16 connected foul-smelling urine to irritation by referring to sound, explaining that "the sound was very like irritating" and linking that irritation to smell (P16, WS3). The available material opened the association, while the participant's explanation extended it across sensory registers.

Participants also used material mismatch to clarify what they meant. A component could approximate a sensation while leaving something unresolved, and this unresolved relation encouraged further explanation. In this sense, material specificity worked through both fit and inadequacy. The qualities of a component supported expression, while its limits prompted participants to articulate the aspects of experience that remained difficult to materialise.

This productive unfamiliarity contributed to knowledge generation because participants had to negotiate meaning with the materials rather than apply ready-made codes. The Data-Probes invited tactile and spatial exploration, while their constraints encouraged explanation, adaptation, and comparison. Material engagement therefore made interpretation more explicit by revealing how sensations were shaped through the relation between bodily memory, available materials, and verbal account.

8.3.3 Metaphor and allegory as extensions of material meaning

When certain sensations could not be directly expressed through the available materials, participants used imagination and metaphor to bridge the gap. Physical qualities such as temperature, movement, or internal bodily sensations were not always present in the kit, yet participants reinterpreted materials symbolically. For example, wood was described as “warm”, while polystyrene was perceived as “cold”, even though both had a similar temperature (P3, WS1). These associations show how material limits supported creative reasoning. When direct correspondence was not possible, participants extended meaning through sensory memory, emotional association, and verbal explanation.

Symptoms were also often represented through combinations of elements rather than through single components. Participants used several shapes, materials, connections, and arrangements to express how sensations overlapped, progressed, or returned over time. Some artefacts took the form of timelines or journeys, representing recurrence, progression, and cycles of discomfort, as in the cases of P2, P5, P11, and P15. Others used figurative or symbolic forms, such as a “boat” (P15, WS3), a “cherry on the top of my cake” to increase instability (P18, WS3), or body-like configurations that supported the localisation of pain (P1 and P6, WS1).

This compositional quality extends metaphor towards allegory. While metaphor connects one material quality to one sensation, allegory builds meaning through the relation among several elements. This is relevant for data physicalization, where physical variables are often experienced together rather than separately. Shape, texture, weight, position, connection, and material perception operated in relation to one another, allowing participants to express symptoms as layered experiences in which pain, burning, pressure, urgency, anxiety, and uncertainty could coexist. In this sense, the artefacts worked as material narratives. Their meaning emerged from the whole configuration and from participants’ explanations of how its parts related to one another.

8.4 Participation as the condition for collective knowledge

Within the workshop setting, participation creates the conditions through which individual symptom experiences can become part of a shared enquiry. Socially, the activity enables participants to speak, listen, compare experiences, and recognise similarities or differences with others. Epistemically, it positions women’s embodied

experiences as valid sources of knowledge rather than as private or secondary accounts. This directly responds to the first research question, which asks how participatory design practices can expand healthcare enquiry by enabling women to articulate embodied experience and contribute to the co-creation of knowledge.

In the workshops, participants were positioned as co-interpreters of their own experiences, showing how participatory design can support women's active contribution to healthcare knowledge. The group setting allowed participants to listen, compare, recognise, and question one another's accounts. Experiences of pain, burning, pressure, urgency, discomfort, and uncertainty gained meaning through exchange. Participants brought different bodily histories and symptom patterns into the discussion, and these differences expanded the collective vocabulary of the condition. Similarities created recognition, while differences clarified the situated character of symptoms.

This movement from individual account to shared enquiry is central to the contribution of the workshops. Collective knowledge emerged through comparison, resonance, and negotiation. A symptom could be understood as sharp, heavy, blurry, unstable, temporal, or difficult to locate, depending on how participants experienced and explained it. Participation made these variations visible and discussable.

Mills' concept of the Sociological Imagination helps frame this movement from private experience to collective meaning. Personal troubles become connected to wider public issues when individuals recognise how their experiences relate to broader social and institutional conditions (Mills, 1959). In the workshops, intimate experiences of recurrent UTIs, bodily uncertainty, and healthcare communication moved from private discomfort into shared discussion about symptom recognition, care, and clinical dialogue.

Pangrazio and Selwyn's concept of Data Imagination extends this point to data practices. They describe data sense-making as an imaginative process through which people connect personal data to wider social and technological structures (Pangrazio and Selwyn, 2023). In this research, participants treated symptoms as forms of embodied data that could be expressed, interpreted, and related to others' experiences. Through participation, bodily sensations became material for shared reflection and collective interpretation.

The group setting also shaped how intimate experiences entered the discussion. Participants encountered accounts that resonated with their own, helping to normalise symptoms often experienced privately, such as pain during urination, urgency, incontinence, sexual discomfort, and frustration with repeated treatment. This shared context supported openness because participants recognised their experiences as part of a wider pattern.

While physical variables and Data-Probes support symptom interpretation by

giving participants material qualities and components through which to express embodied sensations, participation provides a social dimension to this process. These interpretations are developed, shared, and reconsidered with others. Within the workshop, participants listened to one another, compared experiences, recognised similarities and differences, and responded to how others described their symptoms. Through this exchange, personal accounts moved beyond individual narration and became part of a shared process of meaning-making. Women's embodied experiences therefore become situated knowledge that can contribute to healthcare enquiry.

8.5 From measurement to situated validity in participatory data physicalization

8.5.1 Situated validity for clinical relevance

Biomedical measurement remains essential for diagnosis, treatment, and clinical decision-making because it supports precision, comparability, and medical accountability. Yet symptoms such as pain, burning, pressure, urgency, discomfort, anxiety, and uncertainty are not always fully captured through clinical measures or diagnostic language. They are experienced through the body, shaped by memory and context, and often difficult to articulate. This research responds to this gap through participatory data physicalization, creating conditions through which embodied experience can be noticed, expressed, compared, and discussed.

Physical variables and Data-Probes support this shift by moving attention from fixed values to participants' agency in defining what is relevant and how symptoms are interpreted. Physical variables offer participants a structure for working with perceptions, while Data-Probes make this structure tangible through materials. In the workshops, participants associate symptoms with material qualities and test these associations through making, gesture, and explanation. What emerges is not a stable classification of symptoms, but a context-specific description of how each symptom becomes communicable through material engagement.

This understanding of measurement as relational helps clarify how the artefacts produced through Data-Probes become valid within the logic of the thesis. They are not intended as universal outputs that capture common symptoms, but as situated records of interpretation shaped by relations among participants, bodily sensations, physical variables, materials, gestures, discussion, and clinical perspectives.

This connects to the earlier account of collective knowledge as emerging through

resonance and situated difference, where participants recognise shared aspects of symptom experience while preserving the specificity of how each person perceives, materialises, and explains them. In this sense, the validity of the artefacts aligns with feminist epistemologies that value partial, embodied, and contextual perspectives as sources of knowledge (Haraway, 1988). Barad's concept of diffraction further clarifies this point by treating difference not as a problem to be resolved, but as a productive condition through which meaning emerges (Barad, 2007). In this research, variation among participants' artefacts strengthens the validity of the method because it shows how similar symptoms can matter differently depending on each person's embodied experience, material choices, and mode of explanation. Through this process, embodied experience enters healthcare enquiry as situated evidence that is materially expressed, socially discussed, and collectively meaningful without being detached from the conditions in which it is produced.

8.5.2 Artefacts as autographic traces of embodied interpretation

Autographic design helps clarify why these artefacts can be understood as traces rather than as simple representations. Offenhuber shows that phenomena become visible through marks or inscriptions that retain a relation to the process of their formation (2020a, 2023). In this thesis, symptoms are approached as bodily traces of internal states, already carrying an indexical relation to what happens in the body. The workshop extends this autographic logic by creating conditions in which these internal traces can be externalised through material engagement. Participants associated sensations with physical variables and assembled Data-Probes through shape, texture, weight, position, connection, gesture, and explanation. The resulting artefacts therefore act as autographic inscriptions of embodied interpretation. They do not record symptoms directly, but extend the process through which symptoms become perceptible, tangible, and discussable.

The epistemic value of these traces depends on their capacity to support recognition, communication, and situated interpretation. An artefact acquires meaning when it reflects a participant's lived experience in a way that can be explained, questioned, and compared with others. This meaning does not rely on correspondence with a universal measure of the symptom, but on the coherence between sensation, material choice, gesture, verbal account, and collective interpretation. The artefact becomes relevant because it preserves the relations through which the participant makes the symptom understandable.

This form of validity is strengthened by the social and clinical dimensions of the process. Within the workshop, participants compare artefacts, recognise similarities

and differences, and refine their explanations through discussion.

In the medical expert interviews, clinicians engage with these material and narrative expressions as complementary insights into symptom quality, emotional burden, uncertainty, rhythm, and relations among symptoms. The artefacts therefore operate as traces that remain open to interpretation across different perspectives, while still remaining grounded in the participant's embodied account.

Participatory data physicalization therefore shifts measurement away from extraction and towards situated validity as a process of relational meaning-making. Through physical variables and Data-Probes, symptoms become available as evidence because they are materially expressed, socially discussed, and critically interpreted, rather than reduced to fixed values. This reframing supports the broader contribution of the thesis by showing how embodied experience can enter healthcare enquiry as situated, communicable, and collectively meaningful knowledge.

8.6 From discussion to the Apparatus

Through physical variables, Data-Probes, participation, and material engagement, the workshops show how embodied health experience can be articulated as a material and collective process. Participants move from felt sensations to material expressions that can be compared, discussed, and interpreted with others. Symptom knowledge therefore emerges through mapping, making, explanation, and collective reflection.

Physical variables are reframed as interpretive and generative resources for participatory data physicalization, while Data-Probes provide the material method through which these variables become usable in embodied enquiry. Together, they show how design can make lived experience communicable, situated, and collectively meaningful.

The discussion also repositions measurement and validity. Rather than extracting fixed values, the method creates conditions through which embodied experience becomes noticeable, expressible, and open to interpretation. The value of the artefacts lies in their capacity to support recognition, communication, situated interpretation, and dialogue with clinical knowledge.

These insights lead to the Physical-Variable Apparatus. The following chapter consolidates the research into an arrangement of labels, protocol, materials, and analytical tools through which embodied experiences can be elicited, articulated, compared, and interpreted. Drawing on Barad's understanding of apparatus as a material-discursive arrangement, the chapter translates the outcomes of the thesis into a system for participatory enquiry in healthcare and related contexts.

9. THE PHYSICAL-VARIABLE APPARATUS

In this chapter, I introduce the Physical-Variable Apparatus, which brings together the methodological contribution of the thesis in a tangible, adaptable, and replicable system for participatory enquiry. The Apparatus is designed as a practical support that allows researchers, clinicians, and designers to apply the approach developed in this study, enabling the elicitation, interpretation, and sharing of embodied data in structured yet flexible ways.

Drawing on Barad's notion of apparatus as a material and discursive arrangement through which phenomena come into being (Barad, 2007), the term is used in this work to emphasise knowledge as situated, relational, and produced through specific conditions of engagement. The Physical-Variable Apparatus is proposed as a guiding structure for defining the elements needed in a specific research context, rather than as a rigid framework or fixed protocol. This distinction reflects the contextual nature of embodied experience. The labels, materials, prompts, and analytical tools used in this thesis respond to the specific case of UTI symptoms. Other researchers can adapt the Apparatus by defining the symptoms, physical variables, and materials that fit their own enquiry. The Apparatus therefore offers principles for constructing a situated methodological arrangement. It guides researchers in defining how participants engage with materials, how embodied sensations become externalised, and how material expressions can be compared and interpreted collectively.

The Figure 9.1 presents the four interconnected components through which the apparatus operates:

* The sets of symptom and physical-variable labels;
* The workshop protocol for engagement;
* The Data-Probes material kit;
* The cross-format analysis interface.

Finally, to demonstrate the adaptability of the Apparatus beyond the specific case of UTIs, the chapter concludes with Section 9.6, which presents the activity designed for the EKSIG 2025 conference, on data as experiential knowledge and embodied processes. This further application serves to validate the transferability of the Apparatus and its capacity to incorporate new variables, such as sound and gesture, into the representation of embodied experience.

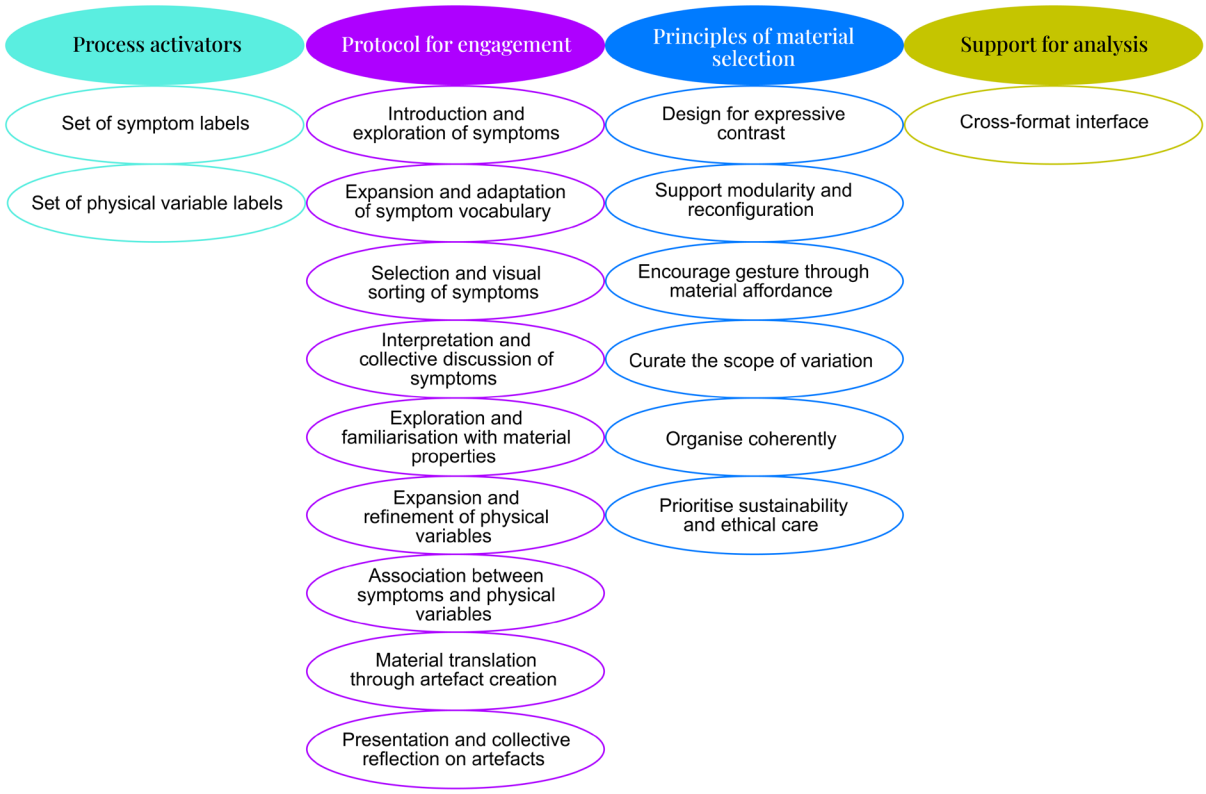


Figure 9.1: representation of the Apparatus components presented in this Chapter.

9.1 Applications and relevance of the Apparatus

The Apparatus has been developed for researchers and practitioners working across design, health, and social enquiry. The aim is to provide a structured method for eliciting and interpreting embodied data, enabling forms of knowledge that conventional medical frameworks rarely capture. Clinical descriptions often detach symptoms from lived experience, overlooking the complexity of how individuals perceive and respond to illness. The Apparatus addresses this limitation by introducing material engagement as a way to explore and communicate sensations that are difficult to express through language or standardised measurement. Through direct interaction with materials, participants give form to emotions and perceptions, transforming subjective experiences into artefacts that can be collectively observed, discussed, and interpreted. This process enables the emergence of shared understanding and supports dialogue around personal and collective dimensions of health.

Evidence from the workshop sessions and medical expert interviews, which I discuss in Chapter 5, 6, and 7, demonstrates the versatility of the approach. Although the research was initially developed to investigate experiences related to UTIs, it opened broader questions about how embodied experiences are articulated in healthcare. For this reason, the Apparatus is designed to extend beyond this specific case and is proposed as especially relevant for chronic and recurring conditions, where patients' perspectives can complement clinical knowledge and connect medical interpretation with lived experience.

Different groups may benefit from the Apparatus in different ways. Participants can use it to recognise and express embodied sensations through material form and discussion. Clinicians and healthcare practitioners can look at the resulting artefacts and narratives to access richer accounts of symptom experience. Health researchers are imagined adopting it to elicit and analyse subjective or experiential data.

Beyond healthcare, the Apparatus also serves as a resource for design researchers interested in participatory methods, material exploration, and alternative forms of data representation. Design researchers can rely on the Apparatus as a structured method for participatory data physicalization. Its structure provides a systematic way to elicit, organise, and discuss subjective interpretations within collective settings, offering a methodological foundation for enquiry through making. For this reason, also scholars in sociology and science and technology studies (STS) may likewise find value in the Apparatus as a tool for examining how illness, knowledge, and experience are enacted in practice.

By translating theoretical discussions on knowledge, practice, and embodiment into a tangible participatory procedure, the Apparatus fosters interdisciplinary collaboration between design, health, and the social sciences.

9.1.1 Functions of the Apparatus within participatory enquiry

The Apparatus functions as an inspirational system that guides participants in engaging, interpreting, and constructing meaning through material interaction. The function extends beyond the facilitation of expression by organising the conditions through which embodied data become observable, interpretable, and transformable into shared knowledge. The Apparatus mediates between individual sensations and collective understanding, allowing private experiences to become communicable without reducing their complexity. Within this structure, three interrelated functions define its role in the participatory process:

1. Elicitation of embodied data

The Apparatus provides material means that help participants attend to and perceive their symptoms more clearly. Physical variables such as texture, weight, temperature, and elasticity offer contrasting sensory cues that prompt deeper awareness of how symptoms feel in the body. Engaging with materials encourages participants to sense, compare, and refine their perceptions through touch and movement. The Apparatus therefore acts as a perceptual scaffold, helping individuals recognise nuances in their bodily experiences that may otherwise remain vague or difficult to describe.

2. Structuring interpretation

Alongside perception, the Apparatus supports participants in making sense of their own embodied expressions. Mapping sensations onto physical variables encourages individuals to articulate why particular material qualities resonate with their experience. Through this interpretive engagement, participants clarify the links between sensation and representation, developing a more precise and reflective understanding of their own symptoms.

3. Generating collective knowledge

At the same time, the Apparatus enables individual interpretations to become part of a shared field of understanding. When participants present and compare

their material representations, their contributions intersect, revealing similarities and differences across experiences. Tangible artefacts serve as common reference points through which perspectives can be compared, negotiated, and expanded. Through these exchanges, diverse interpretations become connected, forming a collective vocabulary that integrates emotional, physical, and social dimensions of experience. Meaning arises through the interplay of material and discursive practices, allowing individual insights to contribute to a broader and more inclusive body of knowledge.

The following sections present the four interconnected components that constitute the Apparatus, which are the sets of labels, the workshop protocol for engagement, the Data-Probes material kit, and the cross-format analysis interface for analysis. Each of the components are described in relation to its role in enabling participation, material interaction, and collective knowledge generation.

9.2 The two sets of labels

At the core of the Apparatus are two interconnected sets of labels that mediate between experience, language, and material engagement. One set describes symptoms, making embodied experiences explicit and communicable. The other describes physical variables, providing a shared vocabulary through which these experiences can be translated into tangible and discussable forms.

The labels develop from the methodological components introduced in Chapter 3 for the Shape Your Symptoms workshop. In that setting, symptom labels and physical-variable labels structured identification, association, discussion, and material making. Within the Apparatus, they are consolidated as adaptable methodological components that can guide similar processes across other research contexts. Their development combines theoretical references from the literature with the situated knowledge that emerged during the workshops. Each set supports the elicitation, expression, and negotiation of embodied data within participatory settings. Their interaction allows participants to connect sensory perception with shared meaning-making, grounding knowledge generation in both material and discursive practice.

In line with the idea of the Apparatus as an evolving tool that invites ongoing refinement through continued use, the labels are available as both printable and digital resources, which can be customised and prepared for participatory activities. This format enables researchers, educators, and designers to adapt terminology, and reflects my intention to support collaborative and context-responsive engagement.

In doing so, the format supports collaboration and collective authorship while ensuring that the vocabulary remains situated, flexible, and responsive to context.

9.2.1 Labels of symptoms

The first set consists of the labels describing symptoms of UTI. I selected these labels through a two-step process. A preliminary list was developed from medical literature to include the most commonly recognised symptoms, providing an evidence-based foundation and ensuring comprehensive coverage of the condition.

This list was then introduced in the participatory setting, where participants described their own experiences of the illness and suggested additional terms. The combination of medical terminology and personal accounts enabled a shared understanding of what was being discussed and ensured that the resulting vocabulary integrated clinical sources with lived experience.

What is considered as symptom

What is considered a symptom within this set of labels aligns with, yet also expands upon, the definition discussed in the theoretical ground of this thesis (Chapter 2), where symptoms are described as subjective manifestations of underlying physiological processes that rely on an individual's ability to perceive and communicate internal sensations (Malterud et al., 2015). While the definition adopted in this thesis is intentionally broad and open to include psychological as well as physical conditions, the lists of UTI symptoms provided in the medical literature mainly refer to physical manifestations. This focus possibly reflects the clinical need to identify measurable indicators that support diagnosis and treatment. However, evidence from the workshops shows that participants rarely described symptoms as purely physiological events. Instead, symptoms were portrayed as felt conditions indicating change, discomfort, or imbalance, often intertwined with emotional states and contextual circumstances. Participants spoke of pressure, burning, and tension together with feelings of anxiety, inhibition, or embarrassment. These accounts reveal that symptoms are experienced as multidimensional phenomena, shaped by the interplay of physical, emotional, and social dimensions, and cannot be fully represented within the boundaries of medical terminology, which tends to isolate symptoms from the circumstances in which they are lived.

Based on this, I broaden the definition of symptom to recognise how causes, effects, and experiences overlap in the progression and understanding of disease. Clinical reasoning often relies on a linear model in which disease produces symptoms and symptoms lead to consequences or complications. When illness is

examined through lived experience, these categories become less distinct. What medicine may classify as a consequence or external factor can instead contribute to shaping or intensifying the condition itself. Acknowledging these interdependencies allows a more comprehensive view of illness, where physical, emotional, and contextual factors work together in producing the experience of being unwell.
This perspective shows that what sustains or worsens a symptom may not reside only in the body but may also relate to emotional states, social interactions, or environmental circumstances. By moving beyond temporal and hierarchical models of cause and effect, this thesis adopts a holistic and relational understanding of symptoms. Within this context, symptoms are considered as changes in the body that become meaningful through perception, expression, and shared interpretation, functioning as traces that connect awareness with processes of meaning-making. This expanded understanding opens a space for deeper dialogue about disease and invites reflection on how its mechanisms are experienced, interpreted, and potentially transformed. Based on this interpretation, the following section presents the list of symptoms considered meaningful for the activity, combining physical conditions from the literature and alternative descriptions and perceptions emerged from the workshop sessions.

The set should not be treated as a definitive or exhaustive list, but as a resource that can be taken up, questioned, and adapted in future activities. Its role is to provide an orientation that supports discussion, making space for further articulation of embodied conditions across different contexts.

The final list of symptoms considered for the labels

The initial set of symptoms, which was also adopted during the activities as the formal reference for the labels, was extracted from the medical literature (Kaur and Kaur, 2020) and includes the following:

* swollen stomach;
* cloudy urine;
* bloody urine;
* need to pee;
* pain when peeing;
* discomfort when peeing;
* low temperature below 36;

* pressure in the groin;
* lower abdomen cramping;
* lower back pain;
* side pain;
* shivering;
* unable to empty the bladder fully;
* incontinence;
* vomiting;
* nausea;
* tiredness;
* aching;
* foul-smelling urine.

Building on the initial list drawn from the literature, additional elements emerged during the study and added in the final set of labels. They are organised to reflect a continuum that connects physical manifestations with psychological and emotional dimensions of the experience. For every symptom, a description is provided, which summarises the different explanations given by participants and situates them within the context of this specific condition.

* bloated stomach: internal sensation of fullness and pressure in the lower abdomen, often associated with swelling or incontinence. It expresses a feeling of expansion and imbalance, where the body is perceived as heavy or distended. The symptom conveys tension and retention, marking the early stage of discomfort and loss of bodily ease.
* burning when urinating: a sharp or stinging pain during urination, often perceived as heat or irritation in the urinary tract. It indicates inflammation of the bladder or urethra and represents a distinct sensory marker of infection, characterised by discomfort and heightened sensitivity.
* tension: muscular or psychological contraction arising from discomfort, stress, or anticipation of pain. It manifests as bodily stiffness or rigidity and reflects the connection between emotional strain and physical response.

The symptom expresses how anxiety or worry can translate into a felt tightness within the body, linking emotional experience to somatic reaction.

* internal heat / 'burning aura': diffuse sensation of warmth or heat inside the pelvic area, often radiating beyond the point of pain. It conveys inflammation and internal irritation perceived through thermal imagery such as fire or glow. The symptom reflects an intensified bodily awareness, where heat becomes a sign of disturbance and imbalance within the body.

* swelling / internal pressure: sensation of heaviness, fullness, or expansion in the lower abdomen or pelvic area. It often precedes pain and signals the onset or progression of infection. The symptom expresses an awareness of internal build-up or obstruction, where the body is felt dense and strained, indicating a loss of fluid balance and comfort.

* dryness: lack of moisture or smoothness within the urinary tract, perceived as friction or roughness during urination. It conveys a sense of abrasion and discomfort, often preceding or accompanying pain. The symptom reflects a surface-level sensitivity, where the body is experienced as raw or unprotected.

* irritation: burning or stinging sensation caused by inflammation or repeated friction in the urinary tract. It conveys a feeling of persistent sensitivity and discomfort, often fluctuating in intensity. The symptom reflects the reactive state of the body when exposed to infection, marking heightened awareness of pain and vulnerability.

* anxiety: state of unease or apprehension related to the anticipation of pain or recurrence of infection. It manifests as mental tension and restlessness, often influencing bodily sensations and perception of symptoms. The symptom reflects a psychological response intertwined with physical experience, showing how fear and uncertainty become part of the illness itself.

* feeling of instability: sense of imbalance or loss of steadiness that accompanies repeated or unpredictable illness episodes. It conveys both physical fragility and emotional insecurity, as the body is perceived as unreliable or easily disturbed. The symptom reflects the progressive weakening of confidence in bodily control, linking recurrence with feelings of uncertainty and loss of grounding.

* vulnerability / shame: feeling of exposure, fragility, and discomfort connected

to the private nature of urinary symptoms. It arises from the difficulty of discussing intimate or stigmatised conditions, often accompanied by embarrassment or self-consciousness. The symptom expresses a social and emotional dimension of illness, where bodily sensitivity is intensified by cultural silence and fear of judgment.

* uncertainty in feeling perceptions: difficulty in recognising or interpreting bodily sensations, such as distinguishing normal from abnormal discomfort. It reflects a state of doubt toward one's own perception, often emerging when symptoms are ambiguous or fluctuate in intensity. The symptom reveals the fragility of bodily knowledge, showing how individuals question their sensations and rely on reflection or comparison to make sense of what they feel.

* fatigue: persistent sense of physical and mental exhaustion that follows or accompanies infection. It extends beyond ordinary tiredness, affecting concentration, motivation, and daily activities. The symptom reflects the prolonged impact of illness on the body's energy and emotional balance, marking a continuous drain that blurs recovery and recurrence.

* sexual inhibition: reluctance or fear of engaging in sexual activity due to pain, discomfort, or anxiety related to infection. It reflects how the illness affects intimacy, trust, and body confidence, often leading to avoidance or emotional distance. The symptom reveals the relational consequences of vulnerability, where physical sensitivity and psychological fear combine to limit sexual expression and connection.

* overwhelming: state of unease or apprehension related to the anticipation of pain or recurrence of infection. It manifests as mental tension and restlessness, often influencing bodily sensations and perception of symptoms. The symptom reflects a psychological response intertwined with physical experience, showing how fear and uncertainty become part of the illness itself.

The final set of symptom labels is represented in Figure 9.2, on the next page.



Figure 9.2: the final sets of symptom labels. The shape is meant suggesting combination with the other set of physical-variable labels, whose contrasting backgrounds support quick and clear recognition of their different content and role within the activity.

9.2.2 Labels of physical variables

To complement the set of symptoms, the physical-variable labels introduce a material vocabulary that enables participants to externalise their experiences into tangible forms. Each variable corresponds to a perceptual dimension, such as texture, weight, temperature, elasticity, or shape, that participants can explore through direct interaction with materials. These variables translate intimate sensations into visible and tactile expressions that can be collectively discussed, allowing the subjective experience of illness to be materialised and shared.

The development of the set of physical variables combines theoretical grounding with participatory experimentation. The framework proposed by Hornecker and colleagues (2023) provided the initial foundation for identifying relevant sensory dimensions, as it analyses how material properties operate as variables in the creation of meaning when materials are used for data representation. While this taxonomy was comprehensive, only a limited selection of variables was introduced during the first workshop sessions to maintain clarity and focus. In subsequent sessions, participants spontaneously referred to additional sensory properties that had not been part of the initial selection. Their repeated mention of these variables confirmed their relevance and led to their inclusion in the final version of the set. During these same workshops, participants also identified new variables that were not present in Hornecker's classification but were recognised as meaningful to describe their embodied experiences.

Although Hornecker and other researchers (2023) distinguish between explicit variables, implicit properties, and consequential aspects, I chose to treat these dimensions as free from categorical divisions. I made this decision because the purpose is not to reproduce an existing taxonomy but to enable open exploration and intuitive association. Since participants are supposedly not familiar with the terminology of physical variables or with material properties more broadly, introducing further classification is expected to create confusion and distance them from the experiential focus of the activity. For this reason, overlapping dimensions are not repeated, and the variables are presented without hierarchical order.

The final list of physical variables considered for the labels

The list of physical variables considered in this study draws from the vocabulary established by Hornecker and her colleagues (2023) and includes:

* position;
* size;

* shape;
* colour;
* orientation;
* pattern / texture;
* fuzziness / blurriness;
* light;
* movement / motion;
* timing;
* 3D-form contour;
* surface texture;
* compliance;
* temperature;
* vibration;
* force;
* speed;
* inertia;
* weight;
* kinesthetic friction;
* viscosity;
* sound location;
* pitch;
* loudness;
* timbre;
* duration;

* envelope;
* melody;
* rhythm;
* taste;
* smell;
* environment;
* scale;
* timescale;
* physical manipulation;
* kinesthetic exploration and engagement;
* reflection;
* material;
* spatial distribution and orientation;
* traces of the maker;
* shadows;
* sound / noise.

The final set also includes the several new variables emerged during the participatory workshops that were not explicitly included in the existing classifications but were considered relevant for future applications of the Apparatus. These additions reflect participants' interpretations of their embodied experiences and illustrate how new forms of material expression can arise through collaborative exploration. These new variables are accompanied with descriptions that illustrate how each was used and interpreted by participants, explaining how material features gained meaning within the context of this intimate condition, they are:

* elasticity: sensed capacity to expand or contract, expressed as tension, fullness, or distortion. It represents how inner pressure and change of volume can indicate the transition from stability to discomfort. The variable conveys the perception of expansion or compression as an indicator of disturbance and altered bodily awareness.

* sharpness: perception of pointed or angular surface qualities that evoke irritation, pain, or intensity. It reflects how edges and spikes can symbolise sensations of cutting, piercing, or burning. The variable expresses the felt acuteness of discomfort through geometrical and tactile associations.

* pressure: sensation of internal force or weight within the body, linked to cramps, tightness, or urgency. It conveys the dominance of compression and density in the experience of illness. The variable represents the internal build-up that marks the body's response to inflammation and discomfort.

* permeability: degree to which a material or body allows substances to pass through or remain contained. It symbolises conditions such as leakage, filtering, or retention. The variable represents the body's openness or closure, expressing experiences of flow, blockage, or imbalance.

* durability: sensation of persistence or duration of a symptom, ranging from fleeting sensations to chronic or recurring ones. The variable expresses how long discomfort is perceived to last and how it lingers within bodily awareness, revealing the temporal aspect of endurance and recovery.

* hardness: perception of rigidity or resistance that evokes pain or lack of comfort. It reflects sensations that feel invasive or unyielding, representing difficulty in relief or transformation. The variable conveys the perception of the body as stiff or constrained, mirroring persistence and strain.

* density: sense of compactness or saturation that expresses heaviness and fatigue. It conveys the perception of the body as weighty or full, suggesting reduced mobility and energy. The variable represents the bodily experience of accumulation and tiredness.

* amount: perception of numerical repetition or frequency used to represent recurrence or intensity. It expresses how symptoms or sensations repeat, multiply, or accumulate. The variable symbolises patterns of persistence and rhythm in the experience of illness.

* integrity: perception of wholeness or fragmentation in a material or form. It reflects conditions of breakdown, fragility, or deformation, symbolising vulnerability and loss of cohesion. The variable represents how the body or its sensations are perceived as intact, damaged, or altered through the course of illness.

Figure 9.3 represents the final selection of physical-variables selected for the labels.

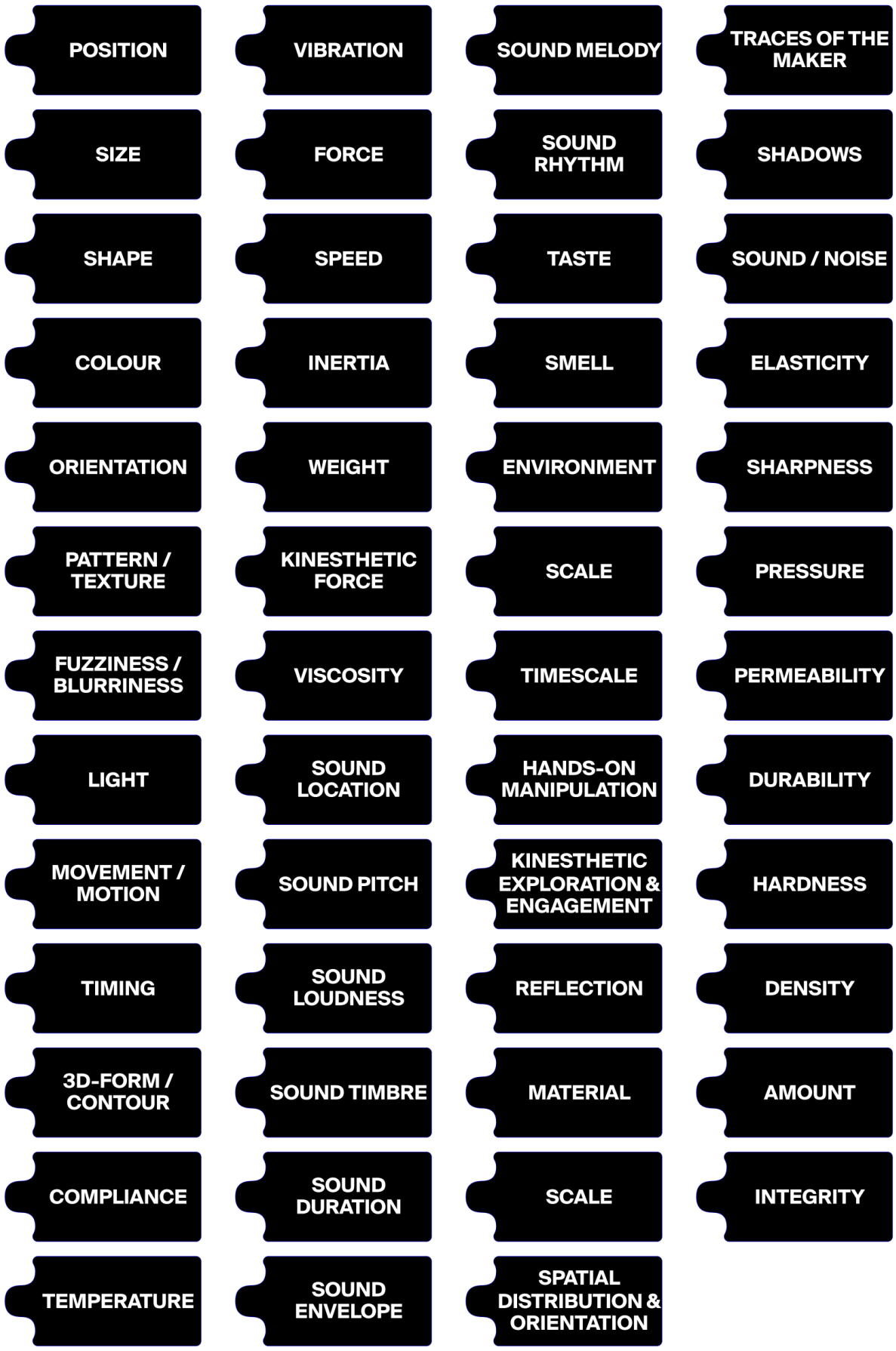


Figure 9.3: the final sets of physical-variable labels.

9.2.3 Labels as Figma components

To remain consistent with the notion of the apparatus drawn from Barad (2007), this thesis positions the labels not as fixed outputs but as material resources to be taken up, adapted, and reconfigured beyond the specific use for which they were originally designed. The Apparatus is conceived as a material-discursive arrangement that must remain responsive to different contexts of enquiry. For this reason, I make the labels available primarily as Figma components. Figma is a collaborative interface design tool where components function as reusable elements that maintain a consistent structure while allowing for specific variations. By providing the labels as components, I ensure that the Apparatus allows future researchers to act directly on the tools. Users can modify the master component to change the shape or style of all labels simultaneously or interact with individual instances to override text and content. This functionality is essential for the adaptability of the method, as it allows researchers to rename existing labels or add new elements to accommodate symptoms emerging from future interactions or to address different diseases with distinct symptomatology. As demonstrated in the EKSIG workshop (see Section 9.6), the set of variables must be able to expand based on the focus of the work, such as sound, or the specific materials available in a given working environment.

The Figma format allows these new variables to be integrated seamlessly into the existing system, ensuring that the Apparatus can evolve alongside the research questions it supports. Access to these components is provided through a public link (https://www.figma.com/community/file/1582302079862223061), maintaining alignment with the open and collaborative approach of this thesis. Detailed instructions are included within the file, guiding users on how to intervene, edit, and personalise the sets of labels to suit their specific needs.

To ensure the Apparatus remains accessible to researchers and practitioners outside the field of design, or those with limited access to design software, the labels are also made available in PDF format. While this format offers less possibilities for intervention, such as limited editing of names or selection of specific portions for printing, it ensures that the tools remain usable for people with varying levels of design skill and technical resources. Both formats are hosted in a dedicated page on the online repository (https://ginevraterenghi.github.io/data-probes/physical-variable-apparatus.html) specifically developed to collect and make available the material of this thesis and further described in Section 9.5.

9.2.4 Summary of the sets of labels

The two sets of labels (symptoms and physical variables) form the conceptual and operational foundation of the Apparatus. Together they establish a shared language that connects embodied experience with material expression, enabling participants to articulate sensations that are otherwise difficult to express. The symptom labels can be adapted to different health conditions, providing a flexible vocabulary that reflects the specific context of each activity. The physical-variable labels, by contrast, are designed to guide the process itself and constitute the core of the Apparatus. They structure how participants engage with materials, interpret their experiences, and communicate meaning collectively. As the first components of the Apparatus, the labels define the basis for participation and create the conditions through which embodied knowledge can be elicited, interpreted, and shared. The following components build on this foundation, expanding the Apparatus through the workshop protocol, the Data-Probes material kit, and the analytical interface that sustain its data collection and interpretation functions.

9.3 The workshop protocol: phases of engagement

This section introduces the workshop protocol by describing the dynamics of engagement that shape the activity. The protocol explains how participation unfolds through interaction with materials, labels, and other individuals, emphasising the relational conditions through which knowledge production becomes possible within the Apparatus. This approach allows the protocol to remain adaptable to different contexts while preserving the core principles of engagement that define the activity.

A key aspect of the protocol is the movement between individual and collective modes of participation. Some phases invite participants to reflect on their own experiences, select materials, and construct artefacts. Other phases rely on group discussion, shared association, comparison, and, in some workshops, collaborative physicalization. These modes are interdependent. Individual work supports the articulation of situated experience, while collective work allows these experiences to become available for comparison, negotiation, and shared interpretation.

The balance between individual and collective phases should be adapted to the nature of the topic. For private, intimate, or health-related experiences, such as the UTI symptoms addressed in this thesis, individual phases are especially important at the beginning and end of the process. Initial reflection and final artefact-making give participants space to attend to personal sensations, memories, and perceptions.

Collective engagement is particularly valuable in the middle phase, where symptom–variable associations are discussed and negotiated. This allows participants to develop a shared vocabulary while preserving the specificity of their individual experiences.

For broader societal issues, such as climate change, artificial intelligence, or other shared public concerns, collective work may be more appropriate across a larger part of the protocol. In these cases, the initial identification of problems, relevant data, and final physicalizations can be carried out collaboratively, because the topic concerns shared conditions rather than primarily internal bodily sensations. Collaborative physicalization can therefore support participants in constructing a common representation of a collective issue. This distinction is important because the Apparatus is designed to support both personal expression and collective knowledge generation. In the UTI-focused workshops, participants mainly produced individual artefacts that were later discussed collectively. In other adaptations, collaborative physicalization may allow participants to construct shared material representations. Both formats remain consistent with the protocol because the central concern is how embodied or situated experiences become material, communicable, and interpretable within a participatory setting.

9.3.1 The workshop protocol phases

To present the protocol, I focus on the forms of engagement through which meaning emerges during the workshop. These phases derive directly from the observed dynamics of the sessions and describe the key interactions that shape participation. Rather than prescribing fixed steps, they outline the essential actions that structure how participants encounter the materials, the labels, and each other. Each phase is presented through four highlights, material, action, purpose, and outcome, which together clarify what is introduced, how participants engage with it, why it matters, and what it enables within the activity. By presenting the highlights instead of specific instructions on how to replicate the activity, this structure makes the protocol adaptable to different contexts while preserving the relational conditions with the context and material from which it generated.

1. Introduction and exploration of symptoms

Material: printed set of symptom labels.

Action: participants explore the symptom labels, read them aloud, and discuss their meanings, identifying those that resonate with their experiences.

Purpose: to introduce a shared vocabulary that establishes a common ground

for dialogue and reflection on individual perception of the disease and related conditions.

Outcome: initial recognition of differences and similarities in experience and the creation of a shared linguistic starting point.

2. Expansion and adaptation of symptom vocabulary

Material: blank symptom labels with pens or markers for writing.

Action: participants add new terms, adjust wording, or propose alternative expressions that better reflect their own experiences.

Purpose: to adapt the vocabulary to the specific context of the group, ensuring that the labels reflect participants' language and perspective.

Outcome: an expanded, situated list of symptoms that combines clinical and experiential expressions.

3. Selection and visual sorting of symptoms

Material: final selection of symptom labels, including any new or modified ones.

Action: participants arrange the labels according to perceived importance, frequency, or relation, creating clusters or sequences that organise their understanding.

Purpose: to identify patterns and relationships among symptoms through collective reflection and comparison.

Outcome: a selection of relevant symptoms and visual organisation based on participants' lived experience.

4. Interpretation and collective discussion of symptoms

Material: display of the symptom labels arranged in the previous phase.

Action: participants explain the arrangements, discuss reasons behind their choices, and explore how symptoms interact or differ.

Purpose: to transform observation into interpretation by articulating how personal experiences relate to each other within the group.

Outcome: individual and shared descriptions of symptoms that capture differences, commonalities, and nuances in how sensations are perceived and understood among participants.

5. Exploration and familiarisation with material properties

Material: printed set of physical-variable labels and materials from the Data-Probe kit for reference.

Action: participants read and discuss the physical-variable labels while engaging directly with the materials from the kit. Through touch and manipulation, they explore how qualities such as texture, weight, or elasticity can convey and differentiate sensations.

Purpose: to familiarise participants with material properties and initiate reflection on their expressive potential.

Outcome: shared understanding of how sensory dimensions can serve as mediators between experience and material form.

6. Expansion and refinement of physical variables

Material: blank labels of physical variables with pens or markers for writing.

Action: participants propose additional physical variables or refine existing ones, expanding the expressive range of the set.

Purpose: to ensure that the vocabulary of physical variables responds to participants' symptoms and interpretations.

Outcome: an enriched and situated set of physical variables that better reflects participants' sensory perceptions.

7. Association between symptoms and physical variables

Material: both sets of symptom and physical-variable labels.

Action: participants connect physical-variable labels with selected labels of symptoms, suggesting and discussing associations that represent their embodied sensations.

Purpose: to establish correspondences between sensations and material qualities, creating a link between sensory perception and linguistic description.

Outcome: a set of preliminary associations that define how symptoms may be translated into physical expression and what material features best suit the representation of embodied sensations.

8. Material translation through artefact creation

Material: Data-Probe components from the material kit with the symptom and physical-variable labels associated from the previous phase.

Action: each participant creates an artefact from the Data-Probes, that expresses their embodied experience through material form. Material components and variables are selected according to the associations previously identified, though they are not required to follow them strictly. They can combine and act on materials to make their tactile properties resonating with their sensations. The making process is individual but occurs within the shared workspace, allowing mutual observation and occasional exchange.

Purpose: to translate verbal and conceptual associations into tangible expressions of experience.

Outcome: a collection of artefacts that represent participants' interpretations of their symptoms made tangible through material.

9. Presentation and collective reflection on artefacts

Material: the artefacts created by participants, displayed alongside the corresponding symptom and physical-variable labels used as references during making.

Action: each participant presents their artefact to the group, explaining the choices made during construction and describing how the selected materials and shapes convey particular symptoms or aspects of the disease experience. The group observes, asks questions, and comments on how the materials communicate sensations, emotions, or relationships between different conditions. This discussion connects individual interpretations to collective reflection, highlighting both shared and contrasting approaches.

Purpose: to extend the process of interpretation from making to dialogue. By articulating how materials have been used to embody symptoms and illness experiences, participants make visible the reasoning behind their choices.

Outcome: insights on the expressive role of materials to communicate embodied data and enriched descriptions of individual experiences of illness.

9.3.2 Summary of the protocol of engagement

The protocol of engagement defines how participation unfolds within the Apparatus, guiding the transition from individual awareness to collective interpretation. Through a sequence of relational actions, participants move from identifying and discussing symptoms to exploring their material expression and sharing interpretations through artefact creation. Each phase connects linguistic, material, and social dimensions, showing how knowledge emerges through interaction rather than instruction. The protocol provides structure without imposing fixed procedures, allowing adaptation to different contexts while preserving the core dynamics of reflection, comparison, and dialogue that characterise the Apparatus. Building on these engagement dynamics, the following section introduces the criteria for material selection, informed by the Data-Probes. These materials provide the physical means through which participants translate sensations into tangible forms and sustain material reasoning at the centre of the activity.

9.4 Data-Probes: principles of material selection

The material kit represents the tangible dimension of this research methodology and served as one of its core operational components. Data-Probes provide the means through which participants translate sensations such as pain, tension, or pressure into physical and tactile forms. By engaging directly with matter, the components link sensory experiences with processes of reflection, interpretation, and collective knowledge production.

The material kit I employed during the workshops includes triangular prisms, spheres, and cubes made of wood, polystyrene, and foam, as described in the Chapter 3. These components are deliberately chosen for their sensory diversity rather than for symbolic meaning. Their design, connected through small wooden pegs, encourages participants to join and separate pieces freely, exploring how relationships between materials and gestures could express different sensations and bodily experiences.

Within the activity, the value of the kit lied in the experiences it enables. Engaging with materials that vary in texture, weight, and resistance allows participants to reason through touch, using manipulation and comparison as ways to reflect on their sensations. The components therefore function as stimuli that evoke contrast, movement, and interpretation.

Within this perspective, the role of the kit in the Apparatus is not to prescribe which materials should be used but to establish the conditions for exploration. The following section introduces a set of principles for material selection and organisation, describing how future applications can identify and prepare materials that maintain the exploratory and interpretive qualities of this research.

9.4.1 Principles for material selection and organisation

Considering the purpose of the kit as a tool that I use to foster embodied reflection and collective enquiry, the following principles draw on insights from the workshops, visual research, and participant feedback to offer instructions for identifying and organising materials in future applications of this methodology. Each principle is articulated through a definition, a rationale, and a set of practical implications, followed by reflective questions intended to guide facilitators in selecting and adapting the kit to different contexts. This structure ensures that conceptual, empirical, and operational dimensions remain connected. The definition clarifies the theoretical meaning of the principle within the Apparatus. The rationale draws from observations made during the workshops, showing how participants engaged with materials and how these interactions shaped processes of interpretation and meaning-making. The practical implications then transform these insights into concrete guidance for future applications of the apparatus. Finally, the reflective questions extend the principles into practical guide for facilitators who wish to develop or adapt their own material kit. By combining principles and reflective questions, this section transforms the choices behind the material selection into an adaptive design instrument to allow future researchers to sustain its epistemic focus on participation, materiality, and situated knowledge across diverse contexts.

1. Design for expressive contrast

> Definition: materials should provide strong perceptual and affective contrast through variation in texture, density, resistance, and weight.
>
> Rationale: during the workshops, participants made sense of their experiences by comparing materials with distinct tactile properties. They linked sensations such as pressure, burning, or instability to contrasts between softness and rigidity or between smooth and rough surfaces. This contrast stimulated reflection and articulation. This attitude also revealed that participants sought materials that evoked, rather than avoided, discomfort. Contrast therefore functions as the first layer of dialogue between perception and materiality.

Practical implications:

- include components which clearly convey different features;
- ensure that contrasts emerge from physical features first;
- consider that contrast extends beyond physical properties and invites emotional and symbolic resonance, enabling participants to express tension or imbalance through the materials.

Reflective questions:

- what kinds of material contrasts (soft vs. hard, light vs. heavy, smooth vs. rough) are necessary for participants to perceive and express their sensations?
- how might the combination of materials evoke emotional qualities such as tension, irritation, or relief?
- are there sensory gaps (e.g., no rough materials, no light elements) that could limit participants' ability to compare and articulate differences?

2. Support modularity and reconfiguration

Definition: materials should be designed or selected so they can be connected, detached, and rearranged easily, enabling participants to build temporary compositions that reflect their interpretations.

Rationale: in the workshops, wooden pegs made it possible to connect geometric pieces, allowing artefacts to evolve through manipulation. This process also transformed pegs from passive connectors into active constructors of meaning. Modularity thus supports participation by fostering experimentation.

Practical implications:

- equip components with simple connectors (such as pegs, or magnets) that allow immediate assembly and disassembly without the need of additional materials and actions;
- encourage the construction of temporary and modifiable arrangements, reinforcing that meaning can change with each configuration;
- suggest the adoption of connectors to build meaning not only to connect elements as both a structural and cognitive principle, where participants think through building and each new form represents a situated interpretation.

Reflective questions:

* what types of connectors (pegs, magnets, clips) would make these assemblies fluid and intuitive within the specific working environment?
* does the design allow for quick reconfiguration so that participants can revise their ideas while working?
* how can the connecting elements expand the construction process and contribute to the production of meaning (for example, tension, cohesion, or fragility)?

3. Encourage gesture through material affordance

Definition: materials should invite bodily gestures that transform perception into action. Their form, texture, and structure should provide cues for engagement while remaining open to multiple interpretations.

Rationale: participants expressed their sensations through movement, pressing, twisting, and stacking materials. Their gestures were guided by the material affordances, such as shapes that invited balancing or surfaces that encouraged rubbing. Through this interaction, physical engagement became a way to think and communicate.

Practical implications:

* select materials that respond clearly to touch and manipulation, offering sensory feedback through deformation, sound, or resistance;
* ensure that materials provide enough diversity in form and texture to suggest different gestures;
* choose materials that can register traces of use, allowing gestures and changes made during manipulation to become visible for later observation and analysis.

Reflective questions:

* what gestures do the materials activate through their physical qualities?
* how do material physical features prompt engagement or reflection?
* how can the design of components and activity make the gestures of manipulation observable and meaningful for analysis?

4. Curate the scope of variation

Definition: the range and diversity of materials should be intentionally limited to maintain focus and clarity during exploration.

Rationale: workshop feedback showed that excessive choice creates distraction and reduced engagement, as participants spent time comparing materials rather than reflecting on their sensations. Limiting the number of elements to a few clear contrasts, such as small and large or soft and hard, helped participants perceive differences more decisively and engage in deeper reflection. A curated selection thus sharpens perception and supports confidence in interpretation.

Practical implications:

* provide a few well-defined contrasts (for example, small and large, light and heavy) instead of multiple intermediate options.
* maintain a balanced variety that stimulates exploration without overwhelming participants.
* prioritise clarity and distinctiveness over quantity, as a smaller, curated set enhances focus and interpretive precision.

Reflective questions:

* how many versions of each property are needed to express meaningful differences?
* does the current selection encourage reflection or lead to indecision?
* are the contrasts strong enough to guide participants toward distinct sensations and interpretations?

5. Organise coherently

Definition: the materials in the kit should be arranged and categorised to make their relationships clear and to support intuitive navigation across sensory dimensions.

Rationale: during the workshops, participants felt disoriented when categories were incomplete or inconsistently displayed. A coherent organisation of materials helps them identify relationships and move logically through the activity. When clearly structured, the layout itself becomes a cognitive tool that supports comparison and reflection while preserving openness for discovery.

Practical implications:

* group materials by recognisable criteria such as size, weight, or texture, ensuring visual and tactile clarity.
* include both extremes within each category to enable effective comparison.
* arrange materials in a clear and accessible layout, such as ordered cases or rows, so that contrasts can be perceived immediately.

Reflective questions:

* are categories complete and balanced, allowing for easy comparison?
* does the physical arrangement of materials support intuitive navigation and clear perception of contrasts?
* how might the spatial organisation influence participants' focus, interpretation, and decision-making?

6. Prioritise sustainability and ethical care

Definition: the material kit should embody ethical and environmental responsibility, ensuring that design and use reflect care for participants and the planet.

Rationale: feedback from the workshops highlighted the need for materials that are safe, comfortable to handle, and reusable. Participants recognised how choices of origin, durability, and waste affect both environmental impact and personal responsibility.

Practical implications:

* select non-toxic, durable, and recyclable materials that can be reused across sessions.
* use stackable or modular containers for transport and storage.
* reflect on the afterlife of materials, such as how they can be repaired, repurposed, or returned to circulation after the activity.

Reflective questions:

* are the chosen materials recyclable and durable enough for reuse?
* how can the same kit be transported and reassembled across multiple sessions without degradation?
* how will materials be stored, maintained, or disposed of responsibly after use?

9.4.2 Summary of the material selection

The material kit forms the tangible dimension of the Apparatus, supporting participants in translating embodied sensations into physical form. Rather than prescribing a fixed collection of components, this section outlines the conditions that guide their selection. Six principles, developed from practice-based evidence and participant feedback, summarise these conditions and offer guidance for choosing and preparing materials suited to different research contexts. Together, they encourage facilitators to consider how materials act as active agents in meaning-making and how their properties shape the interpretive possibilities of the Apparatus.

The next section expands this perspective into the analytical domain, introducing the cross-format interface and repository developed to document, compare, and interpret the multimodal outcomes produced through the Apparatus. This final component extends the process from material engagement to analytical reflection, ensuring that the knowledge generated through making can be examined, shared, and reinterpreted over time.

9.5 The cross-format interface for analysis

The cross-format interface represents the analytical dimension of the Apparatus. While the labels, protocol, and Data-Probes support the participatory production of data, this final component connects the multimodal outcomes of those activities within a unified analytical space. My aim in developing this part is to make visible and comparable the relationships between material, linguistic, and performative expressions, allowing meaning to be understood across different formats.

The need for such an environment arises from the dual nature of the Data-Probes produced by participants and the role of materiality within this research. These artefacts function both as expressive outcomes, formalising embodied data into material representation, and as analytical units that reveal how meaning develops through making and dialogue. Analysing the aspects of the artefacts alone would overlook the interpretive exchanges that accompany their creation, while focusing only on language and context of creation would miss the embodied knowledge embedded in material manipulation. I designed the interface to address this interdependence by linking words, gestures, and objects, enabling a dynamic form of analysis that connects the outcome of the process with the conditions that produced it.

This intervention responds to a broader challenge within process-oriented data physicalization, where analysing and communicating the variety of outcomes

remains complex. Through this integration, the Apparatus extends from material engagement to analytical reflection, transforming the dynamic process of making into a space for interpretation. The interface ensures that the knowledge generated through participation can be documented, explored, and reinterpreted over time, sustaining the continuity between experience, analysis, and reflection.

9.5.1 Integrating multimodal data

The workshop generated multiple forms of data, including written reflections, symptom definitions, audio transcripts, artefact images, material components, contextual observations, and presentation narratives. These materials needed to be organised together because the meaning of each artefact could only be understood by relating what participants made, what they said, what materials they selected, and how they explained their choices.

A comparative table on Excel was first developed to bring these outputs into a single analytical structure. The table responded to the methodological need to collect and organise multimodal data in a way that supported comparison across participants and workshop sessions. It made it possible to place textual, visual, material, and contextual information side by side, allowing each participant's artefact to be read in relation to their symptom descriptions, material choices, and verbal explanations.

Participants form the primary entries in the table because their experiences and artefacts are the central units of analysis. Reading the table from left to right, each row brings together the following information:

- workshop session date, participant ID, and participant role;
- described condition (UTI, cystitis, or eventually others);
- definition of "symptom" provided during the icebreaker;
- written description of the disease submitted before the session (original text and translation if not in English);
- participant's final description of the artefact, transcribed from audio recordings (original transcription + translation if not in English);
- Data-Probe artefact ID and list of components used to build the artefact;
- compositional interpretation, describing the physical structure and arrangement;
- contextual description (outlining the interactions, decisions, and dynamics observed during the artefact's creation – from the workshops' conversation recordings).

The table made the analytical complexity of the workshop visible. It showed that embodied data was distributed across several formats rather than contained in one output. A material component gained meaning through the participant's account, the symptom–variable association, the artefact composition, and the interaction that occurred during making. The table therefore supported a first level of comparison by keeping these data types connected within the same structure.

At the same time, the table revealed the limits of a static format. It could organise the data by participant and category, but it offered limited support for tracing meanings across entries, following recurring symptom–variable associations, or moving fluidly between images, transcripts, components, and contextual notes. The density of the material made comparison possible but difficult to navigate.

The cross-format analysis interface was developed in response to this need. It extends the comparative logic of the table into an interactive environment where connections can be traced across artefacts, symptoms, materials, variables, narratives, and observations. Presented in the project repository (https://ginevraterenghi.github.io/data-probes/index.html), the interface preserves the specificity of each participant's entry while supporting a more flexible exploration of patterns, relations, and meanings across the dataset.

In this sense, the table represents the first step in organising multimodal workshop data, while the interface develops that structure into a more responsive analytical tool. Together, they demonstrate the importance of collecting, organising, and comparing the different forms of data produced through the Apparatus during participatory physicalization.

9.5.2 Deconstructing for re-constructing

This section describes the appearance and structure of the cross-format interface, outlining the data included and how it is organised to support analysis. The interface enables the exploration of each artefact through a dedicated page where textual and visual information is presented side by side (Figure 9.4). On this page, the artefact is shown together with the participant's description, the symptoms represented, and the materials used to shape them. Coloured layers highlight the symptoms referenced in the participant's account, together with the corresponding words and material components associated with each symptom. This visual system supports close interpretation by allowing the material representation to be compared with the related verbal and written accounts. It also makes visible how specific symptoms are translated into physical variables and material choices.

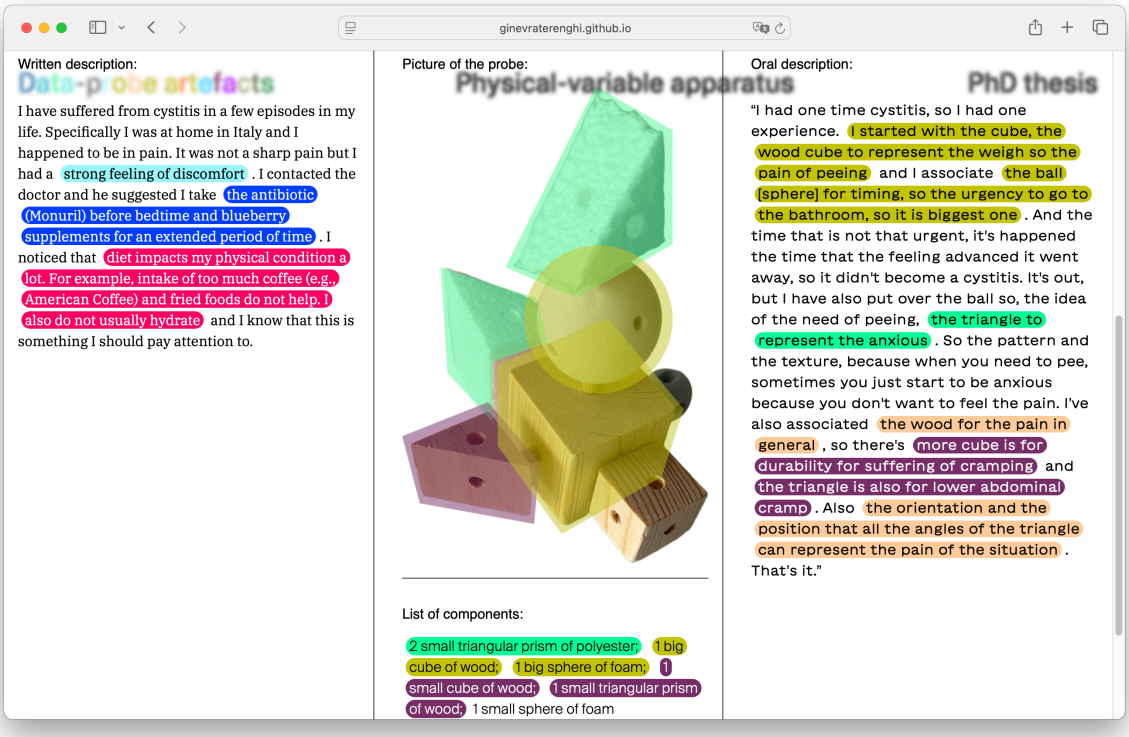


Figure 9.4: a detailed view of Data-Probe artefact 10, showing information specific to this artefact and enabling comparison across data formats.

This detailed exploration is accessed through the main landing page (Figure 9.5), where all the artefacts produced during the workshops are collected and displayed together. The landing page provides an overview of the results and introduces the range of materials, forms, and combinations used by participants. From this collective view, users can browse the complete set of artefacts and select individual cases for closer analysis. In this way, the landing page situates each artefact within the broader workshop outcomes, while the dedicated artefact pages support a more focused reading of the relations between symptoms, words, and materials.

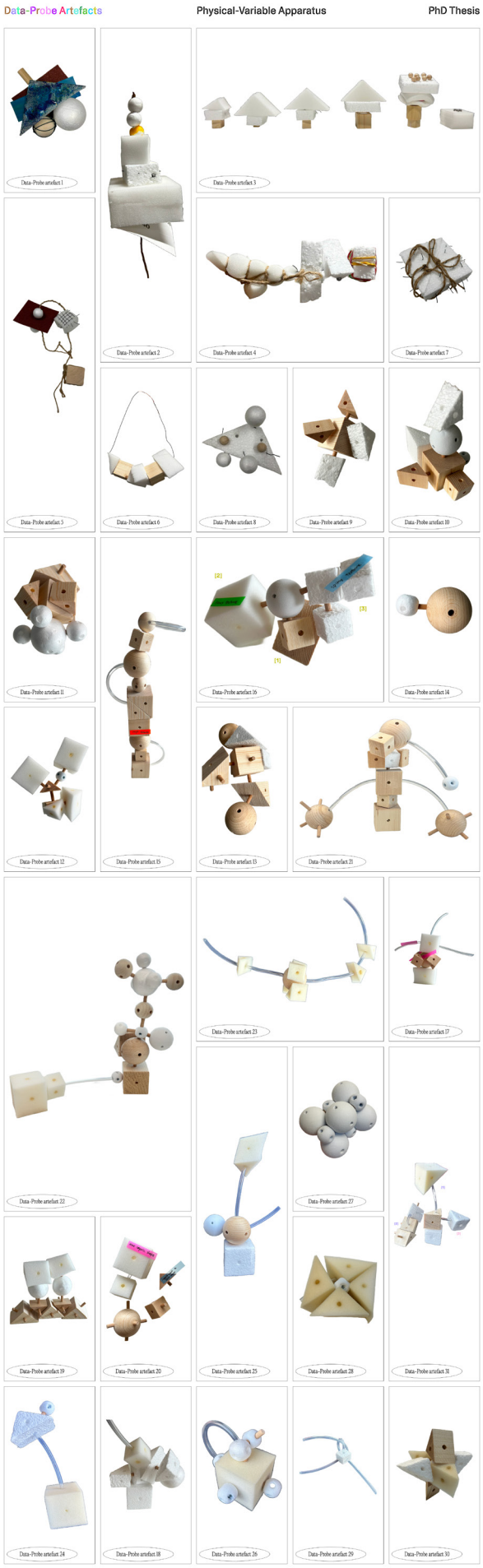


Figure 9.5: a screenshot of the project repository interface, displaying all Data-Probe artefact images and the corresponding pages used for analysing and comparing textual and visual outputs produced during the workshop activities.

The descriptions provided by participants, both before and at the end of the activity, are considered to identify the symptom representations within each artefact. Different fonts are adopted to indicate the original format of each description: a serif font for written input provided by participants before the activity (Figure 9.6), and a sans-serif font for text derived from the transcript of the oral artefact description provided by the participants at the end of the activity (Figure 9.7).

This is how one of the participants (P10) describe her experience and probes before and at the end of the activity:

I have suffered from cystitis in a few episodes in my life. Specifically I was at home in Italy and I happened to be in pain. It was not a sharp pain but I had a strong feeling of discomfort. I contacted the doctor and he suggested I take the antibiotic (Monuril) before bedtime and blueberry supplements for an extended period of time. I noticed that diet impacts my physical condition a lot. For example, intake of too much coffee (e.g., American Coffee) and fried foods do not help. I also do not usually hydrate and I know that this is something I should pay attention to.

Figure 9.6: the initial description of the disease (cystitis) provided by P10 before taking part in the workshop.

"I had one time cystitis, so I had one experience. I started with the cube, the wood cube to represent the weigh so the pain of peeing and I associate the ball [sphere] for timing, so the urgency to go to the bathroom, so it is biggest one. And the time that is not that urgent, it's happened the time that the feeling advanced it went away, so it didn't become a cystitis. It's out, but I have also put over the ball so, the idea of the need of peeing, the triangle to represent the anxious. So the pattern and the texture, because when you need to pee, sometimes you just start to be anxious because you don't want to feel the pain. I've also associated the wood for the pain in general, so there's more cube is for durability for suffering of cramping and the triangle is also for lower abdominal cramp. Also the orientation and the position that all the angles of the triangle can represent the pain of the situation. That's it."

Figure 9.7: the description of the illness experience made through the presentation of the artefact at the end of the activity from the same participant (P10).

Based on the descriptions of the results provided by participants at the end of the activity, the artefact was visually deconstructed into its material components to trace how symptoms were represented. Physical elements and associated words were identified in the image and assigned colour codes according to the symptoms they expressed, creating distinct layers of meaning.

Figure 9.8 shows the decomposition of Data-Probe 10 (DP10) into layers corresponding to anxiety, the need to urinate, and cramps.

This process was applied to all Data-Probe artefacts, with each symptom represented by a distinct colour. In total, twenty-five symptom categories were identified, although they do not all appear on every artefact page. Only the symptoms mentioned orally or in writing by participants are included in the legend of each page.

One participant also referred to a “normal condition,” which was added to the list together with other related categories such as treatments, causes, multiple factors, and doctor intervention. These elements were included, even though they are not symptoms, because participants identified them as important for contextualising and explaining the symptoms that emerged through the analysis.

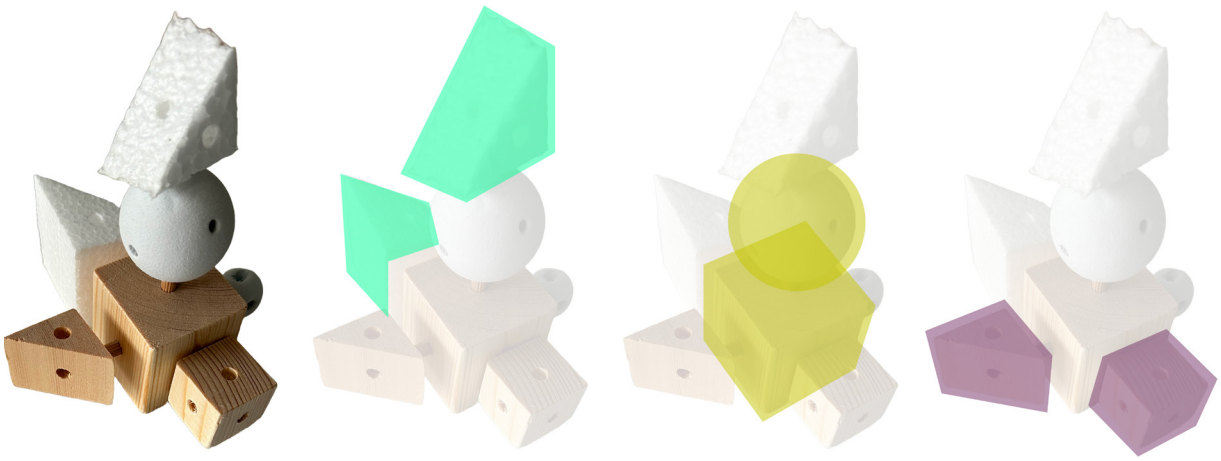


Figure 9.8: process of layering and decomposition. Each coloured layer represents a different symptom and has been created directly on the image. From the cross-format interface, layers can be shown or hidden interactively using buttons that reveal them according to the selected symptom.

9.5.3 The legend for comparison

The final interface brings together the written descriptions, the artefact images with their corresponding symptom layers, and the list of components used to create each artefact. These elements are interconnected through an interactive legend that allows users to select or deselect symptoms according to their analytical focus. Positioned at the top of the page, the legend makes it possible to isolate individual symptoms or compare several at once by showing or hiding their visual layers.

The legend is accompanied by contextual information displayed in the header, including the workshop session number, participant ID, and profile. Each symptom acts as a button that highlights its corresponding representation within both the image and the text. By default, the interface displays all symptoms and their related text, colour-coded to match the visual layers. When a symptom is deselected, its associated layer disappears, leaving only the original data. Users can combine or filter different symptoms, as illustrated in Figure 9.9, where the view shifts from highlighting both anxiety and cramps to focusing solely on anxiety.

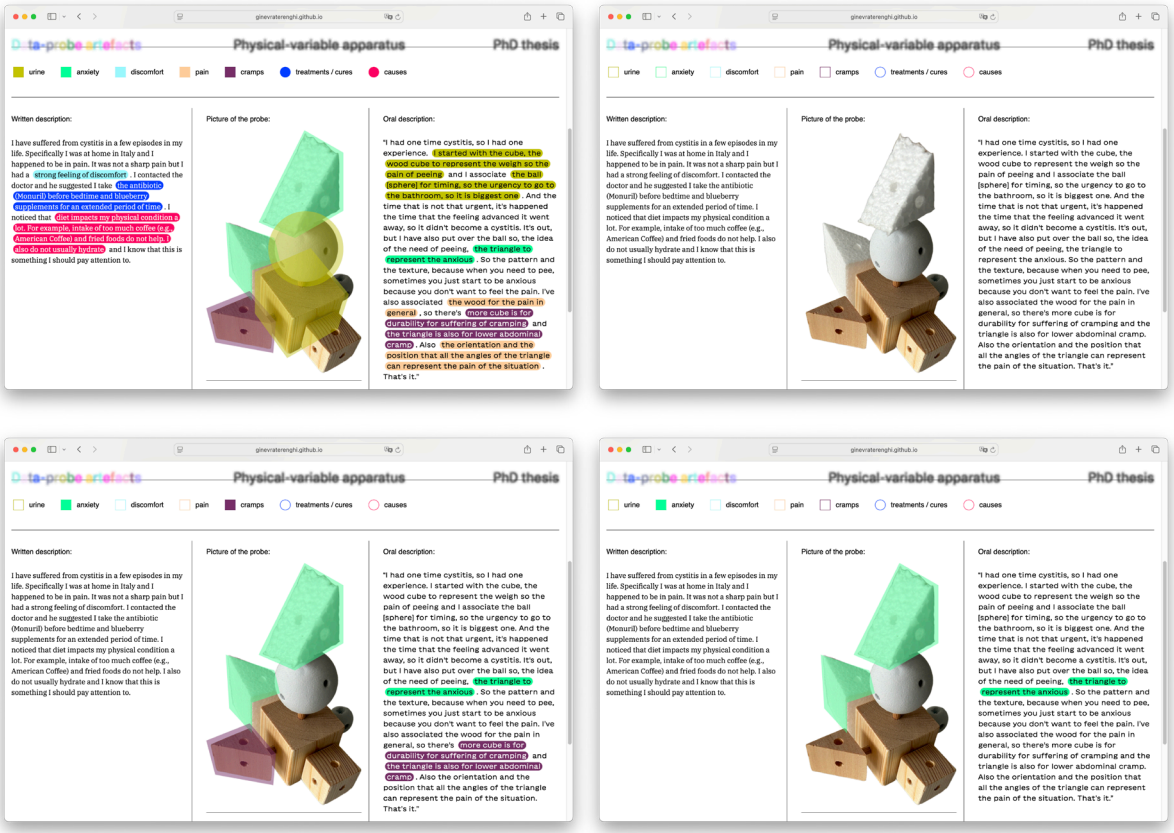


Figure 9.9: four screenshots of the same result (Data-Probe10) showing how the interface responds when different symptoms are selected. Coloured layers appear on the image to highlight how the participant used materials to represent each symptom, while corresponding words in the text are also colour-highlighted. In the first screenshot (top left), all symptoms are selected. In the top right, none are selected. The bottom left shows “anxiety,” “causes,” and “cramps” selected, while the bottom right displays only “anxiety.”

This visual display enables comparison across participants and sessions, revealing both recurring strategies and individual variations in how experiences are expressed. By linking visual composition with verbal description, the interface preserves the dialogue between material and discursive representation that underpins the epistemic logic of the Apparatus. Through this connection, the interface transforms the documentation of participatory outcomes into an active space for reflection, where relationships between making, language, and interpretation continue to generate new insights.

9.5.4 Future potentialities

This first implementation of the interface serves primarily as an analytical tool for this research, providing a structured environment to connect conversation transcripts and material artefacts. I used the interface exclusively to analyse and present the results of this thesis, yet making it publicly available online represents an effort to share the approach and inspire its further development. Although no usability or analytical assessments have been conducted, this first version serves as an initial prototype that can evolve through future testing, adaptation, and collaborative use within participatory data physicalization projects. Future developments could strengthen its methodological and collaborative functions by integrating video recordings of gestures and interactions with materials, adding a layer of analysis to the process. Additionally, enabling collaborative annotation by both participants and researchers would transform the interface from an analytical tool into a shared space for co-reflection, where multiple interpretations can coexist and evolve.

9.5.5 Conclusion on the cross-format interface for analysis

The cross-format analysis interface completes the Apparatus by transforming the participatory and material process into a form that can be documented, interpreted, and shared. This component ensures that the knowledge generated through material engagement remains accessible for comparison, reinterpretation, and dissemination over time, creating continuity between the act of making and the process of analytical reflection. By connecting material, linguistic, and digital dimensions of enquiry, the interface reinforces the Apparatus's capacity to make embodied experience visible, interpretable, and collectively meaningful.

The next section presents an application of the Apparatus in a context that extends this thesis, providing an opportunity to work with other experts and to test the components in a different environment.

9.6 The application of the Apparatus beyond this thesis

I applied the Apparatus for the first time beyond the doctoral research within the workshop Health Self-Revealed: Exploring Self-Narratives and Data Physicalization Practices Towards a Shared Design Vocabulary conducted during the EKSIG 2025 Conference in Budapest. EKSIG ('Experiential Knowledge Special Interest Group') is an international design research conference that focuses on how knowledge is generated through practice, experience, and material engagement. The detailed description of the activity is available from the proposal submitted with Sara Lenzi and currently uploaded to my Zenodo account (Terenghi and Lenzi, 2025). This setting provided an ideal context for me to extend the Apparatus and observe how it could operate among design researchers accustomed to reflective and process-based inquiry. Besides this, the workshop offered the occasion to collaborate with Dr Sara Lenzi, a designer and sound researcher whose expertise in sonification and auditory display guided the integration of sound into the activity. Lenzi's work focuses on the use of sound as a medium for data communication and sensory inquiry, combining design practice with research on auditory perception and embodied experience (Lenzi et al., 2024). Her contribution provided a complementary perspective that allowed the Apparatus to be extended into the auditory domain.



Figure 9.10: Sara Lenzi introducing the activity and sonification variables during the workshop at EKSIG Conference, Budapest 2025. Picture from myself.

Figure 9.10 is taken from the introduction of the activity during the EKSIG Conference, at Moholy-Nagy University of Art and Design, on May 12th, 2025. The workshop focused on exploring sound as an autographic method for representing symptoms, building on insights from this thesis workshops in which participants recognised sonic qualities as meaningful extensions of material engagement (Chapter 6). Building on these insights, the activity developed for EKSIG investigated how sound can unfold from physical interaction with materials and how it can contribute to the communication of embodied sensations.

Through this collaboration, the Apparatus was adapted to explore the relationship between touch, gesture, and auditory expression, expanding its scope beyond the original context while maintaining its methodological foundations.

9.6.1 Adaptation of the Apparatus

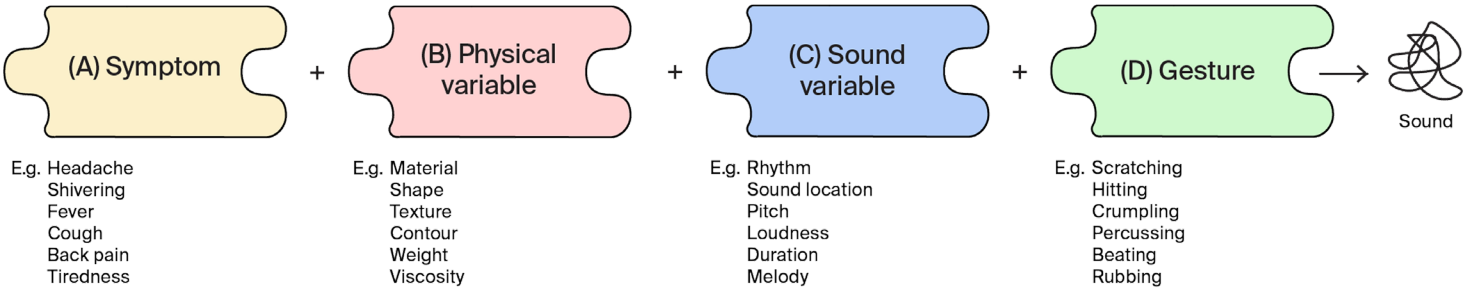
The workshop took place in person and lasted about three hours. Around fifteen participants, all with a background in design research and practice, took part in the activity. They were organised into three groups, each sharing a table equipped with stationery, printed labels, and a wide selection of materials chosen for their tactile and acoustic diversity. These included wood, polystyrene, foam, sandpaper, fabric, bamboo sticks, metal rods of different diameters (some ridged or concave), cardboard, metal spheres, sponge rubber, aluminium foil, a transparent PVC sheet, and a cork sheet (Figure 9.11). The materials were selected for the range of sounds they could produce and gathered according to their availability and ease of sourcing. The environment was kept informal to encourage discussion, experimentation, and collective listening.

In this new context, the Apparatus retained its original purpose of supporting the externalisation of embodied experiences through participatory and material engagement, but its structure was adapted to the specific aim of the workshop. Since the activity sought to investigate the relationship between physical elements and sonification, a new set of sound variable labels was introduced to complement the existing physical ones. In parallel, gesture labels were incorporated to draw explicit attention to the actions through which sound emerges.



Figure 9.11: workshop set-up. The table displays the materials provided for participants to create sounds representing their symptoms.

The addition of gestures responded not only to the practical need of activating sound but also to insights from the analysis of previous workshops, where gesture had repeatedly surfaced as a crucial element in how participants interacted with materials and externalised sensations. While touching a texture or weighing a component often occurs naturally and is perceived as an integrated act of sensing, producing sound requires a more deliberate and physical engagement. The inclusion of these two new categories expanded the expressive range of the Apparatus, enabling participants to move between perception and action, and to explore how sound can emerge as a continuation of material interaction.



[Top]

Figure 9.12: mapping process through the labels available for the activity. The first set describes symptoms; physical and sound variables are then presented together with gestures to enable the interaction.



[On the left]

Figure 9.13: workshop set-up. Sets of labels ready for the activity.

The labels were produced in different colours (yellow, red, blue, and green) to help participants distinguish them easily and collaborate effectively (Figure 7.12–9.13). Their shape was intentionally designed to be bidirectional and open, allowing flexible connections and continuous rearrangement. This openness was essential because one of the main interests of the workshop was to examine the reciprocal relationship between material and sound, and how sound could inspire the selection of a material, and how the qualities of a material could in turn suggest or generate a sound. By leaving the structure open, participants were free to follow either pathway, encouraging exploration of the mutual influence between tactile and auditory perception.

9.6.2 Exploring material–sound relations through the Apparatus

Within the Health Self-Revealed workshop, the labels acted as mediators connecting perception, gesture, and collective interpretation. Participants selected and arranged symptom labels such as “tension,” “pressure,” or “instability,” and linked them with

physical and sound variables like “vibration,” “rhythm,” or “texture.” This mapping process fostered a multimodal form of reasoning, where meaning emerged from the relations between elements rather than from individual associations. By linking each symptom to a sound and identifying the gesture needed to produce it, participants transformed personal sensations into shared expressions.

As in the previous two workshop sessions (WS4 and WS5), the activity did not begin with a predefined disease. Instead, participants were given labels describing general symptoms and were asked, within each group, to agree on a condition to represent based on shared experience. Empty or modifiable labels were used to add or adapt symptoms that better reflected collective perception, rather than to expand medical knowledge of the condition. These additions served to establish a shared reference for expression and collaboration. No new physical or sound variables were introduced, as the existing set already offered a wide expressive range, particularly since physical and acoustic variables were presented as separate categories.

This process confirmed the iterative nature of the Apparatus and its capacity to support collective negotiation of meaning, allowing participants to align around common sensory interpretations rather than factual descriptions.



Figure 9.14: Group 1 during the final performance, presenting to others their symptoms and corresponding sounds. The group described having read the labels as a kind of musical score, where each member “played” a symptom. The arrangement of labels was also used to indicate when sounds should begin and end, creating a shared temporal structure for the performance.

Within this context, sound particular prompted participants to perceive symptoms as unfolding events rather than fixed conditions, emphasising their temporal and causal dimensions. In several cases, groups arranged symptoms along a timeline that moved from a state of health to one of illness, using acoustic features to mark transitions and relations. Smooth metal sticks, for example, produced an initiating sound described as “the beginning of an orchestra,” (Group 1) symbolising the onset of discomfort and the awareness that something had changed (Figure 9.14).

The workshop also revealed how the spatial and visual form of the labels influenced cognitive and collaborative dynamics. Their connectable shape enabled both linear and non-linear arrangements, allowing groups to organise experiences as timelines, clusters, or body maps. When symptoms were represented as concurrent, for example, participants placed their labels in parallel rather than sequentially, forming rhythmic compositions instead of static arrangements (Figure 9.15). Through these actions, sonification encouraged exploration of how experiences develop, overlap, and evolve over time. This flexibility mirrored the Apparatus’s methodological openness and showed that its physical design can guide reasoning and foster alternative modes of knowledge formation.

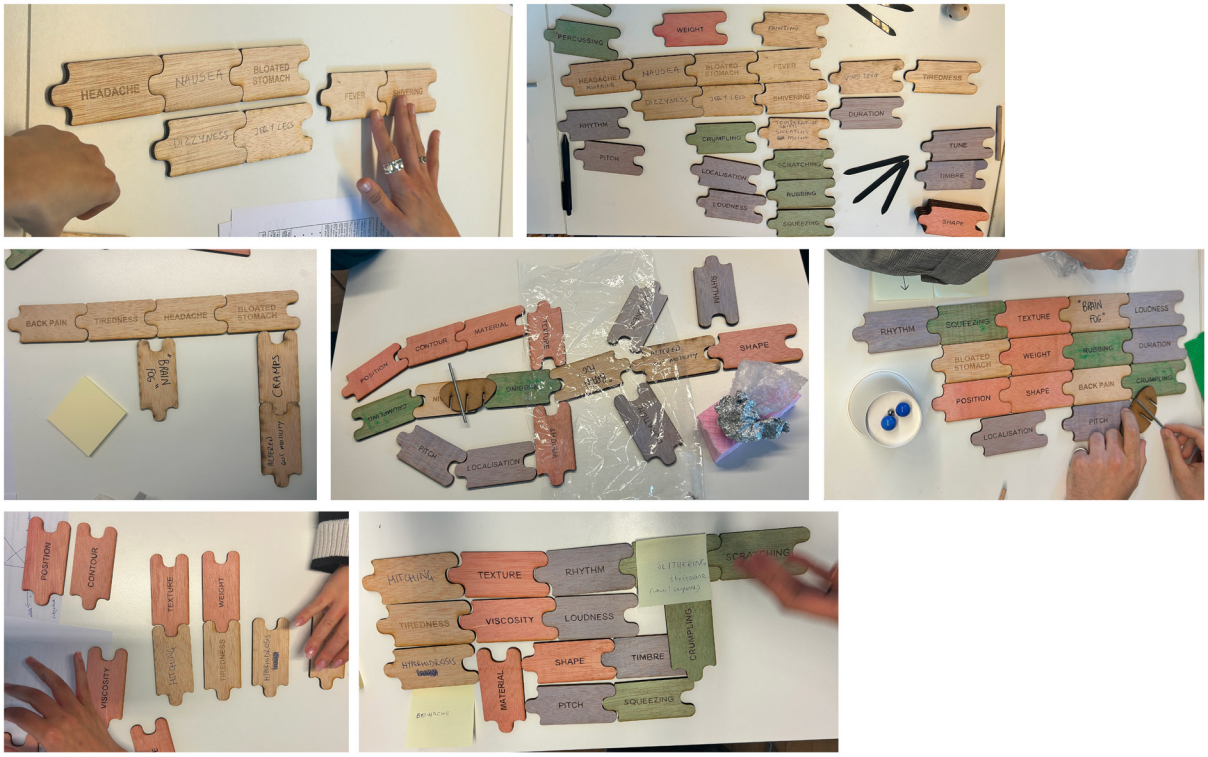


Figure 9.15: organisation of labels across the three working groups. From the initial identification and organisation of symptom labels to their final association with physical and sound variables, including the gestures used to activate each material.

The integration of sonic and gestural dimensions expanded the theoretical and methodological scope of the Apparatus toward a multimodal understanding of embodied data. Sound variables made the temporal qualities of symptoms perceptible, while gestures revealed tacit bodily knowledge through movement and interaction. During the workshops, gestures emerged as expressive actions rather than mere techniques for construction, confirming the initial highlights emerged from the other workshops. Participants pressed, pushed, tore, and deformed materials to externalise discomfort, often associating the intensity of gesture with the perceived severity or recurrence of symptoms. Actions such as twisting, destroying, or compressing conveyed sensations of tension, pressure, and persistence, transforming bodily experience into visible and performative expression.

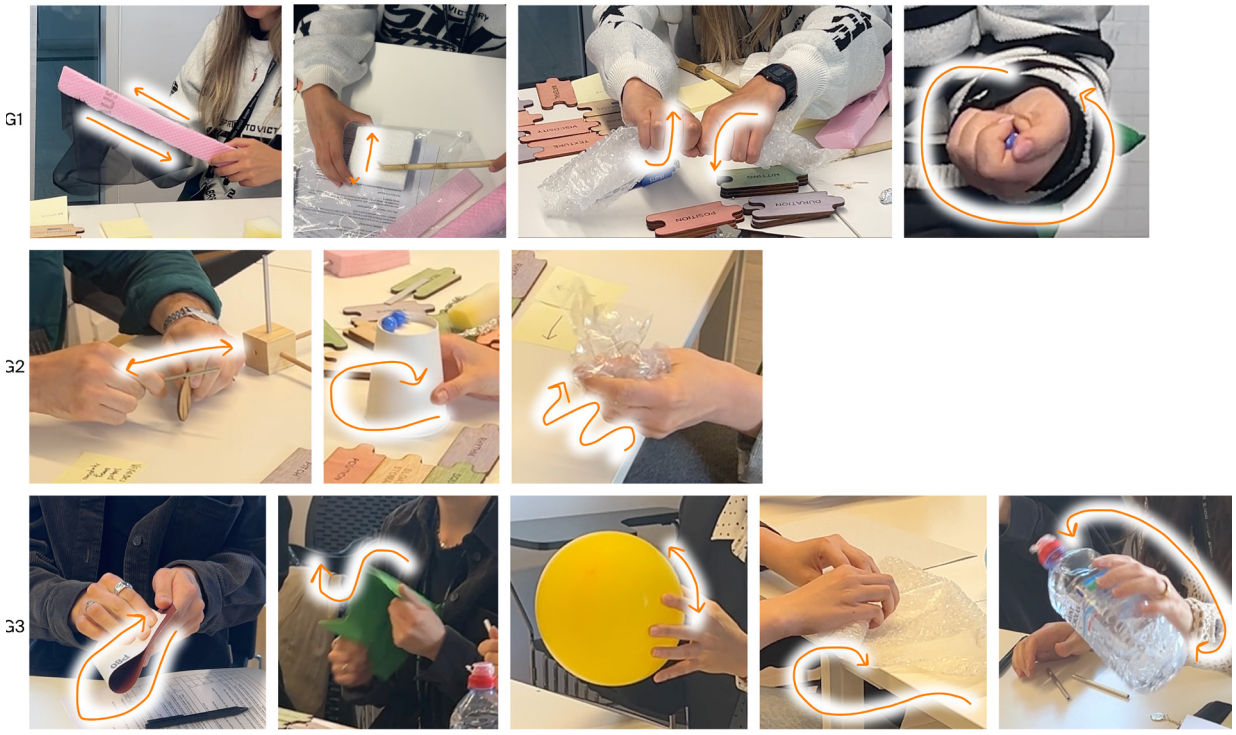


Figure 9.16: Identification of gestures performed by participants across the three groups to make materials produce sound. In some cases, a single component was moved, while in others two components interacted to generate sound—either both in motion or with one fixed and the other moved around or across it. Alongside the provided materials, participants also selected additional objects found on the table that they considered suitable for representing specific sounds. The orange narrows suggest the direction of the movement performed by the participant on the material. [G1, 2, 3] on the left-hand side identifies the working group.

Figure 9.16 highlights a selection of gestures participants performed as they manipulated the material to generate sound. In some cases, gestures were only imagined or narrated, yet they still revealed the participant's impulse to act upon the material as part of the meaning-making process. By activating the materials through gesture, participants enacted relations between the physical and emotional dimensions of illness. Together, sound and gesture complemented the material and linguistic layers of the Apparatus, extending its potential for multisensory and process-based inquiry and demonstrating how embodied movement can operate as a form of interpretation and collective sense-making.

In summary, the application of the Apparatus in this workshop confirmed its relevance beyond the specific context of UTIs. It proved effective as a participatory framework to elicit, articulate, and compare personal experiences of illness or discomfort, supporting dialogue through tangible and auditory expression. Some limitations also emerged during this process. Although sound variables were already part of the physical set, having them separated was useful to focus on sound production as the main topic of the workshop but occasionally created confusion due to overlaps and interrelations between certain variables. Participants' familiarity with sound qualities and vocabulary was limited, and understanding how sound emerges through material interaction required more guidance than expected. While physical features could be perceived directly by touching materials, the abstract and temporal nature of sound made it more difficult to describe and interpret, even with an introductory explanation. Additionally, documentation also presented challenges, as gestures needed to be recorded in real time to capture how sound unfolded through movement. Despite these complexities, the workshop demonstrated the Apparatus's adaptability and its potential as a living methodological tool that evolves with each new use, supporting the production of shared understanding across diverse contexts.

9.6.3 Rethinking materials and gestures in the Apparatus

As confirmed by the Health Self-Revealed workshop, the specific components of the Data-Probe kit are not fundamental but rather they work as facilitators to prompt the use of variables. During the EKSIG session, participants worked with a less structured and more varied collection of materials than those used in the original workshops, yet the activity still succeeded in generating meaningful discussions and expressive results. This confirms that the effectiveness of the Apparatus depends not on the specific materials provided but on the way participants engage with their sensory and conceptual properties. Materials act as mediators that trigger exploration, comparison, and reflection, helping participants externalise sensations through texture, weight, or resistance. Their function is therefore to enable interaction

rather than to define the method or the outcomes of the process.

On the other hand, as shown by the analysis of earlier workshop sessions, gesture assumed a more explicit role than the one currently accounted for in the Apparatus, where it is not explicitly addressed. A specific set of gesture labels was integrated to investigate how movement contributes to the production of meaning. The EKSIG workshop confirmed the importance of this dimension, particularly when materials are explored and valued for the actions they can enact through physical engagement. Gestures expanded the expressive potential of materials, introducing a performative layer to the representation of sensations. In several cases, participants selected materials based on the gestures they imagined performing, such as rubbing, striking, or compressing, indicating that movement not only enriches the meaning of a material but can also determine its selection.

These observations suggest that gestures may become a formal component of future iterations of the Apparatus. Recognising gestures as a distinct set within the system would allow their expressive and interpretative roles to be emerge more systematically, supporting further investigation into how bodily action and material response co-produce meaning. In this sense, the Apparatus continues to evolve within a methodological perspective that prioritises relational engagement over predefined form, shifting focus from artefact design to the conditions that make participation, interpretation, and collective understanding possible.

10. CONCLUSION. PHYSICAL VARIABLES FOR PARTICIPATORY HEALTHCARE

This doctoral thesis investigates how embodied health experiences can be perceived, articulated, and communicated through participatory data physicalization. The research focuses on women's experiences of urinary tract infections (UTIs) as a situated context in which symptoms are often intimate, recurrent, difficult to verbalise, and shaped by gendered healthcare dynamics. In response, the thesis examines how material engagement, physical variables, and participatory methods support women in expressing lived experiences as meaningful and communicable forms of knowledge.

The thesis develops the Shape Your Symptoms workshops, the Data-Probes material components, and the Physical-Variable Apparatus to explore how symptoms move from personal sensation to material expression, and from material expression to shared interpretation. Through this process, physical variables are reframed from design elements used to represent data into methodological instruments for eliciting, interpreting, and comparing embodied experience.

This concluding chapter brings together the overall trajectory of the research. It summarises the key findings, addresses the three research questions, clarifies the methodological, theoretical, and empirical contributions, and considers the limitations of the study together with the open questions they generate for future work.

10.1 Summary of research and key findings

This thesis investigates how participatory data physicalization can support the articulation, interpretation, and communication of embodied health experiences. The research is situated in the context of women's experiences of UTIs, a condition that is common, recurrent, intimate, and often difficult to describe within

clinical encounters. UTIs are among the most common bacterial infections and disproportionately affect women because of anatomical factors (Kaur and Kaur, 2020). This clinical reality is further shaped by structural biases that influence how women's conditions are perceived, recorded, and treated in healthcare (Perez, 2019; Almeida et al., 2020a; Bever, 2022; Billuart, 2024). In this context, the central aim of the thesis is to examine how material and participatory practices can strengthen women's capacity to express symptoms and contribute to healthcare knowledge grounded in lived experience.

The study is guided by three research questions. RQ1 examines how participatory design practices can expand healthcare enquiry by enabling women to articulate embodied experience and contribute to the co-creation of knowledge. RQ2 focuses on how material engagement can support the interpretation and communication of intimate and embodied experiences within participatory data physicalization practices. RQ3 asks how physical variables can transform individual interpretations of embodied experience into collective knowledge. Together, these questions shape the theoretical, methodological, and empirical trajectory of the thesis.

Chapter 2 establishes the theoretical foundation of the research. It frames symptoms as embodied, situated, and interpretive phenomena, drawing on biosemiotics (Hoffmeyer, 2005), autographic design (Offenhuber, 2019), feminist accounts of situated knowledge (Haraway, 1988), material engagement, and data physicalization. Biosemiotics and autographic design support the understanding of symptoms as bodily signs and traces that acquire meaning through perception, recognition, and interpretation. Haraway's account of situated knowledge positions the body as both a source and interpreter of evidence, emphasising the importance of partial, contextual, and lived perspectives in knowledge-making.

Chapter 3 translates this theoretical framing into the Shape Your Symptoms methodology. The chapter introduces physical variables and Data-Probes as the two central methodological components of the workshop. Physical variables are defined as material and perceptual qualities, such as texture, weight, shape, sharpness, resistance, permeability, and blurriness, used to support the elicitation and interpretation of embodied sensations. Data-Probes are introduced as the material components through which participants can explore these variables, construct artefacts, and communicate symptoms through making. The workshop format is designed to move from personal reflection to group discussion, from symptom–variable associations to artefact-making, and from individual expression to shared interpretation.

Chapter 4 presents the visual results of the Data-Probes artefacts produced during the workshops. The chapter documents how participants materialised their experiences through shapes, materials, connections, and spatial arrangements,

and it contextualises these artefacts through participants' explanations and workshop conversations. This visual documentation provides the empirical basis for understanding how symptoms are translated into tangible forms and how the Data-Probes support material expression.

Chapter 5 develops the analysis of the workshop results in relation to the health topic. It examines how participants articulate experiences of UTIs and related intimate conditions across prevention, symptom recognition, diagnosis, consultation, and treatment. The analysis highlights how participants connect symptoms to everyday practices such as hydration, diet, hygiene, and self-management, while also describing recurrence, uncertainty, fear of pain, emotional burden, and relational tensions. These findings show how participants' accounts extend beyond biomedical descriptions of infection to include situated forms of knowledge about how symptoms are recognised, anticipated, managed, and communicated.

Chapter 6 examines the methodological findings of the workshops. It focuses on how participatory data physicalization, physical variables, Data-Probes, material engagement, gestures, and artefact-making support the interpretation and communication of embodied experience. Through physical variables, participants associate sensations with material qualities such as sharpness, heaviness, blurriness, rhythm, and permeability. These associations make symptoms more tangible and discussable, while preserving their complexity and openness to interpretation. The chapter therefore explains how material engagement transforms individual and tacit experiences into forms that can be compared, analysed, and collectively interpreted.

Medical experts provide feedback on the key findings and help contextualise the analysis within healthcare settings. Their interviews, discussed in Chapter 7, address both the topic of UTIs and the methodological use of data physicalization. Twelve healthcare professionals specialising in infectious diseases, UTIs, and antibiotic resistance review selected workshop outcomes, including written narratives, artefact descriptions, and conversation excerpts. Their feedback confirms the clinical coherence of many participant descriptions and recognises the potential of metaphors, contrasts, and materiality to convey sensory and affective nuances often absent from biomedical language. Their reflections also clarify the limits of the method, particularly the need to distinguish between symptoms, consequences, emotional responses, and clinical indicators.

Chapter 8 develops the discussion of the thesis contribution. It clarifies how physical variables and Data-Probes, introduced in Chapter 3 as methodological components, emerge through the results as contributions to participatory data physicalization. Physical variables are reframed as interpretive, generative, relational, and situated resources that support the movement from bodily sensation

to material expression and from individual interpretation to collective understanding. Data-Probes are discussed as the material system that makes physical variables usable in practice, supporting artefact-making, communication, and analysis. The chapter also examines participation, material engagement, autographic extensions, metaphor and allegory, and the implications of the work for measurement, validity, and clinical knowledge.

Building on this discussion, Chapter 9 consolidates the Physical-Variable Apparatus as the methodological outcome of the thesis. Drawing on Barad's notion of material-discursive arrangements through which phenomena become knowable (Barad, 2007), the Apparatus brings together four interconnected components: symptom and physical-variable labels, the workshop protocol, the Data-Probes material kit, and the cross-format analysis interface. Together, these components provide a structured yet adaptable method for eliciting, materialising, comparing, and interpreting embodied experience. The Apparatus is positioned as most appropriate for participatory contexts involving subjective, recurrent, intimate, or difficult-to-verbalise experiences, and as a complementary support for healthcare communication rather than a diagnostic tool.

Overall, the thesis positions participatory data physicalization as a process of situated knowledge-making. It shows how embodied experience can be generated, interpreted, and shared through the interaction of bodies, materials, gestures, artefacts, and conversations. By integrating physical variables, Data-Probes, and participatory methods, the research contributes a design-led approach for making lived experience perceptible, communicable, and available for collective interpretation within healthcare and related contexts.

10.2 Addressing the research questions

This section revisits the three research questions introduced in Chapter 1 and explains how the thesis responds to them through its theoretical framing, methodology, empirical results, expert assessment, and discussion. The questions follow the trajectory of the thesis. RQ1 examines participation in healthcare enquiry. RQ2 focuses on material engagement as a way to interpret and communicate embodied experience. RQ3 addresses physical variables as the structure through which individual interpretations become available for collective understanding.

Across the thesis, these questions are addressed progressively. Chapter 2 establishes the theoretical basis for understanding symptoms as embodied, situated, and interpretive phenomena. Chapter 3 translates this position into the Shape Your Symptoms methodology through physical variables and Data-Probes.

Chapter 4 documents the visual results of the Data-Probes artefacts. Chapter 5 analyses the health-related findings on UTIs and related intimate conditions. Chapter 6 examines the methodological findings of the workshops. Chapter 7 contextualises the results through medical expert feedback. Chapter 8 discusses the contribution of physical variables and Data-Probes, and Chapter 9 consolidates these insights into the Physical-Variable Apparatus. Each research question is presented below with a more detailed account of how the research addresses it.

RQ1: how do participatory design practices expand healthcare enquiry by enabling women to articulate embodied experience and contribute to the co-creation of knowledge?

This research addresses the first research question by demonstrating how participatory design practices enable women to articulate embodied experience and contribute to the co-creation of knowledge in healthcare contexts. By shifting symptom description from an individual clinical task to a collective and interpretive process, participatory design expands healthcare enquiry and creates space for women to actively shape how their symptoms are perceived, understood, and communicated.

This position is grounded in the theoretical framework developed in Chapters 2 and 3. Chapter 2 situates the research within biomedical and gendered perspectives on healthcare, highlighting how dominant medical systems often marginalise women's embodied and experiential knowledge (Haraway, 1988; D'Ignazio and Klein, 2020). Within this context, participatory design redistributes agency in the production and interpretation of health data, positioning patients as contributors to knowledge-making.

Chapter 3 operationalises this perspective through the Shape Your Symptoms workshop. The methodology integrates co-creation, reflection, and material exploration to elicit experiential knowledge that is difficult to capture through conventional clinical tools. Design creates conditions for situated participation, where participants engage as co-investigators who shape both the process and its outcomes. This reframes the activity from data extraction to mutual construction, grounded in dialogue, material engagement, and shared interpretation.

Across the workshops, participatory design supports a movement from personal reflection to shared interpretation. Introspective activities help participants attend to bodily sensations, while collective discussion allows them to compare experiences, negotiate meanings, and refine symptom descriptions through dialogue.

This process supports distinctions between sensations such as discomfort and pain, and helps participants articulate complex experiences, such as burning, as both temporal and spatial phenomena.

The empirical findings develop this point across the disease trajectory. Participants discuss UTIs through prevention, symptom recognition, diagnosis, consultation, and treatment, connecting symptoms to everyday practices such as hydration, diet, hygiene, and self-management. They also describe recurrence, fear of pain, diagnostic uncertainty, emotional burden, and relational tension. These accounts expand the understanding of UTIs by bringing forward aspects of the condition closely tied to lived experience and everyday decision-making.

The expert interviews further support the relevance of this contribution. Medical experts recognise that symptom expression varies across patients and that patients may struggle to distinguish UTIs from other intimate or lower genital conditions. They also acknowledge that richer patient descriptions can add nuance to clinical communication, especially around symptom quality, intensity, progression, and everyday impact.

In response to RQ1, participatory design expands healthcare enquiry by creating a setting where embodied experience can be expressed, compared, and interpreted collectively. The knowledge produced through this process is contextual, relational, and grounded in lived experience, complementing biomedical interpretation with insights that are often difficult to capture through clinical categories alone.

RQ2: how does material engagement support the interpretation and communication of intimate and embodied experiences within participatory data physicalization practices?

The thesis responds to RQ2 by identifying material engagement as a means through which participants interpret and communicate sensations that are difficult to express through words alone. Data-Probes provide an external medium through which intimate symptoms can be explored, shaped, and discussed while remaining grounded in bodily perception.

The workshop results indicate that material interaction supports interpretation through touch, gesture, comparison, assembly, and explanation. Participants use materials to explore qualities such as pressure, weight, sharpness, softness, instability, permeability, and rhythm. In some cases, meaning emerges during making. One participant explained, “I would say first created and then I thought about what it could be” (P2, WS1), highlighting how construction itself supported interpretation.

Materiality operates as an active process of perception, interpretation, and communication within participatory data physicalization. The sensory feedback of materials supports introspection, while manipulating, assembling, and comparing components promotes reflection and dialogue. Materials also provide an external medium through which intimate or stigmatised experiences can be discussed with some distance. Within this process, subjects such as pain, incontinence, or sexual discomfort become approachable topics of shared exploration, supporting empathy and openness among participants.

Material engagement also helps participants communicate complex or affective aspects of symptoms. Some artefacts become figurative or metaphorical, such as a "boat" (P15, WS3), a "tree house" (P19, WS3), or a "cherry on the top of my cake… to make it more unstable" (P18, WS3). Other descriptions use sensory images such as "fire drops" (P2, WS1), "wood chips" (P6, WS1), and "hot pins stuck in the urethra" (P2, WS1). These examples show how materials and metaphors support the movement from internal sensation to communicable form.

The artefacts produced in the workshops function as tangible records of perception and reflection. They embody the process through which participants explore and interpret their experiences. Meaning develops through material interaction, where bodily awareness and cognitive reflection unfold together through sensing, making, and discussing.

The expert interviews reinforce this methodological value. At least four experts recognise that materials, metaphors, or physical prompts can support more precise or layered descriptions of symptoms than standard verbal reporting alone. One expert suggests that recurring patterns in images or textures could become analytically meaningful, observing that "if you basically find that certain groups of signs or symptoms ever tend to result in them using similar images or textures then that would be really something very interesting as an observation" (ME7). Another notes that such patterns would require validation to support more systematic clinical use (ME9).

In response to RQ2, material engagement supports embodied understanding by making internal experience perceptible, shareable, and open to dialogue. Within participatory data physicalization, it operates as a method of interpretation and discovery through which personal sensations become communicable knowledge. The artefacts and associations generated through this process form an initial level of embodied interpretation, which physical variables then structure, compare, and make available for collective healthcare enquiry.

RQ3: how do physical variables transform individual interpretations of embodied experiences into collective knowledge?

The thesis responds to RQ3 by positioning physical variables as shared interpretive references. Texture, weight, shape, sharpness, resistance, permeability, rhythm, blurriness, and density help participants relate bodily sensations to material qualities. Their contribution lies in creating a common vocabulary through which personal experiences can be clarified, compared, and discussed with others.

During the workshops, participants use physical variables to describe, compare, and categorise symptoms and bodily perceptions. Recurring associations emerge, such as pain with sharpness or heaviness, and incontinence with permeability or rhythm. These associations create shared reference points that allow participants to recognise similarities and differences across experiences while preserving personal and emotional nuance.

This process is especially visible during the association phase, where participants clarify the meaning of symptoms and variables before moving into artefact-making. When discussing density, participants relate the term to the consistency of syrup, using a familiar material reference to align their understanding of the variable (P20, WS3). This exchange shows how a material quality becomes a shared point of reference before being used to interpret symptoms.

Peer clarification also supports shared interpretation. The term incontinence prompts questions such as “What incontinence mean?” (P12, WS2) and “This is… incontinence? What is it?” (P19, WS3), before being explained as “when you cannot keep your… keep it inside” (P18, WS3). Through these exchanges, symptom labels and physical variables become shared references through which participants align meanings, test recognition, and refine the group vocabulary.

Physical variables support the movement from individual interpretation to collective understanding by giving situated sensations a structure for comparison. During group discussion, participants recognise resonances, identify differences, and negotiate which qualities best express a symptom. Collective knowledge emerges through clarification, comparison, and alignment, as individual interpretations become recognisable to others and available for further interpretation. This process makes personal sensations more understandable within the group and potentially more legible to medical expertise, where interpretation is shaped by clinical training and diagnostic practice.

This purpose is consolidated in the Physical-Variable Apparatus. The Apparatus structures how physical variables operate across participation, material engagement, and analysis, connecting symptom labels, physical-variable labels, Data-Probes

artefacts, workshop dialogue, and cross-format interpretation. In response to RQ3, the thesis demonstrates that physical variables support the transformation of personal sensation into shared interpretation, establishing participatory data physicalization as a method for making embodied experience communicable and collectively meaningful.

10.2.1 Participatory design as enquiry, materiality as mediation, variables as knowledge: synthesis of research questions

Taken together, my responses to the three research questions demonstrate the progressive development of the thesis from participatory design as enquiry, to materiality as mediation, and finally to physical variables for knowledge generation. The study shows how participation opens space for confrontation and dialogue, how materials make embodied data perceptible and comparable, and how physical variables transform these interactions into structured and interpretable knowledge. Through this progression, the research support the establishing of participatory data physicalization as a generative process in which knowledge emerges through engagement, reflection, and collective interpretation. This methodological and epistemological shift contributes a new understanding of healthcare data through participation, situating the body, materials, and interaction at the core of knowledge creation.

10.3 Contributions to knowledge

Situated at the intersection of design research, data physicalization, and women's healthcare, this thesis contributes to understanding how embodied experience can be articulated, interpreted, and shared through participatory and material practices. The contributions respond directly to the three research questions, which concern the role of participatory design in expanding healthcare enquiry (RQ1), how material engagement supports the interpretation and communication of intimate embodied experiences (RQ2), and consequently, how physical variables transform individual interpretations into collective understanding (RQ3).

The thesis contributes to knowledge by developing a design-led approach in which lived experience is considered situated, communicable, and materially interpretable. It clarifies how participatory data physicalization can support the co-articulation of experiential knowledge, making personal symptoms available for reflection, comparison, and dialogue. Rather than replacing biomedical evidence or

diagnostic categories, this approach enriches them by bringing forward the lived, affective, and contextual dimensions of symptoms.

10.3.1 Methodological contribution: from eliciting to analysing embodied data

The methodological contribution responds primarily to RQ2 and RQ3. It consists of a structured process for eliciting, materialising, comparing, and analysing embodied experience through physical variables, Data-Probes, and the cross-format analysis interface.

The first methodological contribution is the introduction of physical variables as instruments for structuring embodied interpretation. Physical variables provided shared points of reference through which participants could describe, compare, and relate bodily sensations while preserving personal meaning. Through qualities such as texture, weight, sharpness, permeability, rhythm, and blurriness, individual sensations became communicable and open to collective discussion. This directly addresses RQ3 by explaining how personal interpretations can become recognisable to others and available for shared understanding.

The second methodological contribution is the development of Data-Probes as the material system through which physical variables became usable in practice. Data-Probes enabled participants to externalise interpretations by creating artefacts through making, reflection, and dialogue. Their value lies in supporting the process from bodily sensation to material choice, from material choice to discussion, and from discussion to artefact construction and explanation. This addresses RQ2 by showing how material engagement can support the interpretation and communication of intimate embodied experience.

The third methodological contribution is the cross-format analysis interface, which connects artefacts, participant narratives, symptom labels, physical-variable associations, and contextual notes. This interface supports analysis across visual, textual, and material formats, allowing the researcher to trace how meanings emerged through the workshop process. It extends the contribution of Data-Probes by treating artefacts not only as final outputs, but as traces of interpretation, gesture, material decision-making, and discussion.

Together, these methodological contributions establish the Physical-Variable Apparatus as a structured but adaptable method for participatory data physicalization. The Apparatus supports the movement from elicitation to materialisation and from individual expression to shared interpretation. It provides a basis for future research on embodied data, participatory analysis, and healthcare communication.

10.3.2 Theoretical contribution: physical variables as instruments for situated knowledge-making

The theoretical contribution responds primarily to RQ3, while also extending the framing developed through RQ1 and RQ2. The thesis advances data physicalization by repositioning physical variables from design elements used to represent data into instruments for situated knowledge-making.

Existing work in data physicalization has recognised the importance of materiality in shaping perception and interpretation. This thesis extends that work by showing how physical variables can guide the articulation and comparison of embodied experience within participatory settings. Physical variables are therefore not only properties of an artefact; they are relational resources through which participants recognise sensations, negotiate meanings, and create shared references.

This contribution also strengthens a process-oriented understanding of data physicalization. Data is not treated as something already complete before representation. In the workshops, embodied data emerged through material engagement, discussion, gesture, and interpretation. This supports a view of data physicalization as an enquiry process in which knowledge is shaped through relations among bodies, materials, artefacts, and conversations.

The theoretical contribution is therefore the reframing of physical variables as epistemic and relational instruments. They help define what becomes perceptible, how symptoms are interpreted, and how individual experiences can be brought into collective discussion. This positions participatory data physicalization as a method for working with situated and embodied knowledge, especially in contexts where experience is difficult to describe through words or standard measures alone.

10.3.3 Empirical contribution: articulating symptoms differently

The empirical contribution responds primarily to RQ1 by showing how participatory design can expand healthcare enquiry through situated accounts of UTI experiences. The workshops produced insights that extended beyond symptom definition, bringing forward how participants understood the condition across prevention, recognition, diagnosis, consultation, treatment, recurrence, and side effects. This was visible from the ice-breaking and symptom-identification phases, where participants began to define symptoms through time, location, intensity, and relation to other bodily events.

Participants' accounts also clarified distinctions that matter for understanding the disease and improving care. They discussed the relationship between cystitis and menstruation, including recurrence before the period and the recognition of blood

that was “not the blood of menstruation” but “very bright, orange” (P2, WS1). They also described how sex can become difficult to discuss in relation to UTIs, with one participant recalling that she felt ashamed because she thought cystitis was caused by “having too much sex” (P2, WS1). Participants also described uncertainty in distinguishing cystitis from candidiasis, as one participant explained: “I do not know if I am talking about cystitis or candida, I have not figured it out yet. The fact is, however, that I treat with antibiotics, the symptoms are what are on the table” (P4, WS1). These examples highlight how patient accounts can improve understanding of the disease trajectory, clarify overlaps between intimate conditions, and support more responsive communication around diagnosis and treatment.

The expert interviews reinforced the value of these situated accounts. During the second workshop, the medical expert recognised that the order in which participants tracked symptoms followed a logic similar to the way physicians check the progression of a condition (P14, WS2). This suggests that patient-generated articulations can carry clinically relevant forms of organisation, especially when they describe how symptoms appear, change, overlap, and relate to actions or treatments over time.

Through material engagement and shared discussion, participants developed descriptions and metaphors that clarified sensory, emotional, temporal, and relational dimensions of UTIs. These included fear of pain, diagnostic uncertainty, difficulty distinguishing symptoms, the emotional impact of recurrence, and the relation between symptoms and daily self-management. The workshop setting supported participants in recognising patterns, comparing sensations, and expressing experiences that may otherwise remain vague, private, or difficult to communicate.

This empirical contribution does not introduce new diagnostic categories or measurable clinical indicators. Its value lies in complementing clinical knowledge with experiential detail. By making lived experience more perceptible and communicable, the research offers clinicians and researchers richer contextual insight into how UTIs are felt, interpreted, managed, and discussed by women. In response to RQ1, the thesis therefore contributes a participatory setting in which women’s experiences are actively articulated and interpreted, supporting a more situated understanding of the condition and opening possibilities for more responsive treatment and communication.

These contributions define the scope and value of the thesis by clarifying how participatory data physicalization can support the articulation, materialisation, and interpretation of embodied experience. At the same time, they also indicate the conditions under which the method was developed, tested, and analysed. The following section therefore considers the limitations of the research together with the open questions they generate for future work.

10.4 Limitations and open questions for future work

This section brings together the limitations of the thesis and the future directions they open. Rather than separating constraints from future work, it considers how the boundaries of the study generate opportunities for further theoretical, methodological, and applied development. This structure responds to the exploratory and design-led nature of the research, where methodological choices shaped the findings while also revealing new questions for participatory data physicalization and healthcare communication.

The section is organised around the main aspects that shaped the research: interpretive rigour and researcher positionality; comparability and assessment of impact; temporal scope and longitudinal experience; material expressiveness; gesture and multimodal documentation; transferability beyond the UTI case; sample scope and generalisability; the prototype stage of the analytical interface; and the ethical management of sensitive personal data. Each aspect is discussed as both a limitation and a point of departure for future work.

Where relevant, the section also identifies open questions that emerged from the study and uses them to outline a future research agenda grounded in the situated results of this thesis. These questions indicate specific areas for further investigation in data physicalization, materiality, and the wider application of the Physical-Variable Apparatus.

10.4.1 Interpretive rigor and researcher positionality

The analysis of the workshop results relied on qualitative methods, including compositional interpretation and thematic analysis. These methods were appropriate for examining artefacts, narratives, gestures, and symptom–variable associations, while also requiring interpretive judgement. As both facilitator and analyst, I was directly involved in shaping the workshop setting, observing participants' interactions, and interpreting the meanings that emerged. This position supported a close understanding of the material and participatory process, while also requiring attention to how my assumptions influenced interpretation.

To address this, I maintained a reflexive practice before, during, and after analysis. Notes documented assumptions, emerging categories, analytical decisions, and feedback. Where possible, interpretations were discussed with colleagues to introduce external perspectives and question the development of themes. Coding procedures were made transparent through code definitions, inclusion and exclusion

criteria, and concrete examples. Medical expert interviews also helped contextualise the findings and refine terminology and scope. The inclusion of workshop conversations and interview transcripts in the Appendix supports transparency by allowing the reader to trace the movement from raw material to analytical claims.

The cross-format analysis interface was developed to support this interpretive process and was published online with the thesis materials to increase transparency and support reproducibility. At this stage, it remains primarily a researcher-led tool, and structured feedback from researchers, practitioners, participants, or clinicians has not yet been collected. This opens a meaningful direction for future work around shared interpretation and the role of digital support within physical participatory practices. Further research could examine how digital tools might coexist with, extend, or intervene in material practices while preserving the embodied and relational qualities of the workshop.

This raises methodological and ethical questions about participatory interpretation. Interpreting physical artefacts together with the conversations from which they emerged involves decisions about who participates, at what stage, and under what conditions. Future work could investigate whether interpretation should involve the same participants who created the artefacts, different participants with related experiences, clinicians, researchers, or a combination of these groups. It could also examine how participants feel about their artefacts and narratives being interpreted by others, and how they experience being invited to interpret the artefacts of others.

The interface could therefore be developed to explore different levels of participatory annotation and interpretation. Participants might annotate their own artefacts, respond to anonymised artefacts from others, comment on emerging themes, or take part in facilitated collective interpretation sessions. Clinicians could identify which material and narrative elements support clearer symptom communication, while researchers could compare these interpretive layers to understand where meanings converge, diverge, or remain unresolved. In this way, annotation becomes more than a technical feature. It becomes a participatory method for structuring collective interpretation while negotiating privacy, agency, effort, and responsibility.

10.4.2 Iterative protocol, comparability, and assessment of impact

The workshop protocol was refined iteratively across the study. These refinements improved the flow of activities, supported participant engagement, and allowed the method to respond to emerging insights. At the same time, variation across sessions made direct comparison more complex. A fully stable protocol would have made

assessment easier, while an adaptive protocol allowed the workshop to remain responsive to participants, materials, and contextual needs.

To address this, the analysis focused on a stable core of activities that remained consistent across the main workshop sessions. This core included shared materials, symptom and physical-variable labels, collective association, Data-Probes artefact-making, presentation, and discussion. These recurring elements provided a basis for comparison while preserving the benefits of a practice-led and responsive approach. The evolution of the protocol was also documented, making changes across sessions transparent and allowing their influence on participation and expression to be considered.

This limitation opens an important methodological question for future work: how can the Physical-Variable Apparatus remain adaptable while still supporting comparison across contexts? The issue concerns both the protocol and the material kit. A predefined kit makes comparison and analysis more feasible because components can be categorised, traced, and related across participants and sessions. At the same time, the selection of components needs to remain grounded in the topic and context of enquiry, allowing elements to be adapted or differentiated according to the experiences being explored.

Future studies could therefore test the Apparatus through a stable core protocol combined with adaptable material modules. The core protocol would support comparison, while the material modules could be adjusted according to the condition, participants, or setting. This would also help clarify the relation between the kind of data being elicited and the kinds of materials used to express it.

A related question concerns the balance between open-ended making and structured assembly. Materials such as plasticine or Play-Doh may give participants greater freedom to shape personal forms, but they also require more manual effort and may make analysis less comparable. Ready-made modular components reduce the need for technical skill and direct attention towards explicit material qualities such as weight, texture, resistance, size, and connection. Future work could examine how these different material strategies shape expression, accessibility, and analytical comparability within participatory data physicalization.

A further question concerns the assessment of impact and the integration of results into the settings for which they are produced. In this thesis, medical expert interviews provided an external perspective on the clarity, relevance, and communicability of the patient-generated articulations. Their feedback helped identify where the method could enrich clinical interpretation and where its claims should remain limited.

Future research could develop more structured forms of evaluation to examine how the Apparatus affects communication, awareness, and clinical dialogue in

practice. This could include pre- and post-workshop reflection, comparison with standard symptom-description tools, clinician assessment of communicative value, or follow-up interviews with participants on whether the activity changed how they understand or describe their symptoms. Further studies could also explore how workshop outcomes might be integrated into healthcare encounters, patient education, or research reports, so that the artefacts and narratives remain connected to the contexts in which they are intended to have value.

10.4.3 Material expressiveness and influence on outcomes

The Data-Probes kit shaped how participants explored sensations and how symptoms became materially expressed. Its focused range of shapes, sizes, textures, weights, and connection possibilities supported comparison across participants and sessions. Participants could select, combine, and explain components in ways that made their artefacts analysable across the dataset.

The same structure also influenced the range of possible expressions. Some qualities that participants considered meaningful, such as sharpness, fragility, fluidity, elasticity, or amorphousness, were less directly available through the kit. Participants responded by adapting components, combining materials, or imagining qualities that extended beyond what the kit physically provided. This shows that material selection participates in shaping the knowledge produced through the method.

This limitation concerns the balance between expressive openness and analytical comparability. A predefined modular kit supports analysis because components can be categorised, traced, and compared across artefacts. More open materials, such as clay, plasticine, or Play-Doh, could allow participants to create more personal and continuous forms, while also requiring greater manual effort and creating more variation in the outputs. Ready-made components reduce the need for technical skill and direct attention towards explicit material qualities, such as weight, texture, resistance, size, and connection.

The iterative redesign of the kit addressed this tension by refining the balance between personal expression and methodological consistency. The familiarisation phase encouraged participants to attend to material qualities before shaping their artefacts, while the analysis considered both the components selected and the explanations given for those choices. In the final session, participants were also invited to identify missing materials or imagine alternative qualities they considered meaningful. These strategies made the influence of the kit visible within the research process.

Future work could examine how different material strategies shape expression, accessibility, and interpretation. This is especially relevant for the wider application

of the Physical-Variable Apparatus. When the Apparatus is adapted to other health conditions or social contexts, the material kit should be defined in relation to the specific experiences, participants, and forms of knowledge being explored. Materials used for recurrent UTIs may need to change for chronic pain, mental health, menopause, climate anxiety, or other embodied and situated experiences. Material selection should therefore be treated as an adaptable component of the Apparatus, guided by context while still supporting comparison and analysis.

10.4.4 Gestural expression and missing visual documentation

Gesture emerged as an important part of meaning-making during the workshops. Participants used movement not only to handle materials, but also to express sensations, clarify intentions, and connect bodily experience with the artefacts they were creating. Actions such as pressing, rubbing, stacking, collapsing, connecting, or moving components helped communicate intensity, pressure, discomfort, instability, or progression.

This role became visible during analysis, but gesture had not been planned as a primary focus of documentation. As a result, it was captured only partially through photographs, audio recordings, transcripts, and notes on artefact construction. These materials made it possible to recognise the relevance of gesture, but they offered limited access to transient movements and micro-interactions that shaped interpretation during making.

Future iterations of the Apparatus could therefore explore how gesture and process can be documented beyond conventional video recording. Video may capture movement in detail, but it can also make the setting feel more exposed, especially when participants discuss intimate health experiences. Other forms of documentation may offer less intrusive ways to trace how meaning develops through making.

Material affordances could play an important role in this direction. Components could be designed to record or reveal traces of use, such as pressure marks, changes in position, temporary imprints, connection points, sequence tags, or layered arrangements. Participants could also be invited to document the order of their actions through simple process cards, step markers, annotated photographs, or short reflective notes during or immediately after making. These strategies would help capture not only the final artefact, but also the sequence of decisions, gestures, adjustments, and material transformations through which the artefact emerged.

This opens a wider methodological question about how the process of creation can become part of data collection itself. If materials are understood as active agents

in meaning-making, then their changes, constraints, resistances, and affordances are also part of the data. Future work could therefore investigate how material agency can be made more visible within the Apparatus, and how documenting the order of actions, material transformations, and participant explanations might deepen the analysis of embodied data. This would support a richer understanding of how meaning is generated through the interaction of bodies, materials, gestures, and time.

10.4.5 Temporal scope and longitudinal insight

The workshops captured participants' experiences and interpretations within a limited timeframe. This provided depth and immediacy within the session, but it also meant that symptoms were often explored through memory rather than through active bodily sensation. Since participants were rarely experiencing an active infection during the workshops, they recalled and reimagined sensations from previous episodes. This shaped how symptoms were described, materialised, and emotionally framed.

To support this process, the opening phase of the activity invited participants to recall their experience of UTIs through narrative reflection before moving into material exploration. This helped participants reconnect with bodily sensations, personal memories, and patterns of recurrence. However, remembered experience remains different from experience recorded during active illness, recovery, or treatment.

This opens an important direction for future work on the temporal dimension of embodied data. Further studies could examine how material expressions of symptoms change across different stages of illness, including the onset of symptoms, active infection, treatment, recovery, and recurrence. This would help clarify whether participants select different physical variables when symptoms are currently felt, recently experienced, or remembered from the past.

The Apparatus could also be adapted for longitudinal use. Participants might create repeated Data-Probes artefacts over time, document changes in symptom perception, or compare how their material expressions shift across episodes. This would extend the method from a single workshop encounter to a tool for tracking embodied experience as it develops. Such work could strengthen the relevance of the Apparatus for chronic and recurrent conditions, where symptoms are shaped by duration, repetition, uncertainty, and changing bodily awareness.

10.4.6 Sample scope and generalisability

The core findings draw from three primary UTI-focused workshops involving twenty participants. This sample size is appropriate for in-depth qualitative enquiry, but it limits the breadth of perspectives represented in the study. Recruitment across a small number of sites and languages also shaped the diversity of experiences included, while the presence of several design-literate participants may have influenced how the activities were interpreted, discussed, and performed.

To address this, workshops were conducted in different locations and languages, and participant backgrounds were reported transparently. Learning supports were also included during the sessions to make the activity accessible to participants with different levels of familiarity with design, data, and making practices. The resulting claims are therefore framed as transferable to comparable contexts rather than representative of a wider population.

Future work should test the Apparatus with participants from broader cultural, linguistic, educational, and health-literacy backgrounds. This would help examine how different forms of prior knowledge shape engagement with physical variables, Data-Probes, and material interpretation. It would also clarify whether the method requires additional facilitation, alternative prompts, translated vocabularies, or culturally specific material references in different settings.

A related question concerns the role of design and making familiarity. While design-literate participants may feel more confident in assembling artefacts and explaining formal choices, the workshop results also showed that limited familiarity with materials can be generative. Participants' lack of specialised vocabulary encouraged them to explore components more carefully, describe qualities through everyday language, and discuss meanings with others before agreeing on associations. In this sense, material unfamiliarity supported reflection, negotiation, and shared interpretation.

Future work could examine how different levels of material and design literacy shape participation. This would help clarify when familiarity supports confidence and when unfamiliarity opens space for exploration, dialogue, and collective meaning-making. It would also support the development of facilitation strategies that make the Apparatus accessible without reducing the productive role of uncertainty and discovery.

10.4.7 Scope beyond UTIs and transferability

The study was developed primarily around women's experiences of UTI. This focus provided a coherent context for examining how intimate, recurrent, and

difficult-to-verbalise symptoms can be expressed through physical variables and Data-Probes. At the same time, WS4 and WS5 already extended the method towards other health conditions, showing both the adaptability of the approach and the need to investigate how different conditions may require different materials, prompts, and forms of interaction.

This raises an important question about transferability. Some conditions may be more directly connected to bodily sensations or visible signs, such as burning during urination, pain, pressure, skin changes, or localised discomfort. Others, such as anxiety, fatigue, depression, or other mental health experiences, may already be described through metaphors, moods, intensities, and relational effects. In these cases, the Apparatus may offer particular value by giving form to experiences that are otherwise intangible. However, it also introduces a further interpretive step, as participants translate already conceptual or metaphorical experiences into material form. Future work should therefore examine whether this double movement strengthens expression or makes interpretation more complex.

Some workshops and expert discussions suggested broader relevance for the Apparatus, particularly in relation to conditions characterised by subjective, chronic, stigmatised, or ambiguous symptoms. Chronic pain, endometriosis, pelvic pain, menopause-related symptoms, fatigue, and mental health experiences may all benefit from methods that support articulation, comparison, and reflection. However, each condition involves different temporal patterns, vocabularies, bodily locations, emotional dimensions, and clinical pathways. These differences may require adaptations to the material kit, symptom labels, facilitation style, and forms of documentation.

This question also concerns the balance between individual and collective phases. For private, intimate, or health-related experiences, individual reflection and artefact-making may be particularly important because they give participants space to attend to personal sensations, memories, and perceptions. Collective engagement may be most appropriate in the association and discussion phases, where participants can negotiate a shared vocabulary while preserving the specificity of individual experience.

For broader societal issues, such as climate change, artificial intelligence, or other shared public concerns, collaborative work may be appropriate across a larger part of the protocol. In these contexts, participants may collectively identify relevant problems, select data, and construct final physicalizations, because the topic concerns shared conditions rather than primarily internal bodily sensations. Collaborative physicalization could therefore extend the Apparatus towards the material articulation of collective issues.

Future work could test the Apparatus across different health and social contexts

while documenting what changes and what remains consistent. This would clarify which principles are transferable, such as physical variables, material engagement, group discussion, and artefact-based reflection, and which aspects require adaptation to each setting. It would also help identify where the Apparatus is most valuable: for experiences that are difficult because they are intimate and embodied, or for experiences that are difficult because they are abstract, invisible, and already mediated by metaphor.

10.4.8 Sensitivity and management of personal data

The research engaged with personal and embodied forms of data, as participants were invited to reflect on intimate sensations and experiences of illness. Although no medical documents or test results were collected, the descriptions, artefacts, and narratives produced during the workshops carried sensitive information. This required careful ethical management across recruitment, facilitation, documentation, analysis, and dissemination.

To address this, data were anonymised at the point of collection, and identifying details were removed from transcripts, photographs, and digital records. Materials were stored in password-protected repositories with restricted access, and consent procedures explained how data would be used, stored, and shared in anonymised form. The online interface was also designed to display non-identifiable content while preserving links between artefacts, transcripts, and symptom layers for analytical transparency.

A central tension concerns how embodied data can be shared responsibly while preserving privacy, context, and participant agency. Removing too much contextual detail can weaken interpretation, while retaining too much detail can increase identifiability or emotional exposure. Future work should therefore examine how participants can remain involved in decisions about what is shared, with whom, and in what form. This could include selective sharing, staged consent, participant review of materials, or different levels of visibility for artefacts and narratives.

This issue becomes particularly important if material artefacts and narratives are used beyond the research setting, for example in clinical communication, education, exhibitions, or public engagement. Future applications of the Apparatus will require ethical protocols that address anonymity, ownership, emotional safety, and the possible reinterpretation of participants' experiences by others. These protocols should support the communicative value of embodied data while protecting the people whose experiences make that data meaningful.

10.4.9 Conclusion on limitations and future work

The limitations discussed in this section define the boundaries within which the Apparatus and the findings of the thesis should be understood. They show that the approach depends on situated contexts, material conditions, participant diversity, ethical care, and the interpretive nature of participatory research. These aspects do not weaken the contribution but clarify the conditions under which the method was developed and how its results should be interpreted.

The strategies adopted throughout the study supported methodological transparency and coherence. Reflexive analysis, documented protocol changes, expert feedback, material iteration, and careful data management helped make the research process accountable. At the same time, these limitations open further questions about how the Apparatus can be adapted, tested, and extended.

Future work can build on these questions by examining shared interpretation, longitudinal use, material adaptation, gesture documentation, participant diversity, transferability beyond UTIs, and ethical forms of data sharing. These directions suggest a future research agenda grounded in the situated results of the thesis. They can support the refinement of the Physical-Variable Apparatus as a method for participatory data physicalization, healthcare communication, and broader enquiries into embodied and material knowledge.

10.5 Conclusion of this thesis

This thesis originated from the challenge of making embodied experiences that are personal, intimate, and difficult to verbalise available for interpretation and communication, while preserving their situated complexity. Beginning with women's experiences of UTIs, the research developed a broader argument about the role of material and participatory practices in supporting forms of knowledge that are perceived before they are clearly defined.

This situated healthcare context created the occasion for design to advance methodologically. The difficulty of communicating symptoms called for a reconsideration of how materiality, participation, and data physicalization can work together. In response, the thesis repositioned physical variables from material and spatial properties used to make data perceptible into methodological instruments for eliciting, interpreting, and communicating embodied experience. In the workshops, texture, weight, shape, sharpness, resistance, permeability, and blurriness became resources for recognising sensations, qualifying symptoms, and creating shared references for discussion.

The relationship between the healthcare problem and the design contribution is reciprocal. The difficulty of expressing UTI symptoms shaped the development of the method, while the method offered new ways to make those symptoms perceptible, discussable, and collectively interpretable. The Physical-Variable Apparatus is the methodological outcome of this process, offering a structure through which embodied experience can be elicited, materialised, compared, and interpreted, while remaining adaptable to other contexts.

Design contributes by creating spaces where lived experience can be recognised and shared, especially when those experiences are private, uncertain, or minoritarians. This contribution belongs to a wider movement in which lived and personal experiences are increasingly valued as source of knowledge. Meaningful improvement rarely comes from individual action alone but grows through collective efforts that support fairly changes that worth pursuing.

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PUBLICATIONS

Conference papers

Terenghi, G., Autuori, A., Subet, M., and Petraglio, S. (2025). Exploring How Fab Lab Machines and Personal Digital Data Inform One Another in Shaping Physicalization Practices, in Karyda, M., Çay, D., Bakk, Á. K., Dezső, R., Hemmings, J. (eds.), Data as Experiential Knowledge and Embodied Processes, 12-13 May, Budapest, Hungary. https://doi.org/10.21606/eksig2025.117

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Conference workshops

Terenghi, G., & Lenzi, S. (2025). Health self-revealed: Exploring self-narratives and data physicalization practices towards a shared design vocabulary. Workshop at the EKSIG 2025 Conference, 12-13 May 2025, Budapest, Hungary. https://eksig2025.mome.hu/#workshops. Paper proposal available at https://doi.org/10.5281/zenodo.17182290

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Presentations

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APPENDIX

This appendix compiles the materials that support and extend the main body of the thesis. This section begins with the compositional interpretations and contextual descriptions of the Data-Probes artefacts that informed the analytical process.

The appendix then presents the question guides used for the semi-structured interviews with both the initial and final medical experts who contributed to the assessment of the findings.

The empirical material is provided in full, including the verbatim transcripts of the initial interviews with medical experts, the pilot expert interview, the workshop conversations, and the final assessment interviews with medical professionals. As some exchanges alternated between English and Italian, occasional transcription inconsistencies may appear; these have been retained to preserve the authenticity of the conversations.

The appendix concludes with the ethics approval letters issued by Brunel University London and the other institutions involved in the study. Together, these materials offer transparency into the research process and provide the contextual detail necessary to understand how the study was designed, conducted, and interpreted.

A.1 Question guides for interviews

This section presents the interview [I] modalities and the question guides used throughout the study. An initial set of interviews [I1] was conducted to deepen understanding of the topic, including UTIs, patterns of antibiotic use, and the role of patient-generated data in clinical decision-making. The question guide used with the first medical experts involved in the pilot study is also included [I2], alongside the guide used for the final assessment interviews with medical experts who evaluated and reflected on the data generated through the workshops [I3]. Together, these materials outline the structure and focus of the conversations that informed both the development and the evaluation of the research.

I1: The promotion of data literacy to raise awareness on antibiotic consumption and improve symptom description to enhance people's participation in prescription

[Duration] 45 min. **[Modality]** Online - Brunel Teams account. **[Interview intro]** Thank you for taking part in the interview. The interview is part of a Design PhD research project started this year and focuses on the promotion of data literacy to improve the relationship between citizens and doctors. More specifically, data literacy is meant to help in raising awareness on antibiotic consumption and engaging people in bottom-up data collection to tackle antimicrobial resistance caused by urinary tract infections. The interview aims to define the current role of data in the field, hypothesise the role of data in improving antibiotic consumption, and investigate the participation

of people during the antibiotic prescription. You have been asked to participate because of your expertise. The interview will take 45 minutes and you are expected to answer some questions related to the study. Questions are open and you are free not to answer. If you agree, I am going to record the interview. **[The recording starts]** The record will help during the research. You can find all the information related to the interview in the "Participant information sheet" that I shared with you, together with the "Consent form". Please feel free to ask questions, stop or withdraw the interview at any point. If you agree, we can start. **[Interview questions]** 1. Self-intro: I am going to ask if you can first introduce yourself, providing: your name, your occupation and role, your education. 2. General: What is, in your opinion, the current role of data in tackling antimicrobial resistance and urinary tract infections? And what do you think it will be in the future? What data is needed to enhance a better understanding of AMR and UTI diseases? 3. Antibiotic consumption and prescription: What should people know to consume antibiotics responsibly? Why should people follow antibiotic prescription? And which other challenge could people possibly face in terms of antibiotic consumption? 4. Can data have a role in improving and reducing antibiotic consumption? If yes, which kind of data is needed to reduce antibiotic consumption? Is there any data that only people can provide about themselves (and that can not be accessed otherwise) that can be useful to tackle antimicrobial resistance related to urinary tract infection diseases? 5. Symptoms: How is the antibiotic prescription influenced by symptom description that people provide to doctors? How much are people aware of their symptoms? And how accurately are people able to describe their symptoms? What data should people track, collect, analyse and interpret about themselves to improve symptom description? 6. Data: Imagine people using data to support their symptoms description: Can people's reliability take advantage of data-supported symptoms description? Imagine people collecting and analysing data to support their symptoms description: Can the action of collecting and analysing data to support symptoms description influence people's consequent behaviour in terms of antibiotic consumption? 7. People involvement: Why should people be encouraged to take part in the prescription process? What benefit can people gain from collecting and analysing their own data? What benefit can people gain from sharing their own data? Imagine data collected by individuals for personal purposes (such as improving symptom description and taking part in the prescription process), made available through sharing practices: Who might benefit from people's shared data? How can people benefit from each other's shared data? Does the involvement of people during the prescription process risk causing any problem? What risk does the use of data collected by individuals themselves cause, if any? Does the use of data collected by individuals themselves to improve the knowledge related to antimicrobial resistance and urinary tract infections risk producing any bias, or problem? What is the role of privacy and security in this scenario? 8. Question related to interviewee's specific role or project, if any. 9. Next interview recruiting: Do you know anyone that might be interested and available to answer the questions of this interview? If so, would you be able to put me in touch with them? Would you be interested in engaging in future research activities as part of the PhD project? **[Interview conclusion]** Thank you very much for your time and contribution. **[Recording stops]**. I am available for questions if you have any. **[Interview ends]**.

I2: "Shape Your Symptoms": First workshop session medical expert interview

[Duration] 30 min. **[Modality]** Online semi-structured interview - Brunel Teams account. **[Purpose]** To evaluate the method and get feedback. **[Recording starts]**. **[Question guide]** 1. How do you evaluate the activity based on participant engagement, declared goal, material? 2. What step would you improve? Eventually, how? 3. Intro to the project and activity / Symptom definition and collection: What did work? What did not work? What phase was most difficult to understand? What phase was most difficult to perform? What goal was best reached, in your opinion? What is the main achievement? Did you feel engaged? What material would you have liked to have? Was the vocabulary too difficult? Did you encounter difficulties in

interacting with other participants? Would you like to have an other experts on the table with you? Did you feel useful during the activity? 4. Try to define your role within the activity. 5. Provide the following definitions: What is a "variable"? What is a "data-probe"? 6. Any other note or feedback. **[Recording stops]. [Interview ends]**.

I3: Assessment of the research workshop method: "Shape Your Symptoms"

[Duration] 45 min. **[Modality]** Online semi-structured interview - Brunel Teams account, after the interviewee has been shared an online preliminary analysis of results to read and comment. **[Purpose]** To evaluate the workshop in terms of content discussed and method adopted. **[Recording starts]**. **[Question guide]** 1. What is the first thing that impressed you the most (if any) that emerged from the analysis? 2. Is there anything that you read, and you do not agree with? 3. Do any new symptoms or relevant information regarding the disease (UTIs and women's intimate infections) emerge from the analysis? If yes, what is it? And how does it relate to the current information available of the symptom/disease? 4. Have you identified any unusual word to describe the symptoms/disease from the ones that you are in habit to hear from the literature and patients? If yes, does that description improve the understanding of the symptom? Eventually, what other information should the description contain to improve the understanding of the symptom or the disease (from a medical perspective)? 5. What problem do you identify within this method? 6. Any other comment or feedback. **[Recording stops]**. **[Interview ends]**.

A.2 Transcripts of the medical experts' initial interview on AMR and UTI

The transcripts are central to this appendix, as the thesis relies heavily on their interpretation for the analysis. To keep the material focused and avoid unnecessary detail, the beginnings and endings of the recordings have been removed in cases where they include my introduction or other research procedures. These parts are already described in the main body of the thesis.

[IME] refers to Initial Medical Expert and is used to distinguish this group from the [ME] experts who contributed to the final assessment. Each expert is assigned a numerical identifier for ease of reference. This first set of interviews took place at the beginning of the research (Autumn 2023), in parallel with the literature review, to deepen understanding of the topic and identify potential areas for design intervention. Insights from these interviews are also presented in Terenghi, G. (2023), Improving the patient–doctor relationship to fight antimicrobial resistance through data literacy promoted by a women-centred participatory practice, in De Sainz Molestina, D., Galluzzo, L., Rizzo, F., Spallazzo, D. (eds.), IASDR 2023: Life-Changing Design, 9–13 October, Milan, Italy.

IME1

[00:00:00] Researcher: Just to give you a a little bit of introduction. The interview is part of my PhD research project that started last year and focus on the promotion of data literacy to improve the relationship between citizen and doctors. More specifically, data literacy is meant to help in raising awareness on antibiotic consumption and engaging people in bottom up data collection to tackle antimicrobial resistance, specifically caused by urinary tract infection. The interview aims to define the current role of data in the field. I put it, I put it as the role of data in improving antibiotic consumption and investigate the participation of people during the antibiotic prescription. You have been asking to participate because of your expertise. They interview will take approximately 40 minutes and of course you do not have to answer all the question. So feel free to ask anything you want if you need or stop the interview at any point, I will start asking you to introduce yourself providing name, occupation, role and your education please. [00:01:04] IME1: OK. OK, so I'm **. I'm a young doctor. I finished the medical school or Medical University last year in October 2022, and now I'm doing MD PhD, so a doctorate for three years, more or less in microbiology, in the shoe at Lozan. Should I say something else? Did I forgot something? OK. [00:01:39] Researcher: No,

no, I think no, no, I think that's fine. Thank you and. I will structure the interview in three main poem, let's say. A. Pay this. The first one is more general than I will ask you about the people involvement and then some. Some other question related to the relationship between patient and doctor. So what is in your opinion the current role of data in tackling antimicrobial resistance and urinary tract infections? [00:02:14] IME1: What do you mean with the data? Because it's a very broad. So for me, I would say. There are different kinds of data. There is one kind that is more. Really. Scientific. So harsh scientific data. For example. I percentages, incidence, prevalence. Ohh I don't know those kind of data really with numbers. That we can calculate, analyse and yeah and so on. And there are also other data that are much more first difficult to obtain and much more personal. For example personal experience. Awareness. Yeah. Data that we can collect by in lay people, for example. These are for me data that I completely different. We can analyse them also with numbers and so on. This is different in a way. You can have much more answers, much more diversity. So I would differentiate those two and I think we need. Those two kind of data but. Like I said, one is. Much more difficult to obtain, so the the part with personal experience health literacy is also an important concept. So the awareness of the people, yes. But how is it easy for them to use this awareness and knowledge to make decisions? For example, this is a health literacy and. Yes, I I find those data very interesting, but we lack a bit of them I think. So more on the scientific data. It's a bit easier to collect them because you can. Make studies in hospitals or also in ambulatory care. And those data are a bit easier to obtain. But when you want to tackle for example data in the general population. And to obtain it is. Is a bit more complicated. So I would differentiate those two, but I think we we need both of them and to really understand what's going on with the with antibiotic, because the behaviour of the of the patients is very important too to assess compliance. For example, if the patient is taking. The antibiotic treatment, appropriately or not so? [00:05:07] Researcher: Yeah. OK. And what do you think the role of data would be in the future? So you speaking about those data that are lacking that is lacking, if I understand correctly, so you in your opinion will be important to find a way to collect in both direction information from patient to with the final Gov goal of like personalised cure and provide the appropriate cure for patient. Is that the reason why you would be interested in those kind of data? [00:06:13] IME1: So I went to generalise that nowadays how the society develops, we always more. We always have the tendency to use more data. Always more daytime, more precise data and. For example, in enterprises, to how much time the people work, how much time they they are at work, and even you can even find a mail tracking and such things. And all these data is collected and I think in the future, maybe even near future with all those artificial intelligence. There will be mass data that will be analysed to. Optimise the the different fields. It's so it's kind. It could feel kind of this topic too. This topic, can we say that in English? I think, yeah. It's the the the inverse of utopia, so it it can be this topic to think because it can lead to very cold decisions and a very cold analysis of. For example, someone's work but. Now that I have generalised and I think in medicine too, there will be such kind of evolution, we could say, and that data will always be more collected and in a more efficient way, and that will benefit, yes, the the patient and the doctors. But yes, it will also. And bring up some some interesting ethical questions. Um. That's that. Humanity will have to tackle because, yeah, it will be huge change and. We will have more data to. Make real science, that's true, but at which costs this is a bit the question what awaits us in this future of data. [00:08:42] Researcher: OK. Thank you for this reflection. Actually regarding antibiotic consumption and prescription, what should people know to consume antibiotic responsibly in your opinion considering the general population let's say? [00:08:58] IME1: Hmm. What should people know? I think one of the most important thing that they have to know. Are. Some of the basic principles of antibiotic resistance. Because if they can understand them, so not not much of them. But you know, like I would say 3 principles. And I think with those principles in mind, if they can understand. How it is? How is antibiotic resistance developing then they can take? Like a. More reasonable decisions, for example, I would say the three principles. I would say the first one is. Um. The different antibiotics and different bacteria. So this is the first one you you have to to. To take

specific antibiotics to treat a specific bacteria, there are some large spectrum antibiotics. That's true, but if they know this principle, they know that they can't, for example, borrow an antibiotic from someone to treat their infections. That yeah, because this antibiotic that they would borrow maybe. Would not be efficient so. That's the first one I think. And the second one I would say is each time you use antibiotics, yes, it is to cure the infection, but you always increase the risk to select resistant bacteria. It means you. You never should. Take more than prescribed, because if you take more on a long term you are going to select resistant bacteria, so this is also an an important thing. Because if they know that. Yeah, antibiotic is important to cure the infections, but at the same time, there is a like, you know equilibrium within this this principle I would say so yeah and. Maybe a third one is that you can't cure a virus infection with antibiotics, so I really don't know how much people know that to be completely honest, so. This one is also important. And maybe. Ohh yeah, yeah, yeah, maybe the first one. Yeah, yeah, yeah. But also maybe a fourth one. It's that. If it involves. The the entire population, meaning that. If someone doesn't do it. Good enough if if someone don't follow the prescription, for example, and develop resistant bacteria, this resistant bacteria can spread in the population too. So. Yeah, I don't know if if I would say this is this. It's always complicated because it's not you fault that you have a resistant bacteria per se because. So you you can't, you can't really say it's the responsibility of the people, but it's that in, yeah. It's it's more about. We are all in the same situation. So if you. If you don't. If you live at risk, you are also maybe maybe going to put someone else at risk, but it's not it. It's more indirect as a responsibility. It's not a direct responsibility. [00:12:12] Researcher: No, of course I would not say that is the responsibility about having or developing AM R is more about having responsibility in consume antibiotics like consciously and in the proper way has prescribed to kind of avoid the development of of resistance is more in that direction. But yes, I I see what you mean. And and can data have a role in your opinion to improve and reduce the antibiotic consumption? [00:13:35] IME1: Sorry, can you repeat the beginning? The what I don't understand the word. I had data. To. So to decrease the antibiotic resistance. I'm proving the antibiotic consumption OK. Umm. So I think if we can collect data on. What? On the on the awareness in the population or about antibiotics and antibiotics resistance. Also about behaviour. Of these persons, and also about health literacy. We could much more understand what's going on and. We could maybe if we have those those this data we can maybe educate physicians to. You know to to how do you say this? To. To educate the patient, you know. To. To empower the patients. Because maybe. We could sometimes think that, for example. I would say, particularly when it's a well educated person, like in universities or even professor and so on. We could have the buyer or a buyers of thinking, yes, it's well educated person he saw he or she certainly knows. That it's important to follow the prescriptions, but I'm pretty sure like in everything that. You have people that are really, you know it those high sphere of society. I don't know how you can say this in English but I think you you understand me and. With a lot of knowledge that are. That have not the knowledge on that specific topic and maybe there will not respect the prescriptions or give the antibiotic further to a friend that has similar similar symptoms, for example, and this is also something that's complicated in medicine because in the medical field you have. A lot of infections that have a lot of symptom in common. So, for example, diarrhoea can be can be caused by a virus and by a lot of other bacteria, so you can't. You can't really assume, for example, what I think that people assume sometimes is OK, I had diarrhoea, I took that antibiotic. My friend here has diarrhoea. It will work for him. You know what I mean? And after they they pass the antibiotic to to to this friends and. That is also a problem because it's not that simple unfortunately so, but I think I I went a bit far and didn't answer the question or. [00:17:11] Researcher: No, no, no, no. I mean, it's interesting what you're saying. So don't worry. Just like question to start, let's say, speaking about this topics. And the question was if data ever specific role or can have a role in improving the antibiotic consumption, reducing misuse error various but that's fine, I was actually. [00:17:24] IME1: So I would I would, I would say, just to summarise that it's very important to understand. What the general population is doing with the antibiotics, because we don't have enough data on that and. With that in mind, we

can after that. Enlarge our comprehension why antibiotic resistance is increasing. For example, for this antibiotic in specific or and not for this one. For example, maybe it's an antibiotic that everyone uses and everyone passes to. I know I don't know, friends and so on, so that's for to summarise. [00:18:04] Researcher: But. And I remember we were where we met because of the game you were pro prototyping, designing and we actually started an interesting conversation related to. And. Um, let's say starting from. And our understanding how people awareness can be developed, let's say into behavioural changes because once people know about their good way to consume antibiotic, that doesn't mean that people will start the day after consuming correctly antibiotic correctly. And did you have the chance to like go through this topic or? So what? [00:18:50] Researcher: Read something interesting or develop an idea about that. How to let's say starting from our Ness Act on behavioural change of people. [00:19:04] IME1: So I think. It should be possible if you can have a. You know, results at different time points, so data at different time points. And for example, if you're collecting prompts so patient patient reported outcome measurements and. If you have a first time point. Which is, I don't know. Before the you talked about the game we're going to to keep that example before they play the game. For example, if they could. Answer Answer a questionnaire. At that moment. And after a play the game and it that questionnaire, you would have questions about awareness about behaviour. So you can link the two together about health literacy. How they feel if they know more. Is it easy to put it in application for example? Accuse. And. Yes, you can ask all these kind of things also about row knowledge. You can ask things. After they play the game and you could imagine having this same questionnaire at different time points and see if it changes with for example the game. Or even to see by patient if it changes during the treatment. If it changes when they see their physician, for example. You can see a lot of things if but. Here it's I think very important to have this different time points to be able to see if awareness can have an influence on behaviour because if you don't have any change, if you look only at one time point awareness and behaviour, you could make a you know. A correlation? Maybe. But you know it's not. It's it's less. It's less relevant than if you can observe changes and if they change parallelly, if not, if awareness is increasing, the behaviour is always the same that that would be very interesting too. [00:21:26] Researcher: Okay. Thank you. And have you heard about narrative medicine? [00:21:35] IME1: Narrative medicine. [00:21:36] Researcher: Hmm. [00:21:37] IME1: I don't think so. Hmm. Hmm. Sydney. [00:21:39] Researcher: Okay, I actually just went through during my my research recently and it's mainly used for a ohh bological patients or people with dementia. So there are these platform where doctors can invite patients and they have of course a different interface, but they are asked through some kind of stimuli to not rate like writing a diary saying what's happened to them, specifically related with the symptoms or side effects or feelings about the illness or the treatment they they doing. So what happened is that then the the doctor is asked to read the story, the report let's say from the patients before the the meeting. And they saying that in this way they able to collect more intimate information, especially related to sexual disease or anything like which is more personal that people are more scared or somehow doesn't feel comfortable in, say to the doctor face to face during the consultation and so is another kind of way, probably to gather information in this way is specific is the the information and data are specifically from one patient. So someone is already in contact with the doctor. And in this view I was because I find very interesting this way of collecting information as it allowed to gather both qualitative and quantitative information. What is happening now is that for quantitative information they organising a questionnaire. But it would be interesting also to enable people to understand how they can collect quantitative data by themselves and with quantitative data I'm not only speaking about how many pills or how many time you have you drink water or went to the bathroom during the day, but is also related to feeding because as you said, with the scale of number you can also measure more qualitative information still on on quantitative scale, let's say and I was thinking related to antibiotic consumption and you retract infection. If that would be any kind of specific information, qualitative and quantitative, that would be interesting for doctor to read or have from from patient that can be somehow collected from people from home. So

before to go to the doctor or before to have the consultation or even like start a kind of one year diary, something like that. So if you know that you are an UTI patient that chronically suffer from UTI. Maybe having a kind of one year of information from this this person if would be interesting, and if that's the case, what kind of information and data you will be asked to this person to collect. [00:25:10] IME1: First I I would like just to know do. For this daily diary that you just explained, do the patient know that we physician are going to to to read it. I think so. Hmm. [00:25:26] Researcher: Yeah, of course. So what happened? Yeah, yeah, yeah. So is actually a kind of treatment. So when people go, as I said for now, is mainly used for oncological patients and people with dementia. So their physician, the doctor, the general practitioners say we would like to involve you in this kind of treatment because would be useful to have this kind of information would be easier for you, maybe to provide with some information, blah, blah, blah. And then the patient start recording is feeling like on this page, so everything is there is a data protection rules and everything is explained and they start writing the diary and then the the the patient. I mean there are different services and platform that provide these services to hospital or doctors. But usually what happens is that from the application they pay the doctor can enable a allow other physicians to read the diary if needed. Let's say so. If there are some information that will be interesting to share, and then if the patients wants, the doctor can kind of organise groups of people so like little groups, not big communities, but more about the little groups where patients can share their experience and share information by themselves. To others, of course, like in a, let's say secure environment. So it's not like open as a community can be on Internet. And because everything is under this platform, the hospital platform or doctors platform, but still people are able to interact, to to themselves. [00:27:17] IME1: And about the the question you asked, what kind of data could be useful in that? In that kind of. Of how we should say this and that kind of. Treatment like you said. But. I think. Yeah, yeah, yeah. If any, I mean maybe you can just say, I don't think that's useful at all. No, no, no, no. I I think it's it could be useful. But. You you just explained that for example, the doctor could read it before the meeting with the patient. This is interesting too, because in fact patients are sometimes a bit uncomfortable and look for some around some topics. That's true. Often it's we we call this hidden agenda. They call. They come to the doctor. They don't really have something. You you do the anamnesis and to you. You know you you cheque the patient and he has like nothing at and at the end of the consultation, 5 minute, 5 minutes before the end or at the end and they they send them, they said yes and I have a I have, I don't know a problem. Ohh I network tile problem for example which is really. Uncomfortable to say. For example, for for a lot of men that that have this problem and. Yes, it could be useful in that way, but the only problem that I see. And. Because it's always good to to keep the critical. Stay critical, it's. It's. And the. The time, because physicians often don't have a lot of time, and if you write a diary. It's going to. Um. If you read the diary, it's going to take a lot of time. Before you see the patient, it depends on the diary, but you know there, there are always people that will that will write a lot more. But what's interesting is if we can mix this with for example and an A I that could, you know, take out some important words or sentence that could be relevant. And it could be interesting, yes. Um. Forward to people that really are uncomfortable to to say it directly to to their doctors because I think too that some. Some patients. Trust the physician, and because they trust them, they're going to say everything and don't really need this. This. How how can we define? Yes, kind of layer to. Process. Yeah, yeah, exactly. This this step, this process. And yet about the diary on one year, for example, where the patient write all kinds of data and we can compare this to something that's already existing, it's the, you know, the hypertension booklet that's the hypertensive patient receive. For example, a patient with hypertension with blood high pressure. Have a little booklet and in this little booklet they are going to to measure their blood pressure twice a day, for example morning and the evening. And they are going to record that in the booklet and when they come to the General practitioner, for example, the General practitioner can see how. And the blood pressure was in the last, I don't know, two months for example, and adapt the treatment and so on. So this is certainly very, very interesting there also. Ohh, you're so tiger scope that developed something with the. With the

child. Ohh, how do you say this in English? And the thyroid thyroid, I think. Thyroid gland and and this is also. This is also very interesting, I find because you can have precise data. But. On one year, for example. You have such a lot quantity of data that we human won't be able to really analyse that we we can, you know, see a pattern eventually but. We would also need help from, you know, a I once again that. Would analyse those data more precisely and guide the the physician's towards the. The the optimal treatment or. Yes, if the yeah, for example. [00:33:07] Researcher: Yeah, you you mentioned the example of hypertension booklet, but considering like having the blood pressure measure twice a day for example, which is there, can you think already about any specific information or data that you would ask to people suffering from UTI or end AM R? [00:33:08] IME1: I'm from UTI. Ohh. OK OK OK. Um. So something certainly would be every time they consume an antibiotic, they write it in the diary for example. This is one thing so we can have an insight of how much they take in. If they follow the prescription or not, but I don't know even with this process, I don't know if patient are going to be completely honest because sometimes they are not really compliant and don't really dare to, you know, to admit it to to say it to the physician. And um. Yeah, I I. Actually, I experienced uh once during my internship. A patient that that said, yeah, I I take my pills and I take my pills. But it didn't take them. They were always in the, you know, in the in the trash. But he. He did as if, but he he never took them so. And. Yeah, this kind of things can happen. And I don't know, maybe with this layer with this process you diminish that and this would be very interesting. But. Aside from that, I think so. So to to to come back to the question you asked. So antibiotics, when they consume it. How much per day, for example, so all about the antibiotic consumption and maybe. How they feel. About this. Why? For example, if they didn't follow the prescription, why? Um. If they. And how they obtained this antibiotic, if it's a an antibiotic that were prescribed for the infection or if it was prescribed for an infection, you know, two months ago, for example. Um. What else could be interesting about a Mr? Um. Maybe it could also be interesting to have those kind of questionnaire within the AM R. And. A kind of questionnaire. Sorry, a kind of questionnaire that could assess the the patient's awareness. Meaning for example, once again you can. You can answer this questionnaire every time. The patient, I don't know, had to take antibiotics or every time the patient. Read something. About antibiotics, or every time the patient searched for information for data on the Internet or in a book, I I don't know about antibiotics. This would be also interesting to. To have. And and yeah. Ohh yes, UTI too, yeah. Yeah, yeah, yeah. Now, and he might maybe information regarding UTI, so you answering more broadly related to AM R, But if you consider AM R into UTI context, is there anymore specific that comes to your mind or maybe not really? [00:36:57] IME1: So what would be very interesting about UTI is is officially UTI. If you're healthy young woman. We can avoid antibiotic usage. We can prescribe, you know, some some. Painkillers like. I don't know what they use for. For one study they use diclofenac, but for another they use like a if you problem. Which is the classic one. Also on anti-inflammatory. And they showed that. You don't really have a benefit of the antibiotic consumption and most of the UTI are not going to to be complicated. You have some set population which are more at risk. For example a. By not really well controlled diabetes because you have a lot of sugar that ends in the urine and that's why the bacteria can develop. And easier in the the urine and eventually complicate the the UTI into a PL nephritis nephritis. I think it's also the same term in English, I hope so. It's when when the kidney are you know involved if the bacteria goes all the way up to the kidney and after they can even cause a sepsis and yeah it can be it can be quite. Flights by dangerous but in in that sense to to know if people, for example in in the context of UTI, had a UTI which symptoms and did they get an antibiotic from their physician, but told the physician to to. Did did he told for example to take the antibiotic right away? Once, for example? Or did he told take the antibiotic in three days? If it's not better? Until then, you use... profen for example. This would also be interesting. So you mean like asking about a prescription in the way physicians prescribed or not prescribed? I mean they cure physician provided to the patients, OK. And very last question, no, sorry. But also, yeah, but also would be interesting to. Like you said, the scale to scale their. We could say a quality of life. While they had the UTI, for example,

because you know you have to. Expert ibuprofen and so on. This would also be interesting to the impact of the and how they feel about it. Yeah. Yeah. But like I said, after that you have a huge amount of informations and. Yeah, that you have met just somehow. The the way you treat it, this is yeah, this is also also important. And difficult. [00:40:41] Researcher: I would just ask you the very last question, why at this point patient or like even broadly people would have to? Put half what, let's say, in collecting this data. Like, why should people have to collect this data? So we asking and let's say, imagining these people gathering and collecting all these information, let's say from one year. But even like for the period they taking antibiotic or for the period they experiencing UTI. Like. Why they should be motivated, let's say, to collect this information is that because we I mean this information can help the physician and can help at the end. Patient themselves in a avoiding antibiotic, if unnecessary. Or is there any like motivation that you see in this kind of data collection that you can say people first but yeah. [00:41:48] IME1: I see a one. Maybe others while I talk, but I see one it's that. Medicine is. Always more evidence based. Meaning that. Today we have. We have to conduct studies to to have a proof of a feature efficiency, for example for for a drug and so on. And. Data in evidence based medicine is very important, and this is the first thing I see. And the second second thing I see is if we can collect all these data that is important for evidence medicine. It will impact positively I think and patient management because we will have more evidence based. Theory on why the the patient's don't doesn't follow. You know the the bacteria, the bacteria and antibiotic treatment. For example and. The physician will know. Will better know. Not really know, but better know what are the tendency in the populations and what are really the the the problems. Because I think we often have misconceptions of what the real problem for a patient is. I think we could, for example, think that the patient didn't take the antibiotic because. He forgot, which can happen, certainly, but maybe it's just because. He. He has this fear of antibiotic and maybe this fear of antibiotic is much more. Current in the population, you know, much more. Uh. You know what I mean? Frequent you? Yeah. OK. Yeah. Yeah, yeah, yeah. OK. Frequent. Thank you. Thank you much more frequent in the population than we think. Or the inverse that the person took more antibiotics or more than prescribed or other antibiotics because it really impacts the quality of life. So. That's. [00:44:18] Researcher: Yeah. Yeah, make sense. OK. Thank you very much. Actually, I wouldn't just through the narrative medicine, which I find really interesting and somehow relative with what I'm trying to do because that's more on qualitative side and also what they say is that that. They lack a way of also collecting more quantitative information, so would be interesting to see if this kind of data can be. Helpful 1st and how they can be collected and how involved people in collecting this kind of information. So thank you very much and I know if you have anything to add or if you wanna ask. I just wanted to add to that. Maybe we underestimate the lack of. We we underestimate because we. We are often focusing on patient that have UTI or patient that are hospitalised but. I think we underestimate the the proportion of persons in the population that have problems. Health problems. But don't go to the doctors. Don't go to the hospital and this is a lot of information that we. That we lose. Because maybe part of the problem is there, I don't know. Because certainly. I think probably the. The problems comes more from the patient that have an infection because they have access more access to antibiotics. That's true, but all the patients that don't go to the physicians or to the hospital and go, I don't know. I'll ternative medicine for example. I'm I'm not against. I'm... alternative medicine just to be clear, but don't go to the physician but only by alternative practitioner and these practitioners sometimes. Have you know or against? [00:46:43] Researcher: Yeah. [00:46:46] IME1: How did you I academic medicine and this this versa? Also academic medicine. Some some position are against alternative medicine and this is something maybe we miss such kind of data patient that go to alternative medicine and. Often the. Probably they won't consume antibiotics because they go to alternative medicine. But maybe because the alternative medicine doesn't work, maybe. Yeah. I as well as as an antibiotic, they will maybe. You know. Comprare by by an antibiotic at. At at the pharmacy in in. In France or I don't know. Yeah. Yeah, exactly. [00:47:35] Researcher: You mean without proper prescription or they ask for antibiotic to friends or this kind of behaviours? Yeah, I think that's very interesting. I remember

also. Yeah, yeah, yeah. Sorry. [00:47:47] IME1: Because I I would say just to summarise their the with this post covered era, there is a a drop in. You know confidence. Now, how do you say this interest in trust in in science and in academic science, I would say academic physicians and so on, so on and. Maybe this is also something that that can be dangerous and we miss a lot of the population. That uh, that hate physicians, for example. [00:48:23] Researcher: No, I see what you mean actually. Already you're better mention something. Not like you saying, but he said that the lack of data is particular is like a very high related to a out settings of patients. So usually there are more data related from people hospitalised people then has it probably you saying there are more data than after that there are data about people who are not to speak. Lies, but still are inabit. Let's say to go to the doctor and use antibiotic regimen necessary, and then maybe as a very last step we would say that the lack of data is even higher related to people who usually or prefer to avoid doctors or. Plastic medicine. That's very interesting then. And that point my I mean the bigger issue I see in looking for to collect those data is related to how to involve those people because. [00:49:29] IME1: Hmm. Yeah, yeah. [00:49:29] Researcher: Um, as from hospital, of course. You kind of already have their data. Then you can try to interface and interact with the people who are somehow already interested, or as from Angela Hutner. I don't know if you know from strong spirited she doing OK. So she saying that usually my patients are happy to provide data or collect information because first is useful for themselves but also. When the idea of helping others in the same situation, they they are willing to to help and provide information and share information. But then the other group of people that you mentioned then I would say how to to properly reach them. Sorry. [00:50:25] IME1: Prince UTI and here is A is 1 bias is that those people? They are very aware of what they have and. Often how it works. And. This can explain why they are very interested in giving information in helping and so on, because they can. They know what it is, but in the general population where the healthy people or the people that are a bit sick but don't go to the doctor, they they are not really concerned about that. I think. And this is also another difficulty. So. [00:51:13] IME1: Yeah, that's why. That's why we thought about the game with **. [00:51:14] Researcher: Hmm. [00:51:20] Researcher: No. [00:51:23] IME1: Ohh. Principally so yeah, this is this is this is something complicated. How to reach those people? Yeah, it's. Because if if. If someone is going to reach you, for example, about something that really doesn't concern you, I don't know about. [00:51:38] IME1: I don't know what, what do you don't like? [00:51:40] Researcher: Yeah, I mean, I said, no, I not bad. I see what you mean then it really means that. I mean. [00:51:49] IME1: Hmm. It. [00:51:49] Researcher: That's very important because it's something that maybe I didn't know or was not interested for me, but then knowing that can some still how improve my my knowledge and my behaviour towards something that still have power to change, let's say because yes, no, no, no, I I completely agree. And that's very interesting actually. But have you have you managed to find someone for the workshop that's another very difficult point. Oh my God, we're gonna have. Another workshop here in a subset subsea and on the 12th and then they planning a different one in Bern in June. [00:52:29] IME1: Yeah. Yeah. [00:52:29] Researcher: But the problem of recruiting participant is always like a pain because as you said, like people who are not aware or not interested on the topic because personal experience are very difficult to reach. [00:52:46] IME1: Hmm. So by by yes the the communication is on the Shiv website where everyone goes to to find information to find, you know, a phone numbers and so on. And we also I'm going to to. How do you say this? To print, to print the Flyers and give them to the Geneco abstract obstetrics. [00:53:11] Researcher: Yeah, it's gonna be a good target. OK. Hmm. Yeah, yeah, yeah. [00:53:12] IME1: Is this something I will do? Because I I wrote an e-mail. Normally you have to write an e-mail and they they print it for you, but I didn't obtain a a an answer yet, so next week I'm going to directly to to the office to see what's going on and if it's possible. But I think it will be possible to be a problem, but until now we have no participe. Ohh, OK, OK. Yeah. [00:53:39] Researcher: No, I mean I will double cheque after the call, but I actually have a setting that's the website send me an e-mail and all the times that someone submits sign in for their workshop. So I didn't have actually any anyone. That's also why maybe if you know any of these students may be or like groups would be good if

you can. Yeah you already. [00:54:04] IME1: We we also we also wrote to the the. [00:54:09] Researcher: OK. [00:54:15] Researcher: Hmm. [00:54:09] IME1: The student faculty, because Gilbert knew that of biology and medicine so. And we received also an answer that we can write somewhere to. To write to you know. All the students. [00:54:29] IME1: Not only those from. [00:54:30] Researcher: The Community, kind of. OK. [00:54:31] IME1: You know, medicine and biology, but here the the main problem once again is that I I have myself, you know a. A male at university lozan unila. Ohh you Neil. Mail. Mail. Mail. No. An account. [00:54:51] Researcher: OK. [00:54:51] IME1: And you receive a lot of emails. You know, it's like. [00:54:55] Researcher: Yeah, I know, I know. I know. He's upset the same. Yeah. [00:54:59] IME1: You receive a lot of information and I don't think that everyone is really looking into the information every time. Hmm. [00:55:05] Researcher: Reading that, yeah, that's why you usually like personal condemns contacts or if you know, anyone usually work better. But I know what you mean. I mean, keep me updated. I will double cheque on on the website as well and. And keep me updated. Maybe we can have that kind of update. [00:55:32] IME1: Hmm. Yet. [00:55:27] Researcher: Like not. Don't. Not this coming week. Maybe the week later. Also to cheque materials and everything else, because then we'll be like kind of one true 10 days before the the workshop. So just to to have an update that it work for you. We can I mean I will drop you an e-mail something like that we don't have to meet online. [00:55:46] IME1: Yeah, yeah, yeah. Well, you you can. You can write to me and. Ohh one more thing, they want to to say about the interview. And it's. [00:55:57] Researcher: Yeah, yeah, yeah. No, please, I'm happy. [00:56:00] IME1: It's that. It's true that all these data is very interesting and can offer. Can offer a substance to this evidence based medicine, but. The danger that I see in this we also with a I. Is that maybe with a I and all this kind of information we are becoming colder? You know what I mean? Let's. [00:56:41] Researcher: Your mum. [00:56:38] IME1: Less human. Innocent. [00:56:41] Researcher: Banter like care, carrying off like human feelings of like patience. [00:56:45] IME1: Yes, exactly. Because if you base if you base. All you knowledge, all you practise around raw data. You are going to be right for 95% of the time. [00:57:01] Researcher: Hmm. [00:56:59] IME1: Even more, maybe, but for 5% you you can make mistake and you can also. Be less efficient for for 5%, maybe for even more because we know that the facts, for example to go to the physician to have a talk is something that. [00:57:26] Researcher: Hmm. [00:57:26] IME1: Has like a placebo effect. You know, there's this placebo effect is is something that exists. It's someone even said once at the placebo effect. Is this the, you know the the strongest effect because it's always here it's always here because if you take a pill for example even if there is nothing in it the our brain anticipates and. [00:57:57] Researcher: Yeah. [00:57:54] IME1: You know, produce chemicals to to be ready to. To rest, we could say so. This is very interesting too. It was a really nice book from a statistician. [00:58:16] Researcher: So you said that you it also the the idea of going and having the consultation is a sort of plastic boy effect. Is that what you said? Yeah, OK. I didn't know this. [00:58:14] IME1: Yes, and that that, that's that can help too. So was a nice book. I don't remember the name of the the author. I must admit. It's doctor you. [00:58:29] Researcher: Okay. [00:58:29] IME1: And it's a. It's a statistician. [00:58:33] Researcher: Hmm. [00:58:33] IME1: That. That's talks a lot about placebo effect and even talks. For example, you know you you can do the blind placebo effects. The patients don't know what what is in it or even think that the the drug is in it. And this is the placebo effect for example. But you could also. And do a. How can you say this? Nowhere a placebo effect. You give appeal to the patient. You say there is nothing in it. But in some cases it helps and to be very he has a much better sentence. In his book, I think because the way you formulate it is also very important because it's it should not be negative because if it's negative you have no effect. But it should also not be false. So he has a nail. He praised that very well in his book. And he explained even in that case that the person knows that it's not, there is nothing in it. The placebo effect is still there, so it still helps in some cases. [00:59:57] Researcher: Yeah. Yeah, yeah, yeah. No, no, I see what you mean. [01:00:05] Researcher: Hmm. [01:00:12] IME1: So here we we talking about places where you can use the placebo effect and not in, I don't know, cancer and so on, but maybe you you can always use it the placebo effect, but you have to account for also other

diseases that are you know more serious. This is also something that you you should treat appropriately. Besides the the placebo effect. And this was very interesting. And about information, if I could. The I could. Has just said this conversation. To. You know, I I have. I have a bit. I struggle a bit when I talk a lot. I lose my word. [01:00:42] Researcher: It's not only you, don't worry. Yeah. Ohh. OK. Hmm. [01:01:12] IME1: OK, OK, OK. OK. I don't know if it's my concentration on, but yeah, there is a book more about information that I really like and human bias. It's less about healthcare, but it's more about why and how does information spread and why those, for example, false information spread faster or. [01:01:11] Researcher: OK. But is that related to healthcare or more generally about information? I mean, he's OK. [01:01:16] IME1: No, it's more generally about information, but what I find really interesting with this is that because we are actually in the information era, you know. Data actually is. If you have a lot of data, it's very powerful, but you can do with the data and. That's why I wanted to relate this because we are going to have a lot of data in the scientific field too. We are also in this information era. In science, and it's very important to to understand those principle because. All those false information how to tackle them if you don't know how it works. So it's it's very fascinating, but no. [01:02:03] Researcher: No, no, that's a good point. Even like a having question before start. Have you looking into data? Because sometimes the risk is like having data and trying to look for question or or information into that, but that's. No, no, no, no. [01:02:16] IME1: Ohh yeah, yeah, yeah, that's true. That's true. You know, I just wanted to to to say that because I find it really fascinating. What's what's happening in this information era with the COVID, what happened and so on. This is this is really actual and it has a little paradox in it. The more data we have. And the less. Well informed is the general population we could say ohh they or the more biassed informed they are, right, you know. It's. Yeah, I'm. I'm digressing. [01:02:47] Researcher: Yeah, yeah, yeah, the movies. Information. Yes. No, no, actually, if you have, like other references, I'm happy to. If you wanna send me, I'm happy to to have a look into those. [01:02:59] IME1: If it's what, sorry. Ohh. [01:03:01] Researcher: If you have any other references or just that come to your mind later on, I'm happy. If you wanna send me. [01:03:09] IME1: OK. OK, that's. [01:03:09] Researcher: Links or names or or book, etcetera. OK. You OK? OK, that's. I already took a note about that. [01:03:13] IME1: The the main one is the doctor. You with the placebo effect is interesting, but it's not. It's not really about the AM R or UTI, but it's something about healthcare. It's it's interesting. [01:03:28] Researcher: OK. Thank you very much, Alexander. So. [01:03:31] IME1: You. You're welcome. [01:03:34] Researcher: Pick you do you in two weeks, more or less? Let's say like that. And we we will be updated about the the workshop organisation, OK. [01:03:44] IME1: The what? What do you mean? In two weeks, a male in two weeks or meeting. Hmm. [01:03:48] Researcher: No, no, no, no, I I will. I mean, I think I will send you an e-mail maybe like in 10 days something like that not this coming week, maybe the next one. Uh, so we can see about the participants and how we can proceed with the organisation. OK. [01:04:26] IME1: Yes. Hmm. [01:04:21] Researcher: Later on today and of course update you about the the number of participants I will, I will send you an e-mail later on after checking and then I will keep you updated about the number of signing, OK. [01:04:35] IME1: And on the other places, do you you said you struggled too to to find participants. Hmm. [01:04:38] Researcher: Same. Yes. I mean in general I I think I mean in general is very difficult because as you said or it's something that already cannot affect you. So you are already interested in the topic or something happened to you or Someone Like You care for. Otherwise even if they activities kind of participatory and you have to act on something and doing something and even if it's like just an afternoon, it's very difficult to to find participant. Do you have other dates? But still what we do, we usually rely on communities so. For example, Serena, who knows someone in we're going to bed now and in this place, Verna is hosting us in, in this community place. So they already have some connexion and people who who usually going in in that place doing some other activities. So that's the the best way, let's say, to to involve people. Otherwise we also have like advertised on the subsea website on like screen in the university or send. [01:05:54] IME1: Hmm. [01:05:47] Researcher: In emails, but as you said, because there are a lot of female coming from official university accounts, then

people sometimes just don't even read them. [01:05:59] IME1: Hmm. [01:05:59] Researcher: So we usually we try to like speak with people we know like directly and then see or as you said like Jenny, ecologist or like General practitioner who might have like a patient interested. But the the more diet you go there the the, the more chance you have generally speaking. [01:06:15] IME1: Yeah. Yeah. So we're going to see what's going to happen with the gineco obstetric here. Liars. [01:06:29] Researcher: Yeah, yeah. Keep me updated as well. If you have any news, just send me an e-mail. Okay. [01:06:35] IME1: Yes, I. Ohh. [01:06:38] IME1: I would have liked to do to do this today, but I think the printing of this is going to close in 5 minutes so. But you know. [01:06:46] Researcher: OK. Yeah. But I think next week is still fine. [01:06:50] IME1: Yeah. Yeah. Next week. And we'll see and we'll hope too. [01:06:56] Researcher: Yes. [01:06:59] Researcher: OK, I wish you a good yeah. [01:06:59] IME1: But I hope I hope the the information, the data that I provided is not to. [01:07:04] Researcher: No, no, no, that's that's been very it's been very useful to conversation actually because as I said I just went through the narrative medicine recently and having an overview and also like more. Physical let's say concrete information related to what date and what information will be interesting to collect and to have it all very useful because I'm speaking with different background. [01:07:35] IME1: Ohh it's. [01:07:35] Researcher: Different people with different background, yeah. [01:07:37] IME1: Just one thing. And what's what's very interesting, recently I had to do a home homework for, you know, it was scientific mediation. [01:07:51] Researcher: OK. [01:07:51] IME1: Microbiology for lay lay population for lay people. Hmm. And. We we had the the possibility to choose a different between between different topics for the homework and there was one how to use ChatGPT for scientific mediation. And it's very interesting because I I researched a little bit and to brainstorm or to formulate questions and so on it. [01:08:24] Researcher: I know. [01:08:26] Researcher: I know. [01:08:24] IME1: It's a beautiful tool. It's really, really. I think it's really powerful so. Yeah. Ohh yeah yeah. Hmm. Hmm. [01:08:29] Researcher: We I'm actually involved in another project which is related to exploring the potential of a I into design process. So how you can use a I tools to enable or help yourself during the the the phases of design such as like brainstorming or storytelling or deliver the output, prototyping, designing and the blah blah. So we are collecting. All these tools dividing them based on the activity they they they provide and then classifying them into the. My face is so. So I'm also like kind of trying to be because they are so many update. That. Able to. To play. But that's very interesting. No, no, that's very true. You have to. And experiment different, because sometimes you see the difference in like. The way you ask things, sometimes the results is very different and I don't know if you notice that because we were doing some. [01:09:38] IME1: Yeah, yeah, but what? What did you say? Different. What? You you have to use and. [01:09:43] Researcher: Your friend like word. To ask like the the prompts you provided, yeah. [01:09:48] IME1: And the different, uh, the prompts? Yeah, the prompt. [01:09:50] Researcher: Yeah, yeah, yeah, yeah. And I was saying that sometimes it isn't even a little bit tricky because we tried with the summer research and papers and what we gained in some cases that charge deputy was providing a false bibliography, so. [01:10:09] IME1: Ohh, do you know why? Because I know why. [01:10:12] Researcher: OK. [01:10:13] IME1: It's. [01:10:13] Researcher: Right. Because actually the name in there are right. So it's actually appointed to real people who are doing research on the topic. But it just invented the name of the paper of of the research and all the other information. [01:10:30] IME1: Did you? Did he? Because I I didn't verify that. But did he put the names? [01:10:36] Researcher: Yes, and that's. [01:10:36] IME1: Um, I I use the names exist, yes, but the list of name. [01:10:42] IME1: Did it? Does it exist? This is something I didn't verify. [01:10:46] Researcher: The list you mean all the authors of the paper? [01:10:49] IME1: Yeah, the author together. That's what I mean. Yeah, exactly. [01:10:53] Researcher: No, I don't know if they have a work together or not. So what happened is that they do have a experience in the field, but they never wrote that paper. That chat deputy provides for you. [01:11:09] IME1: And they never wrote that paper together or the these are authors that never worked together. [01:11:12] Researcher: Yes, together, yes. [01:11:13] IME1: Yes, but you know why? Because it's it's very simple. In fact, because chats, GPT is trained to assemble words in the more probabilistic way. Do you know what I mean? I he got, he received an input. And with

this input. [01:11:26] Researcher: OK. [01:11:27] IME1: You have more probability to have this word and after this word, this word and his going to to go through like this and for sources he doesn't really have access to sources. [01:11:48] Researcher: Hmm. [01:11:49] IME1: He got trained to have, you know, like an algorithm tree, but he he doesn't really. Sources does don't really exist. [01:11:56] Researcher: He just predict the collaboration. [01:12:00] IME1: Yeah. Yeah and. Yeah, man, maybe. But that's right. That's why. [01:11:59] Researcher: You predict collaboration, so those people should contact the others and try to write a paper together. That's a good suggestion to look for colleague. [01:12:14] Researcher: No, no, no. Yeah, I see. [01:12:12] IME1: Yeah, that's why he he just puts name that other more probable and the and the because I did the same thing and I was why doesn't it work? But he doesn't have access to actual information. This is also very important. [01:12:32] Researcher: Yeah, yeah, yeah. [01:12:29] IME1: It's a this was for the moment, maybe in the future it will, but you know it's a. Yeah, but I I find it fascinating. Yeah, yeah, yeah, yeah. [01:12:38] Researcher: No, no, no. Is a powerful tool not to have like final results, but to have like, brainstorming ideas or something to work on is a very powerful tool. It is. [01:13:00] IME1: Yeah, exactly, exactly. He because I asked him to to write, you know, a a text for children, for example, based on a scientific tests. And it's wonderful. What's what's what's what it did. [01:13:11] Researcher: Yeah. Yeah, that's. [01:13:12] Researcher: Yeah. No, no, no. That for that kind of the contents, I suppose it is. And then of course, you have the experience and knowledge to check it. So that's a good way to use it. [01:13:15] Researcher: Yeah. [01:13:13] IME1: That's very important too. Yeah, but I think the basic principle is he's quite good for for the basic principles. It it doesn't miss. [01:13:21] Researcher: No, no, no, no. It is with this, I do agree. [01:13:23] IME1: Yeah, he doesn't make a lot of mistakes about basic principles after. Yeah. Yeah. But it's interesting. Yeah. [01:13:33] Researcher: Okay, thank you very much.

IME2

[00:00:40] IME2: OK, so my name is ***. My role, so my current roles at the University Hospital Geneva are as a clinical attending physician in the infectious disease division. I work in general infectious diseases, but I also have an outpatient clinic. That is just for urinary tract infection. I also consult specifically it on inpatients for urinary tract infection. That is one of my roles. Another role is I'm the director of the Clinical Trials unit, the Clinical investigation unit. Which is part of our Center for clinical research at the University Hospital of Geneva. And to something else, I was supposed to, any other data. That's good, right? OK. [00:01:37] Researcher: Yeah, I think it's fine. I mean then it's OK. And so, I will start asking some you some general question and then some question related to symptoms and then to people involvement in the process, what is in your opinion the current role of data in tackling antimicrobial resistance and urinary tract infection? [00:02:01] IME2: It's hugely important. It's extremely important we don't have enough of it and the data we have are not well disseminated. We're not sharing the data enough. When patients become informed of the current situation of antimicrobial resistance, they become very immediately less demanding of antibiotic therapy right away: "Treat me, treat me with antibiotics", the knowledge of these data really can empower patients and make them partners. in the decision making which should be happening anyway, but they need to have access to data before they can really be empowered, to be. Sharing in these decisions and to feel comfortable sharing these decisions. [00:03:03] Researcher: What data you referring to? I mean, you said. [00:03:06] IME2: So data on many levels… You know, overall data sort of epidemiologic data, what's happening with antimicrobial resistance, the fact that repeated use of antibiotics drives resistance, enables resistance. They need to be aware of this. They need to be aware of data that is more, you know, patient specific on a patient level that repeat antibiotic use has real side effects beyond just immediate side effects to their body it also affects their flora, their normal microbiota. And can be negative effected. It has a negative effect typically on microbiota, and finally for UTI data show that having a lower urinary tract infection, so just involvement of the bladder, which we call a cystitis. This is really not usually not on its own. It's not a deadly disease, so it doesn't require antibiotics all the time. Obviously, antibiotics would really, really help relieve symptoms much more quickly, but many cystitis

episodes, many substitutes will be will, resolve without any biotics, and patients really don't always know this. And there are other measures we can take you. I mean, you don't leave the patient just alone, but then there's some basic measures we can take that are not pharmacologic and then help patients with their symptoms. And when patients know this, they really can be partners in, you know, in their own management but also in the effort, the overall effort to slow the spread of antimicrobial resistance. So that's what I mean by data. So data on an epidemiologic level and then data on a patient level, data about the actual illness and about its management. [00:05:25] Researcher: And when do you usually share with this data, with them, I mean, do you like, speak about data, during the consultation, you have the chance to explain this kind of data to patients? [00:05:37] IME2: Yeah, I'm extremely lucky because my clinic is. I get enough time with them. It takes time and in a lot of healthcare settings, doctors do not have so much time and they're forced to see patients in 10 minute increments even and I get an hour with each new patient. So I talk and I talk and I share data with them it takes. It takes the full hour and sharing these data sharing this information. You know, it's it's a dialogue. It's not me talking the whole time, but giving the information takes…a long time, at least half an hour. They have to give me their personal history, etcetera, but yeah, but it's it's… they are so happy, so happy to be given some information and it completely changes their approach. I mean, I see it in all my, you know, almost all my interactions with patients. They're very, very relieved to know that. That there are other approaches besides just throwing a new antibiotic prescription at every cystitis. Yeah. [00:06:52] Researcher: OK. Thank you. So, moving to symptoms, is there antibiotic prescription influenced by symptoms description that people provide to doctors in your opinion somehow and if yes, how can be influenced by patients? [00:07:12] IME2: Umm. Yes, if I understand the question correctly, yes, absolutely. The symptom, the history that the patient gives. So the description of their symptoms should very much guide the doctor's clinical decision making and the decision to write a prescription. It is recommended in UTI, UTI guidelines to prescribe an antibiotic based on clinical presentation. You don't have culture results at the time you see the patient, it takes 2 days to get the culture results. So you have to prescribe based on what they're telling you. So absolutely, we listen to them and what they tell us, we have to believe, but they have no reason to lie, you know? So we trust them and the symptoms of lower UTI are very classic. It's not hard to spot them. So it's yeah, it's it's not. It's not too complicated. [00:08:08] Researcher: So how much are people aware of their symptoms? In your opinion? I mean, you said, yeah, yeah. [00:08:16] IME2: No, I mean this patient is the people who have recurrent UTI, they really know their own symptoms. They know exactly. So I really trust them. There's a, I would say that the specificity of the symptoms as that they report the classic symptoms. So as you know the classic symptoms are just huria burning with urination, burning on urination frequency. Feeling, you know, having to go frequently and then urgency, so feeling like you have to go and then not much comes. And then the 4th one, the 4th Classic one is suprapubic tenderness or pressure or some sense of pressure right over the pubic area. That right over the bladder. So yeah, these are women know these symptoms. The patients know their symptoms and there's little doubt what's going on. There is a differential diagnosis. There are some other things that could be happening but there…they're more rare than cystitis. [00:09:18] Researcher: And related to antimicrobial resistance, is there any way that patient can understand to face antimicrobial resistance? Or how do you, let's say, investigate the direction of antimicrobial resistance in case a patients come to you for a consultation? Ya. [00:09:38] IME2: How do I? I didn't understand the first question. Something about chance like the the probability that the patient will have a resistant strain. Yeah. [00:09:47] Researcher: Let's say that a patient came to you and doesn't know about antimicrobial resistance, but there are chances that he already has a case of antimicrobial resistance. How do you, let's say spot, or try to understand if that's the case? [00:10:04] IME2: I take a history. I asked the patient if they've recently had antibiotics because that's the number one risk factor for current carriage of a resistance strain. So I asked them what was there. I asked them all what was their recent antibiotic therapy, if any. And yeah, that's pretty much it. That's the big one. And if they've been treated multiple times, they're very likely to have

a resistant Organism. If they were treated in the last six months, I would say. But uh, and, and if they've had a, or if they've had a recent hospitalization even without antibiotics. Yeah. [00:10:46] Researcher: Is there any data or information that people can let's say track, collect or maybe start analyzing the by them themselves to help during this process, to help understanding, yeah. [00:11:02] IME2: To data that that a patient could look up and then to determine whether they themselves have a resistant strain. [00:11:10] Researcher: Yes. [00:11:11] IME2: Yeah, sure, sure. And the risk factors like I said are pretty, you know you could list them on a website or something if that's what you, you know. So yeah, it's like I said it's this, it's these classic Rick risk factors, recent antibiotic therapy in the last three to six months. Recent hospitalization or even a stay in a nursing home, any healthcare structure. And also for resistance. Recent travel to countries with very high baseline prevalence of resistant strains and you can list those countries. It's Asia, it's the Mediterranean basin including Italy, sadly even including the States United States. [00:11:54] Researcher: I Just read that an article about that actually. Yes, that's good. [00:11:58] IME2: Yeah. Yeah. Yeah. So, yeah, Southern Europe, Middle East and northern Africa and Asia, East Asia, South Asia. Yeah, they have a higher risk of just already carrying it resistant strain. Well. [00:12:15] Researcher: So you don't have to ask them in. Collecting. Let's say they can go and look by themselves to some information, but you don't have. You don't need any. Let's say extra information by them that they can start collecting before to come to you to have the consultation. [00:12:38] IME2: Yeah, they can already. Yeah, absolutely. [00:12:42] Researcher: OK. [00:12:42] IME2: Yeah. [00:12:44] Researcher: And as you said before, you trust your patients completely. I mean, I don't wanna say that they wanna lie to you, but sometimes, like, maybe they can have a misperception of symptoms. I mean can it happen or not really? [00:13:01] IME2: Yeah, I would. Yeah. No, it's true that there could be with men particularly there can be some confusion as to the real the real. The reason for the symptoms, the real source of the symptoms, but. For. Yeah, for women, it's it's usually they know. Usually they know what they have. Umm, so I can't I I think you can remove the word completely because you know. It doesn't mean I completely know the diagnosis, but I do trust that they they're, they know, better than the doctors, sometimes it's a population that has this, you know, cystitis comes back frequently. They have experience with it. So it's they usually it's really important to listen to them. And yeah, I I generally trust them. You could put it like that. But like you say, they're always gonna be exceptions. There could be crazy people who just want to take antibiotics, but that's usually not the case. Yeah. [00:14:07] Researcher: And considering that you are able then to collect and use the data and information coming from your patients, do you think who can benefit from the information you can get from your patient? [00:14:25] IME2: Well, the patients directly, you know, on a larger scale of course. And then also the medical community teaching younger doctors, new teaching, older doctors too. You know who are used to prescribing like crazy. Teaching a lot of other members of the healthcare system. So a lot of times pharmacists will just give antibiotics even though there's no prescription. You know, so many, you know, all players in the healthcare system. You maybe ensure all stakeholders, so maybe insurance companies should also be more informed. Because they end up having to pay for these resistant organisms which cost them all the costs. Them a lot of money. And then, of course, policymakers, you know. You know. How to deal with, you know, Yeah, it it's important for society to keep people aware of this issue so that you know that also can keep costs and morbidity down. Yeah. And mortality even. Yeah. [00:15:37] Researcher: And how do you see the? I mean, people willing to share with their data about like privacy and security concern. Do you see that as a like problematic step or not really because they get involved and then they kind of want to help in this direction. [00:15:59] IME2: I think that. Umm. And in terms of, you know, if we anonymize the data, I don't see an issue. You know, I really don't. You know, healthcare doesn't happen without data. So I feel pretty strongly that you know once it's anonymized, I don't think there's even an ethical issue, of course. But you of course have to trust that the anonymization will happen and be honored and and be successful. But I yeah, I hope does that answer the question. OK. [00:16:36] Researcher: Yeah, yeah, yeah, sure. And is there any, like community, let's say or like

a group of people that comes from after your consultation or that, you know, where people with the same kind of problem can refer to? Or is there any, like, specific willing to kind of create a community from your patients point of view to help each other? [00:17:03] IME2: Yeah, yeah, yeah. No, yeah, the this these things exist. I've I know from some of my patients there are online forums you know for people who have recurrent urinary tract infection. I think some of these forums are really good. They're really well meaning. But here's you know something you might wanna look at in your in your use that you're gonna have for your PhD you know data can be misused right there is. Apparently this big forum, I think that's in the United Kingdom for people with UTI and there are some doctors that have used this patient group and they're making a ton of money, apparently because they are advertised, they are putting out the message in these group in this forum that the only thing that really helps recurrent UTI is chronic antibiotic use. These are not infectious disease specialists. I think these are urologists. And they really don't care about antimicrobial resistance. They're making money out of this, putting people on long term, sometimes intravenous antibiotics for years. And this is also online. This is also a group. This is also, you know, they I went to their website. They have testimonials from patients whose life has been improved, whose lives have been changed, improved. They've been cured by staying on antibiotics for years. And it's insane. And they're also testimonials. People can spontaneously write in saying this is all nonsense, but they're removed to them from what I can tell, they're removed pretty quickly. So. But. Data can be really easily manipulated selectively disseminated, so it's really tricky. You need some kind of governance; you need some kind of. I don't wanna say policing, but you know, yeah, it it's tricky. There. So it's. [00:19:10] Researcher: OK, sorry, I just got the message that the call will end because I started before your arrival. Can I quickly super quickly send you another link for like last I just stopped this call and then send you the other link. I'm so sorry. [00:19:26] IME2: OK, no problem. [00:00:00//second recording] Researcher: Waiting for you. And then, OK, I start the recording again. No, no, no, no problem at all. OK. Thank you very much about sharing about community. So you don't have any specific one that you may suggest to your patients or is there any like not really OK. [00:00:15] IME2: Not actively, but actively. I should do that more. Maybe again, I wonder if it's also an issue of, you know, sometimes these communities, they go off track, you know. [00:00:25] Researcher: Done. [00:00:27] IME2: Yeah. Yeah. So, no, I don't actively suggest anything to the patients. [00:00:31] Researcher: OK. And is there any like I would call it engagement activity or like if not a forum like any other social participation that you? Ask your no, not ask, but propose to your to your patients who are interested in. OK. OK. [00:00:51] IME2: No, no, not actively. No, it's really. [00:00:56] Researcher: OK. No, no, OK, that's fine. And now more like, let's say technical question regarding antibiotic consumption and prescription. What should people know to consume antibiotic responsibly in your opinion? Because from my point of view, we also would like to kind of. Uhm, understand if there are like main guidelines, let's say or like basic knowledge that people can have to approach the topic of antimicrobial resistance. [00:01:29] IME2: Umm, so so the tool. So the question is what things can people regular people know or doctors or? [00:01:37] Researcher: Yes, I'm speaking about people, but if you have any specific, more like from the citizens point of view. But if you have any specific. The thought regarding doctors, please share those as well. [00:01:51] IME2: OK. So yeah, I mean, I think people just need to know that antibiotics, you know it's antibiotic use that drives antibiotic resistance and really a whole many generations of people didn't know this. So just that simple fact really, really helps when people are start to when people start to be told this, they used to be told the opposite, that if you took antibiotics for too short a time, that the infection will come back even though you were feeling better. And we were wrong to say this or my seniors were wrong to say this. It's that's really an exception that it comes back. So we need to reteach we need to reeducate. People need to the older people need to unlearn this this this thing. But yeah. So it's #1 just getting the word out that antibiotic use is what causes antibiotic resistance. And then, yeah, what did I answer? Yeah, basically, it's that it's it's pretty simple. OK, OK, there is. I mean, I could go into more detail and that's why I like to have an hour to talk to each patient. There is nuance. OK. It's not all. It's not. Not every antibiotic is equal in its

ability to cause resistance, especially for urinary tract infection. There's a lot of differences. So there's one interface that we recommend first line, it's called nitrofurantoin. Sure, I don't teen in the, the, the generic name is nitrofurantoin. Umm, but it has many trade names for furadantine and furadantine, macrobid. It has a lot of. I mean it has a lot of different names. Generic is nitrofurantoin. It does not seem to harm in intestinal microbiota that much. It does not cause as much resistance as other antibiotics do, so it's OK, it's, you know. But doctors need to know this. It's not so much the patients that gets a bit nuanced, you know, at that level it's more detailed. But I would wish patients you know that we had the time to teach them even that we don't. But but I do. As in my clinic. Yeah. So antibiotics in general, drive Resistance, but some do it more than others. [00:04:15] Researcher: OK, OK, I see. And I was saying, how do you do you have any follow up with your patients, how do you consider follow up? Yes. Mm-hmm. [00:04:34] IME2: Yeah, yeah, it depends. I mean, it's true that my, my clinic is very much a specialty clinic. All my patients already have a primary doctor. So I don't do follow up for everyone because they all, many of them have several doctors. They don't really need another one. So so often about half the time I just see people once and I I tell them, you know, you can always recontact me if necessary, but I don't fix a follow up appointment, but the other half, you know I have to put in a place a new strategy and I need to see how they're doing a few months later. So yeah, I'd say 50% of the time I still need to see them a second time. But that's me. I'm very, very specialized. [00:05:20] Researcher: So do you usually have the follow up in case of something goes wrong mainly or if there are more problem. Not in case of. [00:05:29] IME2: Yeah, yeah. Yeah, yeah. [00:05:31] Researcher: I mean, you don't have any feedback in case of everything goes right. Do you think that can be useful or not really because you have to face only problem let's say. No, no, no. [00:05:44] IME2: No, it's true. It would be great to have feet like positive, you know, follow up to just know, OK, she's not calling me because she's doing great. I suspect that when I don't hear from patients that they're doing fine because they always find me when they're not doing well. You know, if something you know. So I I, you know, I suspect that when I don't hear from them, it's a success. But that's not my sound a little arrogant because maybe some of them don't call because they weren't happy. You know, but usually they find me, you know. Yeah. [00:06:19] Researcher: OK, so there is no no information that you need. Let's say after considering that the the treatment goes well, so you don't actually need any any other information. Uh. [00:06:31] IME2: Yeah, and that would be a great thing to that would be a great thing to put into place in a, you know, with the data, you know, it's sort of informatics support because the reason there's no good follow up is because none of us have any time, right. The Doctor's, I do. I never would have time to chase after the people who are doing well. I already have too many who are not doing well. You know, so it would be great to set up a system where the patient could be asked automatically just, you know, happy face, sad face three months later. You know, just let me know. Uh, something super automated. Minimal effort, you know, approach the patient. Uh digitally, you know, like in the Swiss airports, you know, like happy, sad media, you know? [00:07:16] Researcher: Yes. No, no. [00:07:20] IME2: You know, just let me know. Did it work? Did our strategy work? Are you doing OK? That would be great. But we don't. I don't. I can't make phone calls. You know? I just it's not realistic. Yeah. Yeah. [00:07:30] Researcher: And the regarding the prevention, do you think any prevention would be possible? In case of urinary tract infection, especially when chronic, is there any suggestion you would give especially to your patients or more generally to prevent instead of like treat the illness? Good. [00:07:53] IME2: That's what I do. You. Yeah, I mean, that's what my clinic mostly is. It's mostly to develop strategies for prevention because when they have an acute episode, I'm not always available. They go to their primary care doctor. So my whole clinic is really about the bigger picture. You know, what can we do to make this not happen again? So yeah, there are plenty of strategies and you'll laugh. But the most effective one is crazy. It's free. It costs nothing. No side effects. Uh, you know, no. And it's easy access. You know what it is? It's water. Drink, water. Drink at least 2 liters a day. Even better, 3 liters for the younger women who can handle 3 liters a day. And it's super effective. But you have to really stick to it. So believe it or not, it's 2022. And my most effective tool is not some fancy,

you know, molecule. It's water. [00:08:52] Researcher: I mean, at least it is available for everyone for now. So it's actually good. I actually heard. [00:08:56] IME2: It's available. It's free, no side effects. It tastes good, you know? So yeah, yeah, yeah. But it's just, I mean, it's. Yeah. [00:09:06] IME2: Yeah. [00:09:07] Researcher: Not sorry please. [00:09:07] IME2: No, I was just gonna say it's crazy. It's, you know, I they come to this very specialized clinic for advice for help. And I tell them drink water, but it actually works. But go ahead. [00:09:18] Researcher: No, because I was actually speaking with someone else and they were also talking about some alternatives remedies and they were mention cranberry as well. [00:09:27] IME2: Yeah, yeah. [00:09:27] Researcher: Uh, so is there any? [00:09:27] IME2: Yeah. So I know the literature very well because this is my job. I'm on the guidelines, the international, you know, North American European guidelines for UTI. So I know the literature really quite well. And sadly, cranberry itself is not the ingredient, it's it's the juice, it's the liquid, it's the movement. You've gotta get the flow going and that's all that really helps. And so cranberry by itself, the actual ingredients, no, it does studies don't really show any superiority. Any. Yeah, probably. All these years. It was the juice. It was just the fact of drinking. [00:10:09] Researcher: Umm. Mm-hmm. [00:10:40] IME2: Yeah, so, so I don't recommend cranberry. There are. So I start with water is key water is simply, you know number one. But if that doesn't work or if the patient clearly has an underlying problem and an anatomical problem or whatever, then there's a spectrum of things, you know, then you move on to something called you can try some some other natural products that are not antibiotics. D-Mannose. I don't know if you've heard of D-Mannose. [00:10:41] Researcher: Umm. [00:10:40] IME2: It's a sugar. It's a not an antibiotic, it's a sugar. And some women have success with it. Some women don't. It's it doesn't really have side effects. It's not dangerous, but it's not covered by insurance companies, because we don't yet have enough proof that it works. So it costs money. So it's, you know, it's only women who can afford it, can take it. You know, it's not super expensive, but over you're supposed to take it every day and it's about 30 francs a month. So it's a. If you know at least a pill every day every, for a year, for the rest of your, I mean it's expensive. [00:11:15] Researcher: Is yes. [00:11:16] IME2: Umm yeah. [00:11:17] Researcher: Do you think? [00:11:18] IME2: So. And then. [00:11:20] Researcher: Not do you see any? No, sorry, go ahead. [00:11:23] IME2: No, no, I just to finish like this whole spectrum in, in some cases I do have to prescribe an antibiotic as prophylaxis, but the only one I do prescribe is this nitrofurantoin because it doesn't drive up resistance. It generally does not. So yeah, but those are cases, those are rare cases where there's really some kind of underlying problem, structural problem the patients never gonna be able to get rid of the infections on their own. Yeah. So. Go ahead. I have only a couple minutes so. Perfect. [00:11:54] Researcher: OK. And no, sorry, not very last question. Very last question. Do you see any barrier in like suggesting natural products from Doctor point of view, I mean sometimes? [00:12:09] IME2: Yeah, I mean that is the barrier that I don't have enough data there. Yeah, we really need more studies, good quality, good, you know, fair studies on the efficacy and safety of a lot of these natural products that there's a real problem on a policy level that these products are easily being sold as nutritional. You know, they're in like the nutrition category. So they don't require any real testing for actual efficacy. But they're being so they're on the market as nutritional products, but they're actually being advertised and promoted as healthcare products because they're being promoted for UTI prevention and it's not in the interest of these companies to subject these products to real good testing, right, because if they get a negative result, they don't get any financial profit, so. It's really a problem and This is why I, as a doctor, I will not prescribe these things because I don't have enough evidence to make my patients pay this money to give them false hope. I just don't have the evidence. So I mean, they're welcome to try anything they need to try. They're desperate. You know, it's fine. But I can't be the mouthpiece for these for these products until I have better evidence. [00:13:35] Researcher: OK, if you don't have anything to add, I'm very happy and I thank you for your time. [00:13:42] IME2: Yeah, I think you I think you're doing a great job. And I'm sorry I was late again.

IME3

[00:00:15] IME3: Yes, OK. So my my name is *** and I am a clinical pharmacist. I'm working at University Hospital in Basil and my education. So my my education is I studied pharmacy at the university and after this I did a how do you say my? Doctoral thesis. In clinical pharmacy. And I did a further education in clinical pharmacy. This is [unclear word] clinician pharmacy. And. So that's my education and my occupation and role in the hospital is, yeah. Work as a clinical pharmacist. [00:01:03] Researcher: OK. Thank you. [00:01:10] IME3: Yeah. [00:01:05] Researcher: And so the interview will be structured more or less in three areas. I am going to ask you some general questions? Then I will move to a question related to symptoms and then people participation, possible participation during the practice of antibiotic prescription and consumption. So starting from the general background, what is in your opinion the current role of data in tackling antimicrobial resistance and more specifically urinary tract infection? [00:01:38] IME3: I'm just a little question with data. You mean, I mean in my understanding data can be. [00:01:49] Researcher: Mm-hmm. [00:01:48] IME3: Anything. So it means like antibiotic consumption data but also things when you question patients that can also be data right or? [00:02:02] IME3: OK. [00:02:06] IME3: Mm-hmm. [00:02:13] IME3: OK. [00:02:01] Researcher: Yes, yes. I mean I would like to start from let's say an open view and then if you one of the other question will be which kind of data is in your opinion more useful to help understanding the situation. But if you would like to start also defining what's data for you in this background, I mean in this field would be very helpful actually for me. [00:02:26] IME3: OK. So yeah for me like. [00:02:29] IME3: Data can really be everything, so for me I'm working a lot with antibiotic consumption rates, but data can also be like what do physicians prescribe on words? For me, it can also be what do patients tell you about their willingness to swallow antibiotics about their knowledge and antibiotics. So if I understand it right, data is quite big. And for your questions. [00:03:00] IME3: The role of data currently I think it's. [00:03:04] IME3: It's very, very important to have data and. [00:03:10] IME3: And now we have some, but I think in the future we will use more data and for now for me and data provides us. [00:03:22] IME3: A first glimpse or a first idea on how we are. [00:03:27] IME3: Umm, moving on and what's the problem? And it it shows us how is the antibiotic consumption. If do we use a lot of antibiotics is the use is it? Do we see an increase or a decrease? Do we see an increase of antimicrobial resistance or a decrease? And so for me, at the moment data provides a a first basis to. [00:03:57] IME3: To see where are we and. [00:04:00] IME3: And helps us to monitor our interventions. [00:04:04] IME3: Yeah. [00:04:13] IME3: Yeah. [00:04:15] IME3: Yeah. [00:04:04] Researcher: OK, very useful. Thanks. So based on what you said you could we say that you consider data both quantitative and qualitative information from patients. OK, thank you. [00:04:16] Researcher: And maybe you already just kind of answered this question, which is what do you think the role of data will be in the future? [00:04:28] IME3: Umm, I think it will be much more important. [00:04:33] IME3: Umm. Or we will need much more data to tackle antimicrobial resistance, and for now, I think that we are lacking a lot of real time data. [00:04:47] IME3: So we do have a lot of of retrospective information. So for example I am gathering data on antibiotic consumption, but it's always not real time, it's always retrospective. And then I tell physicians maybe, let's see, you did use a lot of carbapenems in the past and I think it will be useful also for the future to to gather more real time data where you can really intervene in time. [00:05:19] IME3: And I, in my opinion, we lack of. [00:05:23] IME3: Proper real time data. [00:05:26] Researcher: OK, so what's the kind of data do you think would be useful to have? So in real time to to understand or like tackle AMR? [00:05:39] Researcher: Specifically related to UTI, I don't know if you wanna do like a kind of introduction on AMR and then maybe speaking more specifically about UTI up to you. [00:05:49] IME3: Mm-hmm. [00:05:51] IME3: Umm, so in in my field of of or in my occupation I. [00:06:00] IME3: I rather work with physicians. [00:06:03] IME3: Prescribing behavior then with them with the patients. So I do have a lot of contact with the physicians more than with the patients. So for me it would be very nice and interesting to to gather real time alerts every time when a physician prescribes an antibiotic. [00:06:26] IME3: I get an alert or maybe only with some with the critical antibiotics, and then I can directly check if the

indication is right. If the dosage of the antibiotic is right and then I can intervene so that for me this would be really helpful real world or real? [00:06:48] IME3: Time. Whatever in time. Don't know how to call it. Data that would help to. [00:06:56] IME3: To combat or to to prevent antimicrobial resistance. [00:07:02] IME3: Umm. [00:07:04] IME3: And in the. [00:07:07] IME3: In the area outside of the hospital, maybe in the future. [00:07:12] IME3: I think you have some more questions in the interview about this, but you might involve the patients even more with them social media chats or whatever where they can really ask you questions and they get answers right in time. Do I have to swallow the antibiotic until today or tomorrow? And then they really get. [00:07:34] IME3: To help. [00:07:36] Researcher: Yeah. [00:07:36] IME3: Umm yeah. [00:07:38] IME3: And. [00:07:38] Researcher: OK. Because it no please. [00:07:39] IME3: Yes. Sorry and and. [00:07:42] IME3: Concerning the urinary tract infection, this would be nice also. [00:07:46] IME3: Umm, because I know that there are a lot of patients who who are aware that there are urinary tract infections and they are very common amongst women for example. And there is always this questions. Do I need antibiotics, yes or no. And when do I need them? And? [00:08:06] IME3: Yeah. And I think with with this. [00:08:09] IME3: Real time. [00:08:11] IME3: Data or this chapter. Whatever you could intervene even more. [00:08:17] IME3: Yeah. [00:08:22] IME3: Yeah. [00:08:16] Researcher: Yeah. Thank you. So you said you work more with the physician rather than patients. How do you consider, let's say, the responsibilities of a prescribed antibiotics if you consider both patients and clinician taking part? [00:08:36] Researcher: In the prescription or diagnosis more generally. [00:08:41] IME3: So who is responsible for the right prescription? [00:08:53] IME3: Yeah. [00:08:45] Researcher: I mean, I I don't wanna say that's your fault, but the how you see the balance of, like sharing responsibilities, let's say if it's possible or not. [00:08:55] IME3: Between physicians and patients or between also between physicians and pharmacists. [00:09:04] IME3: OK. [00:09:00] Researcher: Uh, I mean, if you have, uh, another stakeholder to bring in, just mention it and you can. Yeah. [00:09:07] IME3: Yeah, but for me, the if I understood you right, the the main responsibility. [00:09:14] IME3: To prescribe or for the prescription of antibiotics for me is with the physician as he is the person who knows best when the patient should receive an antibiotic, and when he doesn't, so I think. [00:09:28] IME3: This is. [00:09:30] IME3: Umm. [00:09:33] Researcher: Mm-hmm. [00:09:31] IME3: Yeah, he is the main person who is responsible. Patient should not be able to choose or to make this decision by themselves. [00:09:42] IME3: If they want an antibiotic or not. [00:09:45] IME3: Umm but. [00:09:48] IME3: I am. [00:09:50] IME3: Convinced that you have the best success or at a therapy is only successful when you share a certain responsibility with patients and when you take them serious and explain it to them and and when you. [00:10:08] Researcher: Umm. [00:10:07] IME3: Yeah, when they also feel that they have a certain responsibility also for their health and their. [00:10:13] IME3: bodies and we as pharmacists, I think we also. [00:10:19] IME3: It would be ideal to to share the responsibility with the physicians in order to just. [00:10:28] Researcher: Mm-hmm. [00:10:28] IME3: Advice or give them advice is when we see that a prescription might be not ideal, or a dosage might be wrong. So then I feel like yes, we also have a responsibility to ensure that the therapy is given in the correct way. [00:10:45] Researcher: OK, because your, let's say you role, it's kind of like not considered very active in. [00:10:56] Researcher: Taking part or let's say change, what has been prescribed by the physician? [00:11:00] IME3: Yes, yes. Unfortunately, yes. So there are other countries I think in in. [00:11:06] IME3: Germany sometimes or in England, and where they have much more clinical pharmacists on the ward and and they tend to be much more active in. [00:11:17] IME3: In giving advices and also the prescriptions, I think in in some hospitals they even have to. [00:11:24] IME3: And give their OK. [00:11:27] Researcher: Hey. [00:11:30] Researcher: Mm-hmm. [00:11:27] IME3: When the physician prescribes something, pharmacists have to to give their OK and we are. [00:11:36] IME3: Are not that active we. [00:11:40] Researcher: Mm-hmm. [00:11:39] IME3: Would love to in the future, but at the moment we don't. If they prescribe an antibiotic, we also don't get a lot of alerts. So most of the prescriptions are just. [00:11:52] Researcher: That's Umm. [00:11:52] IME3: Done by the physicians and that's it. [00:11:54] IME3: Yeah. [00:11:54] Researcher: OK. OK, thank you. Now let's move to the symptom

section and I would like to ask you, how is the antibiotic prescription influenced by symptoms description that people provide to doctors? [00:12:10] IME3: Umm. [00:12:14] IME3: I think. [00:12:19] IME3: A lot. So in the in the. [00:12:24] IME3: Umm. [00:12:25] IME3: Inside of less if you are staying in a hospital, then I think the prescription is less influenced by symptoms that the patient tells you about because we do make a lot of laboratory tests and then. [00:12:38] Researcher: Sure. Mm-hmm. [00:12:40] IME3: I'm. Yeah, it's more based on laboratory values, but outside of the hospitals, I think it's it's a lot influenced by the symptoms that the patient tells you. So if a patient comes to the GP and tells him that he has a little bit of of pain while peeing. [00:13:01] IME3: That's completely different. And then if the patient tells you that he also experienced fever and has a lot of blood in his urine, so yes. [00:13:12] Researcher: OK. And how much do you think people are aware of their symptoms? [00:13:18] Researcher: I mean. [00:13:19] IME3: Both. I think this various a lot. [00:13:23] Researcher: OK. [00:13:24] IME3: I think. [00:13:26] IME3: Young women who experienced a lot of urinary tract infections, I think there are. [00:13:33] IME3: Quite good in in judging their symptoms. [00:13:37] IME3: Umm. [00:13:39] IME3: But the men, I mean, if if they have a urinary tract infection, which is quite rare, I would guess. [00:13:47] IME3: They are not very much aware of their symptoms, so I think it differs massively. [00:13:53] IME3: Yeah. [00:13:53] Researcher: OK. And how accurately people are able to describe their symptoms? [00:13:59] IME3: I also think that varies a lot from very good to almost. [00:14:08] Researcher: Which is. [00:14:07] IME3: I am very poor. [00:14:10] Researcher: Sorry, which is probably related to how often they. [00:14:15] Researcher: Perceived that those kind of symptoms that might be related. [00:14:17] IME3: Yeah, I yeah. Did they experience the urinary tract infection before? How good do they know? Or the signs of their body? How much knowledge do they have? [00:14:34] IME3: In the field of urinary tract infections. [00:14:39] IME3: Yeah. [00:14:40] Researcher: Mm-hmm. Yes, sure. And what data should people track, collect and analyze and analyze about themself to improve their symptom description, if it's possible in your, in your opinion? [00:14:55] Researcher: Is. [00:14:56] IME3: What date Umm. So they I think they. They can provide like the symptoms that are easy to track, like the fever. It's easy to measure if you have fever or they can tell you if they have pain while peeing. [00:15:25] Researcher: Mm-hmm. [00:15:28] IME3: And some of them might be able to. I think you, you know these urinary sticks, do you know like the combur test? [00:15:28] Researcher: I hear about that. [00:15:28] IME3: I'm so yeah, it's on me as a pharmacist, I had urinary tract infection once in my life and I bought the combur stick. So if a patient has a nice health literacy and a good knowledge and he might also collect data on blood in the urine and the amount of like asides. [00:15:50] IME3: Yeah, but I think that's it. It's like, yeah. [00:15:53] Researcher: OK, OK. And now imagine people using data to support their symptom description. Can peoples reliability take advantage of data supported symptom description? I mean, do you think their symptoms description and their conversation with Doctor can take advantage of having a data supporting what they are saying. Do you think the physician can consider differently what the patient is saying because kind of supported by data or can they reliability of the description be more accurate in your opinion or not really? [00:16:46] IME3: And. Yes, if the patient is considered as a. Trustworthy. Or maybe that's the wrong word. As a patient? Who who can? Collect the data in a correct way and who can interpret the data in a correct way. Then I think that this can be helpful for a physician, but I I think the the question if the collection of the data was correct might be a very difficult one or difficult one to judge. And I I think it's maybe more for. For the patients who are not at. Who are not that high risk patients because I think for the high risk patients physician always want to be sure and they might. do more laboratory tests. [00:17:44] Researcher: Sure. And for people not at risk, do you think what's in your opinion are things that can make them more reliable when going to doctor and describe the symptoms based on data. So probably could be something that you just mentioned as like a health literacy for example. What would you like to consider to give trust. [00:18:11] IME3: So the question is, which patients would I would I take serious or like this and? When they are healthcare professionals, I would consider them as I would trust them a little bit more because I think they are more familiar with the topic.

People with. Repeating urinary tract infections as they might also be more familiar with all the symptoms. Maybe also if they. I would rather trust him if they have no huge language issues, so if they can understand. Umm. Literature or like the? And they. Yeah, and. And they need to be mentally. So people with dementia, I would not trust them that much. [00:19:23] Researcher: Makes sense, OK. And now imagine people collecting and analyzing data to support their symptoms description. Do you think the action of collecting and analyzing data can somehow influence their behavior. I mean, as a way to become aware of some information, some symptoms, some consequences of the treatment or the disease they are suffering from. [00:20:01] IME3: Yeah. Yes, I do. For so, for me, this is kind of a patient empowerment. Umm, which I think is a very good thing. Umm. In all the areas of of health that you empower patients to be aware of their symptoms and to know them, so I think. Yes it. Can be a good thing. [00:20:31] IME3: Yes. [00:20:21] Researcher: OK. So you think the patient empowerment can happen through, let's say data collection to better understand their symptoms can be related to that. OK, that's. [00:20:34] IME3: Might, yes. [00:20:34] Researcher: OK, thank you. And now let's move to people involvement. So why should people in your opinion be encouraged to take part in the prescription process? So as you said also before, it's not like only one part responsibilities, but patient have a role during the prescription as well. Why should they take part actively in the in the prescription process in your in your opinion? [00:21:02] IME3: Yeah, I think that's that's really this part with empowerment for. So for me when. I am a patient and. I. I feel that I'm taking more seriously. When I am involved in this process and finally the physician is prescribing you and antibiotic, but it's up on you how you take it and. And and there are a lot of of days without a physician where you have to take these meds and. The more I think that you share responsibility and the more that you feel that you matter and and you are. Yeah, it's important what you are doing. I think the better you are doing it and the more you are interested in doing it in a proper way. So I I think that. The time. When physicians just prescribed you a drug and that's it and you have no right to comment on it. And whatever, I think that's over or that's not the right way in my opinion. [00:22:17] Researcher: OK. Yeah. Thank you. And what benefit can people gain from collecting and analyze their own data? Maybe you already somehow answer this question. So I would link to the following question, which is what benefit can people gain from sharing their data? With the physicians first. And then I don't know if you can consider any other way of that a patient can share data. [00:22:56] IME3: So for me they are. Maybe three different ways of sharing. So first sharing data with the physician. And I think that that's always, I hope that always this improves your outcome of the therapy as the physician is fully aware of all your symptoms and your adherence. And and the patient is aware of the of the opinion of the physician. Ideally, patients would share or patients and physicians would share their data also with the Community pharmacists and in order to check for interactions with other medications that the patient is taking and and the the pharmacist could also be a perfect person to check if the adherence is is alright of the patient and so if patient is taking the medication as prescribed. Or maybe just a tiny details. Do not take this active ingredient together with milk and whatever and. Sharing data with. Other people. Yeah, you you might distinguish between friends and just anyone, but for some topics and urinary tract infection might be such a topic, it might help to. To increase. The knowledge about this disease and the knowledge of the symptoms. And maybe also. There are other topics who are more at taboo topic and then urinary tract infections. But nevertheless I think it can help to to show I was also or it it's common. It's a common infection and talk about how can you protect yourself or what can you do to to get less infections and. And why did? I received an antibiotic and another person maybe not, and I think it it can help to spread knowledge and sometimes it's easier for other people or patients if they hear it. In the words of a another patient and always the language of the physician, that might be. Yeah, uh, a language that might be too complicated, so maybe it's sometimes it's easier. Among. People citizen instead of like with specialists? Sure. Exactly. So for this I I think that sharing. They thought might be. An advantage? [00:25:43] Researcher: And what and why people should be agree, let's say, on sharing their data. I see with the in the doctor patient relationship. But do you think is there any like

specific idea that can be promoted to like a ask people to to share data for communities as you mentioned or for research more broadly. [00:26:10] IME3: Umm so. For sure it's it's a very sensitive topic with all the data protection and so on. So it it really must be discussed in what way do we share data, do we share it on an anonymously or not and. But sharing data can for you personally also provide. Umm. Maybe first a nice feeling that you have the feeling that you can help others. Umm. You may be also get nice tips from others so for the next time take it like this or do behave like this that might. And. Support or that might lower your symptoms, so you can also receive feedback. Maybe you can receive maybe some words or some sentences that reinforce you and they support your behavior, but it can of course also turn the other way around that you receive comments that are not correct. So that's always the risk, hopefully sharing. [00:27:17] Researcher: Yeah, exactly, exactly. My next version actually was about communities. So if the, you know, any specific communities where people share their experience, feedback information, and how do you consider community is in this particular field? [00:27:39] IME3: I I only. No, the communities there are some cancer communities. That I know. And in this area, I also heard from patients that it can very helpful to share. Umm, opinions because you get support. Also mental support, but it can also be very devastating or or too much if you get all these comments or if you see all the bad stories and another example is. Their whole discussion about do you need to vaccine or not and there you need you see a lot of communities and they argue with arguments that are just horribly wrong and and these ones I've they are very harmful for the whole population because they are just spreading horribly wrong information and for urinary tract. Infections, I think. There might be a risk that there are people. You have this strange ideas about. You should always receive antibiotics or do never receive antibiotics because you will die or just pharma industry just wants to make some money and this might influence you in a in a bad way. Yeah, or they might cause you harm by just adding silly comments. Are you a silly person? Why did you take the antibiotic or whatever? [00:29:27] Researcher: OK, OK. And maybe somehow related to the communities. Is there any? I mean, what's the role of alternatives remedies? For you to trat urinary tract infection. In your opinion, if there is any and if. What's the relationship? What's the sorry. What's the approach of a physician in, like, considering alternatives? If they, they might suggest any or is something more possible to find in the communities or among peoples without official supervisor? [00:30:10] IME3: So did I understand you in the correct way because you you had or there was just a lack of Internet connection? [00:30:17] Researcher: No, it wasn't a proper question because you just mentioned this stuff. So I was curious, yeah. [00:30:18] IME3: I'm. So you are considering. Alternatives for an antibiotic therapy maybe like? [00:30:31] Researcher: Uh, yes. Or I know that some people specifically related to UTI are looking for or are in habit to use some alternatives remedies that doesn't want to substitute or in some cases the idea is to substitute antibiotic. But what's? In more general, what's your opinion about alternatives and the role of alternatives in treating UTI? [00:30:59] IME3: So. Basically myself, I'm coming from the non-alternative side of medicine. Umm, so I rather. Treat with antibiotics if it's needed, and then I think that it is important and it is important not to substitute an antibiotic by some alternative medicine if really needed. And if the infection is like this and that happens a lot that you don't really need to treat it with an antibiotic. Then I feel like if someone wants to add some alternative medicine to that might be helpful for their symptoms. If it's placebo or not. That might be OK if it's not interfering with other diseases or other drugs that might be OK and that might also be a nice suggestion by that's my by the physician, but I. I don't know how much. They suggest alternative method depends on the physician. Yeah. [00:32:15] Researcher: And what's the role of prevention in the field? [00:32:19] IME3: It's huge. Umm. Yeah. For me it's it's huge. And therefore I also feel like this self empowerment of patience is so important because you. You can you can prevent a lot of urinary tract infections in the way you behave after sexual intercourse or. With the hygiene when you shower or when you go to a Wellness bar, whatever. So there are a lot of. Of tips, what you can do to prevent so I think. Guess that's very, very important that people are aware of these things. [00:33:05] Researcher: OK. And

then speaking about the like negative side of like a having people engaged during the process, do you see any problem in their taking part during the prescription and like, yeah, during the prescription phase. Or do is there any risk that? Uh data collected by individuals might cause in your opinion. [00:33:38] IME3: Umm. Yes, for me there are always risks when people. Are enabled to collect data, but they don't understand the way how they. Should collect data so then you have wrong data that might mislead. The physician. Or if they collect data but they interpret data in the wrong way and then people might force the physician to prescribe them antibiotics because of a test, whatever they made at home. And then it might be really hard for the physician to convince patient why the test that they did at home is maybe not that accurate. And so I think when people should collect data and. It should only be data that they. Understand and that they can collect easily. Yeah. Or you just select. What people should be able or might be unable to collect it? [00:34:57] Researcher: Yeah, yeah. OK. And I do have last question of more, say technical and what, in your opinion people should know to consume antibiotic responsibility? [00:35:06] IME3: What facts? [00:35:08] Researcher: Yeah, kind of a huge like open question, but is there any like specific idea or like let's say tips advice that you would like to suggest? [00:35:18] IME3: Yeah. So I think that most most, most important message is that antibiotics are. The trucks to treat bacterial infections and not viral infections. There are still a lot of people who don't know this. And they should be aware. Of antimicrobial resistances. So what? What is this? What does it mean for me? If if I have this? Umm. And then they should know precisely on how long do you take an antibiotic. You should continue with the therapy even when you feel better after two days. And then you should continue as long as your doctor tells you. And pharmacy industry sometimes provides quite silly packages of like 100 pills. And then you should be fully aware on how long do I take the medicine. When do I take them? One time daily, two TimesDaily, and when two TimesDaily doesn't mean like 8 in the morning, eight in the evening or like 8 in the morning and at lunch and that they should be aware that they shouldn't share their drugs with all their friends when they feel that their friends are in need of antibiotics, they should be aware that. And to throw them away that you don't throw them in your toilet or there are plenty of. Of important information. Umm. Yeah, I think it's it's just it's so, so important. And for me it's much more important than to take antihypertensive drugs. And I mean, you can take them a little bit in the morning in the evening and in the end it doesn't matter, but not that much. And for antibiotics, it's really does matter how you take them. [00:37:33] Researcher: And if you can imagine a way to. Ohh, convince people to consume antibiotic correctly. What would you like? To tell them or engage them with or explain them. What would you say them? [00:37:46] IME3: And we we want realized a project with the Ministry of Health. And and I was involved in this project together with other pharmacists and physicians, and we created a website on why do I need antibiotics or why? And don't. Umm yeah, and there we provided like basic information in different languages together with them images. On different channels like linked to videos and now I forgot the the question but I think like we we try to provide information in in many different ways. And on many different channels. Umm, linked to videos and pictures and different languages. And I think it's just important that we don't provide information only in one way. [00:38:52] Researcher: Hmm, it may ask you the name of the project. [00:38:56] IME3: I'm yeah, I I can. I can send you the link. Yeah. Yeah. [00:39:01] Researcher: Ohh you can send me the link over. Yes would be great. Thank you very much. OK. [00:39:06] IME3: And I I'm actually not aware on how many people click on the website, but it's like a a huge official website. I will I will send you the link in. [00:39:18] Researcher: OK. OK, maybe I know that because I did a lot research but and I found some official from the Swiss healthcare. The website. Yeah, there. [00:39:19] IME3: It might be this one colored in blue and yeah, but I will send you the link just in case, yeah. [00:39:32] Researcher: OK. OK. Thank you very much. I think my questions are over. I don't know if you have any like suggestion or opinion or feedback you would like to add. [00:39:35] IME3: No, I hope it it helped. [00:39:35] Researcher: No. OK. Yes, it helped a really lot actually, yeah. [00:39:41] IME3: Yeah, maybe I. I feel like people are using more and more apps for everything. So this might also be an interesting channel to provide information on. [00:39:54] Researcher: OK. But you

considering something like tailored or kind of like main guidelines that can people access why they need some specific information? [00:40:08] IME3: Maybe. I I would need to to think it through. And I maybe maybe both. So in my experience, so if guidelines are too long and too complicate people don't read it, so. Guidelines yes, but easily accessible and and easily. As an easy to to read. Made ideally also tailored information where you might be able to set filters or whatever or enter information and based on these informations you get. And tailored content. [00:40:49] Researcher: And what's what's the role of physicians in this then? Do you think they can kind of like answer question through the chat or just have less interaction with the patients because patient start using this kind of interactive service more and more? If you have an idea, I mean you don't have. [00:41:11] IME3: I I think it might be more, but this might be an in an interesting question for what is the name of the physician Angela? And who is working with their patients? So she might be able to judge if this would be something good or not. But for me it would rather be an app. That you can use to send to make. To increase awareness of urinary tract infection and and that I could access if I would have symptoms and where I would go and and check do I need to see a physician or not? And and then you if you need to see a physician, you go to the physician and he might prescribe you antibiotics and then he might also link to the app and tell you see and you can also read additional information on this truck. Ideally he would give or provide the information, but you would also have the app and you could. Maybe also track your therapy and make a cross when you. Took the pill and you could see for how many days you need to take it. Umm yeah. [00:42:26] Researcher: Yeah, you actually highlighted one more thing that I was curious about, which is the follow up. Do you think how could be relevant having a follow up with the patients? Uh. Is that important? Only if the therapy doesn't go. How it was supposed to go? Or do you think even in like, positive cases would be interesting and useful for you and then other patient to to know what happened? [00:42:55] IME3: Umm. I think a follow up is. Important but. It doesn't need to be done by the physician all the time. So if you are young and healthy, I I think the follow up could also be in the pharmacy. Umm. Yeah, and it. I'm not sure whether it does it always needs a follow up. So for me as a healthcare professional. I would know how to take the antibiotic and if I feel like my symptoms are gone and therapy is. Over I think I wouldn't need. I'll follow up. Yeah, I think you don't need it for everyone. And it really depends. [00:43:47] Researcher: OK, speaking with you, actually been super useful. Thank you for your time. I don't know if you if you know anyone else interested and maybe available to answer similar questions or. [00:43:54] IME3: Yeah, I thought about, did you contact? [00:43:59] Researcher: Not really and. [00:44:10] IME3: Umm is it? But you know the Andreas tutor she she is also involved in the in the whole inner Swiss project. Umm, I don't know if you remember her. The lady with the brown red hair. She worked. Umm. Years ago she worked in a hospital in Schaffhausen. And and in this hospital they. They were pharmacists who were really involved in all the antimicrobial therapies. She played a huge role or she was an important person as a pharmacist in this hospital, talking with physician about the prescription of their antibiotics. So she might be an interesting person. [00:45:12] Researcher: And more generally, yeah, if you have also or no anyone with like specific chronic UTI your AMR I know that then it's about data, but if you can share my contacts and they happy to contact me, I'm very happy to to. [00:45:15] IME3: Also, so you mean with patient if I know patient? [00:45:27] Researcher: Yeah. Yes, patient or I mean physician and patient as well. If you know anyone that can be interested and you can share my my details or suggest the name I will be more than happy to have a chat with them. [00:45:33] IME3: Yeah, I will. [00:45:34] Researcher: But actually I don't know anyone with. With urinary tract infections. [00:45:42] IME3: I might know like one or two very nice community pharmacists with a lot of experience. Just they are just experienced pharmacists in the community area, so they might also be interesting partners to speak with as they have a lot of contact with people who come to. To get there antibiotics. [00:46:07] Researcher: Yeah. I mean, if you can send the the name of the communities, I will have a look, but even more if you know anyone there and share my contact with be useful. [00:46:18] IME3: Yeah, I think the one is to uptake. So my friend, she's quite busy, but she's called Adriana. Lucy. And she works in

the Ricky Apoteket. And for example, she is a very, very nice community pharmacist. She might. Have time or? [00:46:47] Researcher: OK. [00:46:54] IME3: Welcome. Thank you. You too. You too. Thank you. [00:46:48] Researcher: Thank you very much for your help and time again, and I wish you a nice holidays if we will say that. See you soon. Thank you. Bye. Bye bye. Thanks. [00:46:58] IME3: Dieting with thank you very much.

IME4

This interview was not recorded because hosted by the interviewee who specifically asked it. For this reason, notes were taken and reorganised as following. The interview was conducted with a medical anthropologist whose research focuses on the social and cultural dimensions of disability and care. At the time of the interview, this person was working with Digital Narrative Medicine (DNM, available at https://digitalnarrativemedicine.com/it/, accessed on 2 December 2025), and she offered a comprehensive overview of the platform, illustrating its structure, functionalities, and role in integrating patient narratives into therapeutic pathways.

[Introduction to the service] DNM is based on the guidelines of the Italian National Institute of Health regarding indications on how to integrate narrative medicine into clinical practice for the treatment of rare and chronic diseases. DNM refers to these directives to modify therapeutic pathways, transforming the collection of narratives into a clinical-assistance intervention. The platform is web-based and accessible from any device connected to the internet. It is available and currently used by several hospitals that purchase the service. At present, it is used mainly in oncology and for patients with Alzheimer's, diabetes, epilepsy, and other conditions, integrating evidence-based medicine to support healthcare providers. Its use involves the collaboration of multidisciplinary teams, allowing a systemic view of patients' issues. Among others, physicians, midwives, and psychologists were mentioned; their involvement depends on the specific cases of use. The advantages apply to both parties involved: patients and healthcare providers. **[Interface]** The service offered to the healthcare provider requires the lab manager to invite other providers and patients to access and use the platform by entering the new users' first name, last name, and email address. In addition to patients directly under care, caregivers can also be involved in the process. Through their first login, users confirm the processing of their data by consenting to the GDPR policy. Healthcare providers can be "basic," meaning they can only see their own patients, or they can have access to all teams. Providers and assistants can request help from a technical manager through a dedicated function in case of problems. An introductory paragraph on the patient's page provides the provider with some demographic information, while the available functions include instant messaging, access to clinical data, and the possibility of adding notes visible to the patient. On the patient's side, the main function is the diary. Writing one's story is facilitated by what are called "stimuli," which are questions and prompts from which to start writing. The story is private and shared only with the patient's doctor unless the patient decides to share it with others; in that case, the provider creates a group of patients who can access each other's stories. [Doctor–patient interaction] The platform allows the customization of stimuli to facilitate patients' narrative expression. Narrative stimuli are short open-ended sentences that encourage the patient to talk about their experience of care, their needs, challenges, expectations regarding treatment, etc. Usually, the stimuli are created by DNM's project team together with the center's multidisciplinary team before starting the digital narrative medicine process. The patient finds them inside the digital narrative diary once they have been invited by their provider to access the platform. Currently, the platform is not designed as a doctor–patient communication tool. Patients are invited to freely tell their story, facilitated by the stimuli. Providers are expected to read the diary before the visit. What is written becomes a point of discussion during the appointment, and providers usually give feedback on what they have read. Having the possibility to keep a diary is advantageous for patients, who can discuss topics they would not normally address during a visit, for various reasons—primarily embarrassment and lack of time. Indeed, writing usually occurs in a protected environment that encourages the emergence of issues that

would otherwise not be addressed. For example, in the context of oncology-related problems affecting women's sexual health, the platform helps patients feel more comfortable and overcome the embarrassment of discussing intimate topics with their doctor. Reading the diary allows the provider to personalize the therapy, as the narrative helps outline details and information useful for defining the treatment. **[Healthcare providers' feedback]** The ability to access and read patients' stories before the appointment allows providers to reduce the duration of the visit. Moreover, this type of data collection increases the amount of information available; once initial skepticism is overcome, providers generally recognize the added value of the service. **[Quantitative information]** Currently, narrative medicine is considered mainly a qualitative tool. The collection of quantitative information can also occur through questionnaires designed to detect the symptoms of a disease, the effects of a drug, or the impact of treatments on patients' quality of life. There are many different standardized questionnaires. These questionnaires cannot be customized, as they are standardized. The DNM platform, however, is customizable since users can choose to integrate the administration of standardized questionnaires within the digital narrative diary. The platform allows for viewing aggregated results for each individual patient or for all patients, through a word map that highlights the most frequently used words in the narratives. The provider's interface also allows reading all responses separately, and if the questionnaire is administered more than once, differing responses are highlighted in red. Finally, a report collects all results, showing the percentages of responses. The main purpose of the questionnaires is to investigate patients' quality of life, detect symptoms of a disease, and assess the toxicity of drugs used during therapy. **[Narrative medicine trends]** This period appears to be particularly productive for narrative medicine, and there is a greater openness to collaboration among the parties involved. This phase of change is likely encouraged by the broader trend toward the humanization of care.

IME5

[00:01:03] IME5: Okay. So my name is ***. I'm a lecturer and researcher at IDSIA, but actually I'm a researcher at IDSIA and I'm a lecturer at SUPSI at Delle Molle Institute for Artificial Intelligence. In in terms of education, actually I do my current research in machine learning, but I studied physics. I did the bachelor and Masters and also PhD in physics and then I switched to to to machine learning. [00:01:46] Researcher: Okay, thank you. So I suppose that you know about antimicrobial resistance, or maybe I can easily can ask you if you ever hear about antimicrobial resistance and if you ever worked on this topic. [00:02:04] IME5: Yes, I am currently working on this topic, but I have I I have already heard about antimicrobial resistance before starting the project, but I I didn't have it really precise knowledge of how relevant the problem was. I knew it was a problem, it was a problem especially occurring in in in in hospitals where things are getting worse and worse. But I didn't have any clue of the implications of this. So of the numbers etcetera. [00:02:34] Researcher: OK. Thank you. And. And what's your role in in the project related to antimicrobial resistance you just mentioned? [00:02:45] IME5: Yeah. Well, in our sub project, the idea is to to develop a machine learning model to support clinicians in making optimal user of. A antimicrobial S, while in particular in our case it will be antibiotics for during the tract infections. So the idea is to provide declinations with. One more tool to. To prescribe in the best way they can. [00:03:17] Researcher: OK. And more generally, what is, in your opinion, the current role of data in tackling antimicrobial resistance? [00:03:26] IME5: Well, I think. This is not really specific to antimicrobial resistance, but uh. Data in for our society is the new gold oil or I mean it's like in the past. Now it data is like fuel for, for, for for everything I think and getting data, analysing data, producing models when we have a lot of data I think some methods of automatic methods are really fundamental because. Analysing all of the all of all of those data is really beyond the the possibilities of a human because you don't have time, you don't have the really the capability of analysing why sources of data and from data we can learn a lot. [00:04:13] Researcher: Okay. Yeah. And you actually mentioned a division intelligence mainly to analyse data. Do you see any space for also collecting data or do you see the task they paraded. [00:04:28] IME5: Well, pricing, I would say analyse that's one one level and then the other level is. Learning something

making which is what permits you to make a prediction, then to predict, for example, whether you will have a resistance episode for one patient with specific antibiotic. So learning and prediction, which is a little bit more I would say than now than just analysis where you analyse your data but with. With machine learning model model, you have a more. Let's say I would say active role of data in the sense that you can extend your knowledge to something else. Um for collecting data. Uh. Well, uh, that's a good point. Hmm. For example, while that's not artificial intelligence, but like. Some automated method to look into the content of website and download the information of interest. That could be a possibility. Because for new collection of data it's mostly. While either data from the labs, which are analysed by my by machines or. Um data I am which are. Which came from questions answered by patients or by clinicians. I would say, yeah, maybe some automatic metres can really help in locating already existing data rather than collecting new data I would say. [00:06:06] Researcher: OK. OK. Thanks. And. And you mentioned already prevention, but what do you think might be the role of of data in the future at this point I feel to consider data in the healthcare scenario, so medicine related data. [00:06:27] IME5: OK. Well, uh. The word prevention that you mentioned makes me think to awareness because in this case the impact from impact camp can come from awareness. OK. So we can use data to make people more aware of the problem and to showcase how things are now and how they could be worse in the future. So that would be of huge impact in on the entire antimicrobial resistance, because if we can reach people. With the message and the message is clear. It is not only clinicians, but it's also people that abuse, but it's different levels at first, if you reach clinicians that then it's even more effective because they they, they prescribe. But I think it's also useful to to to reach, to reach people so that that's 111 point but more in general the the relevance of the entities I would say is specific to to the kind of problem that we are talking about. But in terms of. Have I would say that more in general data could be very useful for many different things like I don't know. Improving diagnosis identification of biomarkers of the given disease, which would then lead to identification of. Ohh. I don't know. Way you could you can deal with people suffering from it that from a disease improving a life of people in general. It's quite vague I would say, but uh. I see many different possible levels of improvement that you can get by using data systematically in in healthcare. [00:08:23] Researcher: Okay and the related to the trust ability of those data. If we imagine like a before, if we imagine. If you imagine people collecting themselves data, I mean collecting data about themselves or how, how do you see possibilities in having a these data more trustable? [00:08:53] IME5: Yeah, that's that. That's risky. I mean, how to improve the trustability of this? I think it's a very difficult question because in general when you have some clinician inserting data and providing data, I mean it's it's related to to their jobs. So did they. The quality is much much better, but with what you leave room to to people while you never know whether the person is inserting data in an honest way or whether they are lying, or whether they are just trolling for having fun or something like this. So I don't know how. I mean, this is much more general question like about I don't know how do you say. I don't have anyone, not even in Italian like. Social awareness. Or uh and social like irresponsible social behaviour or something. It's. I think it's really related to to that, but it depends actually. Because if people, if you manage in like. Presenting what you're doing as something which is useful and relevant. Probably this was this would lead people to. The more I don't know, keen on helping. And would avoid that they feel like it's like again they usual thing where people like stop you in the street and they they ask me questions and they want they. They want my data. So probably like trying and presenting a a project like really something which could have an impact and which is really. Uh, it's science, basically. I mean uh. The potential is to do something good for for for science. [00:10:41] Researcher: Is there any? Sorry. Now is there any parameter or situation that you consider more trustable or kind of data that you would consider more trustable while working with the healthcare data? Or it depends? [00:10:57] IME5: You mean again data collected by asking patients or? [00:11:05] Researcher: No, actually, honestly, I I. I don't know if there are any way. You kind of cheque or consider. [00:11:07] IME5: I don't have any experience with data with healthcare data collected from patients. I've always only use the

data coming from I don't know, the electronic health record of addition or lab exams or genetic data. So in in all of these cases, the data where either. Selected or produced by professionals. So I really don't have died some. Any direct experience on that kind of data? So probably I'm not even aware of. Ohh. Of how the quality could could change, yeah. [00:11:48] Researcher: OK. So that's the other question though. The data you worked on that are related to add care are basically quantitative data, so. [00:12:00] IME5: No, but in many cases it's quantitative data like well, again, lab xams. So any measurements of something concerning the patient, anything describing some events in the past history of the patients from quantitative point of view, quantitative point of view. But actually what you find in in healthcare often is also some like free text. So and what what you typically do is to analyse this free text through some methods, some automatic methods and to extract some quantitative variables that then can be used for if you want to do some machine learning models, which is what we typically do. The idea is that you cannot provide to the model directly the free text that you have in from the nodes of a clinician concerning your patient. So you're. [00:12:53] Researcher: OK. So that's that was my question. Sorry the free text is about notes of the clinician related to the patients, OK. [00:13:00] IME5: For example, you could be anything, yeah. For example, it could be something like. Like like this. [00:13:08] Researcher: Okay and yeah, go ahead. Sorry. [00:13:10] IME5: But in general, when you have this kind of all of data. What you should do is to try to map this to something quantitative. I think in the past. Yeah, but I don't have enough years of experience to say so. But since this kind of standards I have been there for a few years, but I guess that's some I don't know. 10-15 years ago it was much more common to have some free text. Uh now, for example, you have international standards like the the I CD10 for creating like a standardised way of classifying diagnosis. So naturally we are going towards the direction where we try to have something which is a little bit more. Um, quantity, quantitative or general? I mean a common standard, because what do you what is often necessary I would say is a common standard. So if you have the ICD 10 and you have the code for the diagnosis of something it it is the same in Italy and in I don't know New Zealand. Otherwise things would be completely different. And you also have international standards for like for drugs for example for many other things. But of course there are things that you cannot. Classify into this, so there will always be something, probably that we will need to analyse in in, in, in a different way. [00:14:35] Researcher: Yeah. And what's the output? Sorry. You analyse text to create. What kind of output? [00:14:42] IME5: While for example you can, uh from uh from text. Embedded with a sword, you can embed text into some something which is more numerical. So for example, one simple example is is is this one, but actually the very basic things for example could be defining variables for whether the text contains or not some important keyword. So you have a piece of text like a sentence, and I don't know. You're looking for something which is really important for for a, for what you do. And you look for a specific word. So if the sentence contains the words you set your new variable to 1, otherwise you set it to 0. So you have created a very simple Boolean variable describing the presence or absence of a given keyword of relevance into your data. That's probably the easiest thing that you can do. Then there are eight. Does a huge quantity of data, for example. This method swing embedding. The idea is that. You can describe, let's say, simplifying a little bit words. And in terms of the position in space, so imagine for example that you have two-dimensional space. It is a plane. And the idea is that you will describe every word in this case by two numbers. So Diaz coordinate and the white coordinate, right? So that you can move around in the plane and with some methods, Sir, you can learn a way to put words which are are, let's say, close from a lexical point of view. Into similar regions of the space. So for example, if you do something like this, the typical example is the word King and queen. You would expect it will King and Queen to be very close in the space. And very far away from, I don't know any. Any other words related to I don't know, pizza, whatever. But pizza and spaghetti would be a little bit close, for example, so that's that's the idea. And in this way you are able to describe each word with two values, 2 numbers. And that's an embedding, for example. [00:16:58] Researcher: OK, OK. And how do you see the role of data privacy and awareness of the use of data from patients? [00:17:14] IME5: Okay that's that's also a big question in, in, in, in

health. Since the rules on data privacy are quite, uh strict in general, there is a European GDPR as well, which is a very, very important. Well, I think privacy is, is, is is fundamental because I can think to many cases where. If you don't respect previously, for example. You can get into. Into bed situations like uh, I think to this case of people doing a test in the US and if you do a DNA full DNA test, you can get like a you can understand whether you you have a pretty position for some kind of disease in, in, in the future and insurance companies could be interested in buying this data, right. So at some level I think it is very important to to be careful with the with this. And. But yeah, on the other hand that. For doing research and for improving. And has good in general. It would be very useful to have more data and to have access easier, easier access to to people's data. For doing things that are actually potentially useful for for a, for everybody. [00:18:47] Researcher: OK. [00:18:50] IME5: So I think it's really two different like uh on the one hand, I think it's absolutely necessary on the. The other one, I hope that it will not be too strict also for a a working for doing some, some, some research but actually. I should I continue? OK. Yeah. Actually, also in in the approach that we use in the process we were mentioning before on chemical persistence is actually an approach which is really aware of data privacy since we use this technology which is called Federated learning. And the idea is that we, let's say we learn a machine learning model from multiple sources, but without moving the data from any of the sources. So we have several different hospitals. And basically the data stay where they are, so security and privacy are really preserved in this case and what we do is we. Move some model parameters instead and these are fully anonymous data, so there is no risk in general. By moving these kind of data rather than a patient data, it's itself. And. Yes. [00:20:23] Researcher: And make hospital in this case, or maybe even patient or to to use their data in this direction for healthcare. [00:20:30] IME5: What for me? Yeah, absolutely. That's what I would do. I mean, I would share my data if I I know the data is will be given to people working on improving healthcare. So I will. I wouldn't have any doubt in saying, OK, you can use all of my data and that's fine. [00:20:50] Researcher: Do you think people, uh data that are used in this direction? I mean do you think people who what data are used in this direction are aware the way their data are? A useful for what they data use is useful for or sometimes not really. [00:21:14] IME5: I would say probably no. [00:21:18] Researcher: No. OK. [00:21:18] IME5: No. [00:21:22] Researcher: Hmm. [00:21:22] IME5: And which is also why maybe sometimes people would say no because they are not aware of the potential that they their data have. So and sometimes they don't realise how useful it can be to to share it data. [00:21:40] Researcher: Hmm. [00:21:40] IME5: Yeah, that's probably there is. I don't know whether there is, like also misunderstanding about anonymity of the data, because in the end I mean research has always get data in a fully anonymous way. That's also I mean that's for preserving. Previously it's it's fundamental, you don't need to know exactly the name and last name of the person tool to to use the data. Absolutely. Absolutely not. So. Yeah. [00:22:00] Researcher: OK, now let's make sense. And do you see any risks? In a. Using data mainly to predict as you mentioned before or for the different purpose of each project. [00:22:27] IME5: Yeah, I know. I think so, yeah. [00:22:27] Researcher: Is there any specific you you I don't know if the question is clear, but is there any risks OK in using this data? [00:22:27] IME5: Yeah, the point is that. What a model learn can do a machine learning model can do is what the model has learned from data. So it is important to be aware that we learn our model with something with some data. And that's what the model knows. [00:22:49] Researcher: Can you? [00:22:50] IME5: Okay, so there might be cases where the model cannot be applied or the model would give some results that don't make it make it any any sense. But this kind of things can be detected of course. So in general the models are validated before before using them and it is in general clear whether there is something. Some situation where you you you cannot apply apply your model. [00:23:18] Researcher: Hmm. OK, yes, this is general about machine learning I suppose. OK. [00:23:22] IME5: Is it general? Yes, but I in I wouldn't say there is a. Um. Something specific to well, there is actually something specific to have to to healthcare which is related to this in the sense that. Uh, what models do is they do not replace people. Mother Sara tool for people. So in the end, clinicians take the decision. So what can my model can do? For example, if a model gives you a prediction which

is not what you would expect. That might trigger like further investigation on on on the case and now there are a lot of methods for like. You know, this interpretable machine learning, so you could for example say OK, but I think this the model says this. Why? And then you can try and analyse why the model gave that prediction and this might lead you to analyse things a little bit more. [00:24:21] Researcher: Hmm. [00:24:26] IME5: What in detail and try and understand why? Why the what the moment say is different from what the person says, for example. [00:24:46] Researcher: And this is actually related to one of my questions. So how the role of physician more generally humans is related and will be in the future related to the A I decision making I mean. How to combine, let's say what's the result? [00:24:49] IME5: I I think the keyword is combining. That's that's really that's really the keyword. It's a tool, and it's a powerful tool. It also has some mutations and limitations, so. [00:25:07] Researcher: Hmm. [00:25:10] IME5: Yeah, he's the same thing as when you like in the past, there were some other situations where the introduction something. Ethnology in general or even data sorting or these kind of things had an impact and this is another one. Things are going very fast now because things go very fast, let's say, but I I do think that it's it's it's a tool, yeah, a very useful one. But still a tool. [00:25:42] IME5: Hmm. [00:25:42] Researcher: OK. In related to the data and the risk you just mentioned that of course the results depend on what you with the data you use to train the model and. Have you ever noticed or how do you consider the gender imbalance in data? Do you see any is? [00:25:57] Researcher: Hmm. [00:26:07] IME5: OK, I will say something now that you when it comes to my mind, since you said ohh the data, actually the role of the clinician can also be deciding identifying the data to train your model. [00:26:13] Researcher: OKOK. [00:26:21] Researcher: Hmm. [00:26:21] Researcher: Hmm. [00:26:28] IME5: That's also. That's how you could use the the knowledge by by a clinician, which is a training, locating a all of the relevant things that you would need for a for the problem, and this could be like an iterative process. You see you miss something and you can try and locate some other date. Etcetera, yeah. And then about. Gender in in gender bias in models. While this is much more general than health, I would say. But uh yeah, it is of course an issue since uh. In I mean the one we live in is for sure a sexist world and. Science models learn from a Bale worth the end up being sexist, and that that's a fact. And that's something to be to be, to be aware of. Of course. But again, this is really that models reflect the world and they reflect what they they learn from. [00:27:21] IME5: Ohh OK you this this kind of things, OK? [00:27:25] IME5: No, this I I. [00:27:26] Researcher: So this means that both there are there is more data from men collecting and used to train their mother. And I don't know. And no, no, no. What do you mean? What do you mean? [00:27:27] IME5: No, no, no, no, I I. [00:27:30] IME5: Yes, exactly. Yes, yeah. [00:27:33] Researcher: Or is more about the way you read the data, so it's because physician are mainly men and the way you OK. [00:27:37] IME5: Yeah, I know. I mean, outside of healthcare, like, I don't know. Um, any kind of model like if you do experiments with degenerative models and you ask. Draw a a doctor so Doctor will be a woman or a man in English, right? You will get the man. And draw a nurse. [00:27:55] Researcher: Hmm. [00:28:00] Researcher: Hmm. [00:28:11] Researcher: OK. [00:27:55] IME5: You will get it won't. Typically, I think I didn't try, but I I expect something like something like this, right. But the fact that we have more data for men and for women in healthcare, no, I wouldn't say so. I don't. I don't expect this kind of thing because I mean in the end when you get to the hospital. [00:28:20] Researcher: Hmm. [00:28:20] IME5: The procedure is standard whether you are a man or a woman. It doesn't change anything, I would say. Ohh and I don't see any reasons why men or women should be more prone to. Or maybe there is some cultural reasons why where for which in summer, probably in some cases are. Yeah, thinking about availability of data. There might be some gender imbalance in. Providing accessibility to your own data. [00:28:45] Researcher: Okay. [00:28:45] Researcher: Hmm. No, no. Yes. [00:28:54] IME5: Maybe men or women might be more prone to sharing their data or not. I've no idea, and it could be something cultural. It could be something. I I don't know. In Europe, I have no idea whether it would be men or women or there. If I don't, I don't have any expectation that could be difference that would be. [00:29:03] Researcher: Okay you never like notice. Let's say anything in this direction related to the data you

work on. [00:29:08] IME5: No, I didn't, because I actually I. I've always used data provided by hospitals. [00:29:17] Researcher: Hmm. [00:29:17] Researcher: With. [00:29:17] IME5: Ohh no. Yeah. No, no, no. I I think it's why for example one study it was only women because they it was about pregnancy. So in that case, yeah. And the others. Ohh. [00:29:33] Researcher: Okay. [00:29:33] IME5: I know it's a question that I actually never asked myself. But I mean now that. Yeah. [00:29:52] IME5: OK. Yeah. No, something that I can say. [00:29:36] Researcher: Okay okay. Now you. I mean it doesn't. They were just too. Because there are a lot of field where for example, I read about a car. The way car are designed for example that are based on men's data for example. Or like even a tool to measure walking walks or runs fast, whatever our standardised. [00:30:04] IME5: Yeah. Ohh something that I can that that I can say that I was reading about some time ago, I don't remember exactly what was the topic but. The between men and women. The I don't think there is much difference in availability, but for sure there's a difference between. Ohh. And ethnic differences. [00:30:23] Researcher: Yes, that's another one. [00:30:24] IME5: So for example, for some cases I think it was they did example of like these models to recognise Melanoma or something like this. They work much better for a wide Caucasian people rather than people of African ancestor ships. So because you have more data and in general most data are collected in Western countries like Europe, the US or I think in Asia as well. So in general. In a structured databases you don't have. Ohh. You don't have like irrelevant presence in many cases, so of. Ohh. People of African origin, for example, like, like, like African American people, for example, their less so sometimes model work. Was for this kind of. For these people because. Yeah, they. Probably that's. Yeah, that's probably one point. There is an imbalance in. In ethnic imbalance in some cases. [00:31:33] Researcher: Okay. [00:31:35] Researcher: So you're not the ethnic one, but not really the the the one related to the gender. [00:31:39] IME5: No, I didn't even notice the the the ethnic one is something that I've had about just, OK. [00:31:41] Researcher: Okay, I think one. OK, OK, OK, OK. [00:31:46] IME5: No, no, no. [00:31:48] Researcher: And. [00:31:48] IME5: OK. [00:32:00] IME5: OK. [00:32:12] Researcher: Related to the, I think it's more related to the output. How do you consider the visualisation role in all of this sector? Let's say if you do consider any if you just use for, let's say yourself to explore some some data set or to represent the some results. [00:32:12] IME5: OK. [00:32:15] IME5: I think it's really important because. I I think how you provide a message. It is something absolutely relevant because you can provide the same message in many different ways. If you use a confused way and you provide the visualisation with which is not really really. Clear to understand. Your message is way less powerful than. The message provided in in the right way in with a a clear visualisation which is essential which has only the things that are necessary for understanding the data not to. Too much things that could result in moving their attention away from what is really crucial. So I think it is extremely important. OK, I really believe that visualisation, especially those for. Um, the technical public here should be as clean as as simple as cleaner and and and clean as possible. So it's really a powerful tool to combine messages and also when you use visualisations outside of this technical world, they're also extremely important because visualisation is also a way of capturing the attention of someone. So if you are trying to engage someone in, I don't know, a collection of data or something and you provide this person. If. With a poorly shaped page with a lot of. The graphs that are. I don't know difficult to understand. You say, OK, we need your data to do this and to improve this. No, it doesn't work. I mean they the way you talk to people is important and I think that visualising is a way of talking. It's a way of using the visual language because in the end it's it's language and I do believe that the language is important at any level. Better one visual one. So yeah, for me it's super important. [00:34:23] Researcher: Okay, and more generally, how do you think people like general public need to be aware or understanding from? In general, how these data are collected and analysed? [00:34:42] IME5: Understanding, Sir, promise said. [00:34:55] Researcher: Now, how did how much, in your opinion, the general public would need or to understand and know how these data are collected, analysed and then used? [00:34:55] IME5: Ohh OK. [00:34:58] Researcher: Which is related to the to the way machine learning. [00:34:59] IME5: Yes, yeah, yeah. [00:35:01] Researcher: Use data. [00:35:06] IME5: Yes, I

think it would be very useful to put people a little bit into. Hmm, respectively, so let's say. Give them an idea of what the impact of providing their data would be, and this can be visual. For example. Yes, that's that. That's the point. I think it is a it. It is important, yeah. Because if you see what you can do with data then probably you're more prone to say to saying yes you can use my data. [00:35:34] Researcher: Okay that's related to data. And what about the way this data are analysed with machine learning? I mean it's more related to machine learning literacy. If we can consider. [00:35:43] IME5: Yeah. OK. No, what? OK. So. [00:35:56] Researcher: Hmm. [00:36:07] Researcher: Hmm. [00:36:07] IME5: The point is, the main point is I would like people to be more aware that machine learning is not magics, it's just mathematics. It's algorithm there, there is no magic in machine learning. It's written literally, a machine which is learning, which is extracting some patterns. That's it. No magic involved. [00:36:19] Researcher: Okay but still machine learning can become more clever than humans as the last interview. [00:36:30] Researcher: OK. [00:36:30] IME5: Yeah, but that that's that's more I am I in some other topic so but this the kind of models that you do with people's data for for healthcare, it's really I mean that's that that's The thing is I think the demystifying a little bit of all of this. [00:36:35] Researcher: Hmm. [00:36:42] IME5: The all of these thing which in the end is yeah, it's algorithms, it's it maths, it's setting parameters, it's it's staffing. Yeah. [00:36:48] Researcher: OK, OK. We can discuss about the article tomorrow Italia. [00:36:49] IME5: Which is Nicola? [00:37:02] IME5: Ohh OK. [00:37:07] Researcher: Not the one from the. I don't remember the name back who just left the Google saying that he left Google because now he can stay and speak about the mother day developing and that because that would be more clever than humans in the next coming year. [00:37:07] IME5: Okay yeah. [00:37:09] IME5: A GI. [00:37:12] IME5: Yeah, yeah, okay. [00:37:14] IME5: No, no. Yes. [00:37:31] IME5: Known for me, it's OK. [00:37:31] Researcher: OK, no, no, but this is more this interesting for me, but not really related to the interview. So OK, I think I mean I'm you already answer my question. I don't know if you have anything to add in any direction you think might be interesting or or if there is any like point let's say that we didn't touch. OK, OK, so thank you.

IME6

[00:00:18] IME6: OK, so my name is ***. I'm a full professor at the University of Losan. I'm teaching at the School of Medicine at the School of Biology at the Post doctoral school, and the School of Technician. I have also teaching to nurses. And. And I'm involved in communication, especially being the current President of the League Communication section of the Swiss Society of Microbiology. [00:00:48] Researcher: OK. And may I ask your education please? What have you studied or? [00:00:52] IME6: My education I I'm I'm a medical doctor. I have studied medicine in Geneva and in Geneva and then I got. PhD in science at the University of Marseille and the MD at the University of Lausanne. So I have those MD and PhD. I'm also a specialist in infectious disease with the FMH specialist in mythology with the FMH specialist in internal medicine with the FMH and the specialist in community science and public health Tropical Medicine. It's a certificate from the University of Geneva. [00:01:37] Researcher: OK. Thank you. And the interview is more or less structure in three main area. I'm gonna ask you some general question then some question related to symptoms and then the involvement of people during the the prescription process and the communication with doctors. So starting from some general question what is in your opinion the current role of data in tackling antimicrobial resistance and specifically urinary tract infection? [00:02:08] IME6: OK, so I think it's important to have data on the respective resistant rate of *Escherichia coli* for instance causing the. It's a major agent of urinary tract infection, so the resistant of two different antibiotics that we have as first line treatment for unary tract infection because if you know that the resistance in our area is high for clotrimazole. ...will then have to use beta lactams or quinolones. Conversely, if we know that there is a high resistance to beta lactams, we will have use commitments instead of quinolones. So it's it's really important for doctors and I mean General practitioner to know about the resistant rate in in the field. [00:03:04] Researcher: OK. And do you see any like improvement, I mean related to to data, what's the difference between data available now and how do you see the situation like after improvement in the future? [00:03:17] IME6: So the problem we have with the data today is that we mainly have the data from

laboratories and for instance in our laboratories, which is a university based hospital laboratory, we have a bias towards patients that are at the hospital and it does not really reflect the ecology that is present in the Community. So we have a tendency. In University Hospitals to provide data that are overestimating the resistance. And it's really important to make the difference between subjects that are having another corneal infection at hospital infection or community acquired infections. [00:04:05] Researcher: OK. Thank you. And what data is needed in your opinion to enhance a better understanding of AMR and UTI? I don't know if you wanna start from AMI, if you wanna like start speak about both as you prefer. [00:04:24] IME6: OK. So regarding AMR, I think what we need is of course, data about antibiotics society about antibiotic consumption, about antibiotic. The awareness of the population of the resistance risk and how to decrease the usage of non necessary antibiotics. For instance, what is the current education of subjects laypeople regarding the treatment of viral infection? Uh, lots of persons do know that we don't use antibiotics for viral infection, but some do notA really understand the difference between viruses and bacteria. And this is a problem because they want just to go to the doctor to get antibiotics. [00:05:16] Researcher: OK. And do you think regarding because you mention awareness of antibiotics resistance and consumption, do you think be aware can really improve the consumption of antibiotics can help at least in reducing the consumption? [00:05:36] IME6: I I think that it's not only the prescribers, the doctors that need to be informed, but also the laypersons, because then they will better understand why there is a need of an effort. So I think yes, it it can improve even through the lay people. But of course the first on the really important things that all the doctors are aware of the problem. [00:05:59] Researcher: Umm yeah, sure. Mm-hmm. [00:06:00] IME6: And and this is regarding AMR, the second question was regarding UTI. I think for UTI. There is a lots of false belief. For instance, some people consider that every UTI needs antibiotics. And of course you can, with a proper idratation, if you have just small symptoms of dysuria, you can improve just by rinsing the bladder by proper idratation. And also there is a lots of small tricks to prevent UTI. So we we don't speak of course of the severe UTI, like nephritis, infection of the kidney, but for simple infections, I think it is possible to do a lot by improving the information. [00:06:54] Researcher: OK. May I ask an example or if you can mention anything related to what you mean by preventing and little tricks that you mention. [00:07:03] IME6: But, for instance, uh, after sexual intercourse, it's good that both partners go and urine because this is well known to rinse and decrease the risk of secondary urinary tract ascending infection. [00:07:21] Researcher: OK. OK. [00:07:22] IME6: That's one example. [00:07:23] Researcher: Mm-hmm. OK, thank you. And then? Mm-hmm. [00:07:25] IME6: And also proper hydration is another example. [00:07:29] Researcher: OK. And do you think doctors do usually suggest this kind of like preventive tricks as you call them or maybe there is a kind of like sometimes bias in suggesting what is not related to medicines and antibiotics mainly? [00:07:49] IME6: I I I think the doctor's today have been formatted just to think scientifically, to be quick, to be fast, because every 8 minutes you need to have another patient. And as there is so much economic pressure around medicines that it's not the same way that it was done in the past. And I think we are losing this type of small tricks and interactions between doctor and patients. [00:08:18] Researcher: OK, so do you how do you consider the new generation of doctors, let's say, who is like finishing right now and how can be like improve this site? [00:08:30] IME6: I I think yeah, currently the new generations there are more based on test, more based on technology and unless based on a really what, what makes sense and and so we you know we have too much teaching that are making them a binary thinking. [00:08:54] Researcher: OK. [00:08:54] IME6: Uh, for instance, so all these uh questions where they just have to put cross is not a good way to train people. [00:09:03] Researcher: OK. OK. Thank you. And then moving to the section of symptoms, I would ask you, how is antibiotic prescription influenced by symptoms description that people provide to doctors in your opinion? [00:09:20] IME6: You mean uh? [00:09:22] Researcher: I mean. If when the patients go to doctors, if they have any way to influence the prescription they get, by the way they describe the symptoms. [00:09:35] IME6: Yes, of course. Of course. If the patient say it's terrible, I have a lots of pain. It's frequent. I have a dysuria here which is really frequent every 10

minutes, it's come again. I I cannot sleep with this urinary tract infection. These symptoms may of course. Help the doctor decide to prescribe. There is always a risk to being influenced by the patients and of course we are influence. I remember of a case where the patient. She was a nurse, so she came to the emergency ward and said I suffer from a UTI and I need antibiotics and she received antibiotics and she it was not a UTI, it was a malaria because she was so focused on her diagnostics because she had a rare current infection that she did not say that she went to Africa and that she did not take pills for malaria. [00:10:45] Researcher: Mm-hmm. [00:10:45] IME6: And it's only when I seen her. That she was a hospitalised because she was high fever and not doing well, and it's only when I seen here at the in the hospital ward that we have corrected and we looked for malaria by bootidae. So it means that the doctors at the emergency but the doctor in the private practice as well make it influence and I can myself also be influenced if I was first line doctor. [00:11:19] Researcher: Yeah, sure. Actually, you're kind of answer to the next question because I was. I'm also curious about how much people are actually aware of their symptoms. So sometimes as you mentioned, maybe they're not completely like. I would not say trustable because they don't wanna lie, I suppose, but more like. With. [00:11:41] IME6: Yeah, it's it is. They make an interpretation. They make their own diagnosis, especially when they work in the field. And this is one of the difficulty when you have a patient with doctor or nurse because they know lots about disease. So they have they made some interpretations. They don't say what they feel they say, what they think they have. And this is something we have always to go back to science and symptoms and not to diagnostic level. We need to know. [00:12:09] Researcher: Mm-hmm. [00:12:10] IME6: But yeah, let's do your step back. You think that you have a urinary tract infection. But why? What are your symptoms? Do you have pain when you urine? do you have a frequent urine which is called ** and so on. Do you have back pain? Do you have fever and so on. [00:12:31] Researcher: Yeah. [00:12:30] IME6: OK, so we we need to do that. I think most of the patients are well aware if it's a a female with a recurrent infection. So this type of patients, they know well and they recognize well and they can self treat themselves. [00:12:48] Researcher: Mm-hmm. [00:12:48] IME6: Except with a few exception and this exception are exactly what I told you just before when you have high level fever, when you, you start to have. Signs or symptoms of severe UTI like back pain or a shiver. [00:13:06] Researcher: Yeah. [00:13:04] IME6: Then it means you should be cautious and you say, OK, you can treat yourself if it's just symptoms of a. Lower urinary tract infection, uncomplicated with dysuria and polycoria. This is cystitis. You can treat yourself, but as soon as there is something that looks like disseminated infection with. [00:13:36] Researcher: Umm. [00:13:32] IME6: Fever or with back pain or with headache. And then you you have to go to the doctor. [00:13:39] Researcher: OK. And still related to the accuracy of people able to describe their symptoms, which kind of data do you think they could track, collect, analyze? To interpret their symptoms and improve the their description of their symptoms to doctors. [00:14:04] IME6: OK, so simply they can tell you if they have pain when they go to urine, which is called dysuria like burns when you urine. This is easy to get and the 2nd is the frequency of this and also the amount of urine. If it's small amounts and the number of emission per day. [00:14:28] Researcher: OK. [00:14:28] IME6: This type of data are easy to get from patients because you, you, you you have a three or four questions. So do you have pain when you go to urine? First questions is that a on a scale of 10 if it is 10 or one then is really big on one is slow. [00:14:50] Researcher: Mm-hmm. [00:14:51] IME6: Then second questions is do you have frequent emission and if yes, how many per day? So. Yeah, of course. [00:14:58] Researcher: OK, OK. And and considering like also data, they can kind of collect previously to go to the doctor, is there anything you suppose can be useful and help? [00:15:12] IME6: What was the they can collect is to say whether they've already in the past urinary tract infection. And how many and when was the last time he it and how many in the last year? Ohh. [00:15:26] Researcher: OK. And while related to AMR, is there anything that can help to link UTI with the AMR when doing the communication with doctors? [00:15:39] IME6: Yeah, you can also ask them what they think about antibiotics. Do they have regular use of antibiotics? When was the last time they get antibiotics? And for what purpose? These type of questions. [00:15:52] Researcher: OK, and

imagining people using data to support their symptoms description, do you think people serialize reliability, take advantage on data supported symptoms? Description Can help in make them description more trustable from a doctor point of view. [00:16:17] IME6: Yes, I think, uh, if you have examples of description, it will help them to report their own symptoms. [00:16:25] Researcher: OK, OK. Yeah. OK. [00:16:26] IME6: But you you may have also suggestion that one of the difficulty because yes because you will suggest an answer. So that's why I'm. [00:16:39] Researcher: You mean suggesting by kind of interpret the data and try to suggest the doctor what your symptoms are related to? [00:16:46] IME6: Yeah, yeah. [00:16:47] Researcher: OK. OK, while imagining people collecting and analyzing data to support their symptoms description, can the action of collecting and analyzing data influence people consequent behavior in terms of antibiotic consumption? Maybe this one is related to the question I already asked you before, but do you think the way the fact that they become aware of their consumption can influence positively? or negatively, I don't know, the the proper consumption of antibiotics. [00:17:26] IME6: Yeah, I think. Yeah, to be aware, of course might help decrease the consumption. [00:17:35] Researcher: OK. [00:17:35] IME6: Increase the awareness might help. Of course not for all patients, because there is a. Yeah, different level in somehow, really smart and will easily understand. And you will have likely more impact with them. But sometimes, yeah, what you expect is not what is reality so. [00:17:58] Researcher: OK, OK. Moving to the involvement of people, I would ask, why should people be encouraged to take part in the prescription process actively? I mean instead of like the classic communication between patient and doctors, why they would have to ask, do question to doctors and like try to. report or bring some information during the consultation? [00:18:29] IME6: I think it's always good to have a good interactions when you prescribe drugs because it will increase the compliance. Patients are more likely to take all the pills at the correct timing and until the end of the full treatment. So we call that compliance and also because. If they are aware of possible side effects, they will be more likely to report them. [00:18:58] Researcher: Good. [00:18:58] IME6: They could be aware that this could have a relationship with their drugs. So I I think it's so important and also because of what we discussed before, if it's not really needed to have an antibiotic, we need to discuss this point and to have a. A real acceptance of known non-antibiotic based treatment. [00:19:27] Researcher: Umm. [00:19:27] IME6: If not, the patient will judge change and go to another doctor. [00:19:33] Researcher: OK, So what do you think about the follow up? Because I know from consultation usually is happening just in case the treatment doesn't work, but how do you consider to have a follow up even if the treatment goes well? I mean not to. I I suppose doctor can be happy, but at the same time can it be useful to collect some information, even if? The treatment like were right. [00:20:05] IME6: So I I think as part of research it makes sense to have follow up of course, outside research is more tricky because. [00:20:33] Researcher: Mm-hmm. [00:20:16] IME6: We don't have enough doctors and and we. Yeah. So we generally in the private practice only see the patient when there is a problem and not so many times for just a check up. So I think it could be of use because you can drink a checkup consultation discussed of many other things that were not prominent. That first place, there is lots of small problems that people have, and when they are focused on their emergency. [00:20:54] Researcher: Mm-hmm. Yes, but. [00:20:54] IME6: Is it will not speak of the other problem, so I think we should ideally in a rich world, in an ideal world always a follow up because I don't know somebody has a UTI but has also for fungi or nails, dermatome mikos or only comicos or the type of things, or have migraine or have is depressed or have a question regarding. [00:21:27] Researcher: Mm-hmm. [00:21:23] IME6: The pills to avoid to get pregnant or any type of questions or or this person is smokers but wants to stop. But there is no time in the emergency consultation to discuss all these issues and also you can just discuss about cardiovascular risk factors, not only tobacco but over white. [00:21:49] Researcher: Yeah, yeah. [00:21:46] IME6: Uh, hypertension. You can. You can discuss, offer lots of things, so I think. [00:22:01] Researcher: OK. [00:21:54] IME6: If it's a a new patient, you should not only treat the UTI, but also have follow up and it could help a lot in terms of prevention. [00:22:04] Researcher: OK. Thank you. And related to data collection,

what benefit can people gain from sharing their data to improve the practice and like bring some knowledge into the field? It is the question clear, I mean you. [00:22:29] IME6: Maybe you you can ask again. [00:22:31] Researcher: Yes, sure. I was asking because you said that it would be useful to have also data and information from patients to better frame and understand AMR and also relation between antibiotic consumption and urinary tract infection. And let's say that people can kind of help and collecting to collect the data about the these relations to to better understand these relations and why should they. The let's say share their data and who can benefit from their sharing data. [00:23:08] IME6: OK, so I I think of course the first person who benefits from this share data will be the person doing the research. [00:23:29] Researcher: Mm-hmm. [00:23:17] IME6: Because you can draw conclusion he can describe. Uh data obtained, the second person could be the the doctor because he has increased knowledge of his patients so it can get a better personalized treatment. And then of course, if you give a better personalized treatment because you know better your patient, the patient at the end should also benefit and a stakeholders could also. [00:23:58] Researcher: Mm-hmm. [00:23:48] IME6: A benefit from that and among those stakeholders there is a politicians in order that they be aware of. All this data collected from the research. [00:24:00] Researcher: And do you see any possibility of people sharing data among themselves, kind of creating a community can be useful in the field, in your opinion, to for people to know and learn from each other, related to about maybe prescription of symptoms or this kind of information. [00:24:25] IME6: OK. [00:24:24] Researcher: Or not really. Is there any disadvantage? OK. [00:24:27] IME6: There is lots of people who do that in routine. For instance, we have people who are. a group of patients who suffer from tick borne infections. So you have a lat sequel Liga, which is take care of that. It's a group of patients and in all this form of patients it works well especially when these are devastating disease like cancer or when it's chronic infection like HIV or tick borne infection with chronic tratments To send home which type of things because you need to have the problem in mind for prolonged time to be part of this network. If it's just an acute infection, people will not go in this type of consortium. A group of patients the risk with this consortium or group of patients if there is no moderators, if there is no contact with science and doctors, is that there is a wrong information that circulates there. And these wrong information can be dangerous. We have seen for instance. So. The the President of USA or the previous one said you need to to take a javel water in order to treat the Sars Covid-2. This is completely nonsense. So you need moderator. [00:25:59] Researcher: OK. So is there any other bias or problem that you identify in based the prescription or more generally the understanding of the disease based on data? [00:26:14] IME6: So based on data, it's it's not too much of a problem except if the data are for a hospitalized patient. And then you look at outpatient. So this is one of the big problem. Another problem is of course you cannot consider the data for male and female reciprocally. Because for UTI there is huge difference just due to the length of the uretra. And then of course, there is difference between patients age, the children's, the young females, old female, all these different age makes lots of difference, especially in females because you. You change in term of hormones when you have 40, when you don't have your periodical bleeding, then it changed a lot in terms of. Or of hormons and a risk of vaginitis and vaginitis may be mistaken with UTI. [00:27:25] Researcher: OK. You mentioned gender and like to separate data related to women and men because there are still data that are collected without any gender distinction. [00:27:39] IME6: Yeah. I think for instance, if you consider cystitis in female, most of them are due to **, likely 90%, but cystitis in mans nearly does not exist. It will be prostatitis and there you don't have the same patterns. [00:27:57] Researcher: Umm. [00:27:58] IME6: One of the big problem in prostatitis is otoki, for instance. [00:28:05] Researcher: OK. OK, thank you. And and then I read something related to the project you work on the Swiss pathogen surveillance platform and more generally, how did it work? What did not work actually? And if you have any like idea or like feedback that you would like to share? [00:28:29] IME6: OK. So. The Swiss pathogens will platform works nicely in terms of data exchange because it's relatively easy to exchange genomic data. It's it's done mainly for that. So we can exchange full seconds of pathogens for instance Sars Covid-2, but also staff Aarhus and so bacteria and virus. Yeah, the difficulties is of course to maintain this service

because nobody is interesting in pathogen surveillance. People are interested in pathogen biology in pathogen resource, but surveillance is long lasting and after excitation during the the the start of the project, you run out of money after four years. And then it's really difficult to sustain this. It will be likely the same with spearhead we we we got some funding for the first four years, but what will happen after that? And this is really the problem because we are not thinking of research. We are thinking, thinking of changing things. And when you want to change things you you should think on the long run on the long term and this is difficult to sustain economically. [00:29:54] Researcher: OK. OK. Thank you very much.

IME7

[00:00:04] IME7: Yeah. So, hello, ***. My interaction designer and educator and I'm specialized on Women's Health through wearable technology. Well, I combine wearable technology and biotechnology to destigmatize taboos in Women's Health. And I my background is in front of the design. And then I've been graduating in social design and material future. So. With much more focus on technologies and biotechnologies in design. [00:00:36] Researcher: OK. And the what, in your opinion also related to the project you're working on the most challenging and interesting topic that we can like face in the near future? [00:00:50] IME7: Well, for me it's really how technology is gonna show that our present and especially our decision in prevention because it at this point we like my culture in my Italian culture, prevention is missing a lot. So I'm really wondering if technology can have this role and introduce tools to really make as much more aware and prevent specific issues and in my. Specific case. What is very challenging. It's really to to address it in a intimate care where it's not only like based on missing research, but on taboos, which dance is in is influencing research, so is influencing just like a complete mistrust from women to the medical care. [00:01:38] Researcher: OK. And how do you see the participation of citizens? Of course. It's quite important related what you said. How is the people also? The role and interested in those kind of topic and project. [00:01:57] IME7: Looks from mine and our point of view. So with the other team it's it's super active. So participant in season should be active in the decision that we as designer as a company producing new technology we are developing because of course we should move on from companies that so far they've been building something that is for their needs and from their necessities but rather really following what it's really meaningful and necessary in this world. That where we are running on scarcity, I mean there is scarcity from material, from lack of knowledge or lack of studies. So we really need to create those basics and I'm sure that only through a participatory process you can create it. [00:02:44] Researcher: Yeah, I see. Actually from your slide, you were referring to females sometimes with the some I mean specific reference to women. But even like women with the trans experience and trans women and of course your project is very like related to the word of in the body of the the female body. So I can imagine also when he's about. Inviting people to workshop you target a really specific part of a citizenship. And how do you, let's say, uh still being inclusive, uh, try to address those specific kind of people. [00:03:30] IME7: Yeah, it's. [00:03:30] Researcher: Because actually ask this because we, uh, have not. I would not say a problem, but we face this issue during the first workshop advertising when we recognize that we were trying actually to engage women because we needed to talk about women problem but we didn't want to say to men who were actually interested. No, you cannot come. Mm-hmm. Umm. [00:03:52] IME7: Yeah. No, it is a problem. So it really comes with a language and language awareness. So when we started the workshop in 2018, even the Shiva say so, like reading closeness that we have now in the Italian language, I was coming. And so at that time we were referring to female to be more inclusive. And what I miss to say before in the lecture, but it was only written is that yes, when we talk about criminal women we we talk about people with Google. Because well from the technologies people with wolves from the the the person in the society is actually a woman, which can be a woman with Russian sperience or a trans woman. So yes, we have to specify. I learned it last year in Rome when I did a workshop and I to collect women. I people coming, I was saying I didn't mention about vaginal infections. So in that case I exclude. [00:05:02] Researcher: Mm-hmm. Mm-hmm. Yeah. OK. [00:04:53] IME7:

At trans people to come because I didn't mention that we were talking about vaginal fluids. So what I learned now is that I have to be specific. So if we are going to like develop a workshop where the vaginal vulvar area is very important, we should refer to people with *****. If we are gonna talk about the woman female in the society, we should refer it as a female or woman. A person. That is a fields and is a woman. So we just have to be more specific because I feel that we are just still in a transition, of course so. Still, things is not very understandable and also from language and you have different word. So what I'm learning now is that I have to be specific. Umm. Yeah. [00:05:36] Researcher: Umm, starting from the description of the activity. So you saying yeah, OK. And because I'm working for my PhD on data literacy, I'm wondering in your area. How data is considered? I mean I I of course you collect data and use them to analyze and see about healthcare. I'm just wondering if people who actually collect themself their own data and then enable or how you imagine them to understand and read their own data or is about just collecting them and leave the reading and understanding of data. Through the application or doctors or like specialized people. [00:06:27] IME7: Yes. So what we did before with the sensor, because now we feel that the sensor we're keeping in in a side and we're moving on a bit more. We have not toolkit, but the idea is to create a literacy that is online in the app, maybe physical. We don't know yet. [00:06:51] Researcher: Umm. [00:06:46] IME7: UM, but let's for sure like a blueprint of knowledge, because they idea is that you give the power, the tools and the power also to the women, [not only by seeing OK pH 7 but understanding why pH 7 because that is the most important part.]. So yes, everything would be designed with a sort of literacy behind that would be available and especially what we will try to do now with Alma toolkit that will be a like available. So from an inclusive language. [00:07:33] Researcher: Umm. [00:07:17] IME7: Because otherwise, what is available until now is either too medical or unaccessible for everyone, or not translated in many languages. So it's something that we have been like already looking from long time. But of course it's gonna be a process of different layers building up. [00:07:36] Researcher: OK, so you consider people being able to read their own data through the way you build the interface. I imagine of the application. Yeah, yeah, of course. [00:07:46] IME7: Yeah, it will have to be or maybe in the way that the the the product will come to you there would be this sort of knowledge cause otherwise it will for us still doesn't make sense. You know if we will still own the the knowledge. [00:07:59] Researcher: And have you thought to include this part of literacy into the activity, the workshop or you see that as a more kind of secondary steps that comes later? After collecting and understanding which kind of data collect. [00:08:17] IME7: No, we already do it. So most of the time when I run workshops, it's it's really an exchange. So I share. Then I ask in and then maybe I can explain it it. Yeah, I know it's a constant sharing and exchanging of knowledge. [00:08:30] Researcher: OK. OK. Thank you. And why you just mentioned during the presentation, like UH Theresa May, uh, Mary Magic and the other people working in the area. And as you said there is something, I mean if I got correctly missing from there work compared to the idea of like having a toolkit at the end to be shared and. The to to empower people at the end is something that you can tell more about this kind of what is existing analysis or like the differences between what you're doing compared to to some of them. [00:09:14] IME7: But this is something we're starting now. So we are starting now there research and then analysis, it's gonna come. So what I can tell you now from my gut and from what I'm like as from a superficial point of view or well from what I know and that I can compare is that and probably the biggest reference is the Ginevra punk. So this collective in the surface pain that started to really revolutionize intimate care from a hacking point of view about your hacking. Perspective and is that their language? Because it's really coming from the ground and it's also coming with a political statement. It's also very exclusive, but not because they want to be exclusive, but it's just also the the way they do it. So it's it's like people maybe like us that we are interested. We are like going through connect to connect with them. But most of the time like maybe it will not be so easy to have it in academics like it would be much difficult to have it like. Spread it. So what we feel is that it's missing like a sort of blueprint that can one day entering school or that that one day should be personalized locally, so that every collective can personalize it based on their needs based on

their local also resources. So to make it just much more available. And that will be maybe by having also platform that everyone can then use an update and reshare and the top. Yeah. [00:10:44] Researcher: Umm, OK, no, no. You have been like effective. So you trying to with your former, let's put in a different way how you position let itself compared to them. So it's more about trying to be inclusive and try to kind of translate those kind of contents for for people even like in a very effective way. So with the shirt session, let's say they can effectively learn and participate to create something in that direction. May I? Umm. [00:11:17] IME7: What I think our idea would be much more toward with specific collectives to install in that in in their group this sort of sense of carrying and of an Anon learning because what is missing most of the time like why we have a lot of collected, a lot of families, even collective, but they never even for example try the self exploration. Because it's at the booth right, it's a taboo to maybe even hold the speculum like inserted yourself or have the help of a friend inserting yourself, watching it with the mirror together, understanding the differences because we are come, we are crude like we are coming from, like like me from like A at the church that told us not to watch, not to touch, not to share. [00:12:05] Researcher: Mm-hmm. [00:12:06] IME7: So of course for us. [00:12:38] Researcher: Yes. [00:12:09] IME7: We would like to be a sort of like intervention. It will go, we create some sort of space, some sort of language and sort of toolkits to develop together. And then ideally they should continue themselves. So ideally then all those collective, all those like nodes, they become independent and then they will slowly create more things, putting it in the cloud and going out is the same like Arduino does, right? The inventing, the kit of the microprocessor. And then people is then using it updating. Upgrading it because everything should be used by upgrading it. [00:12:45] Researcher: OK, that's very great. OK, thank you.

IME8

The labels IME8a and IME8b are employed to differentiate the two participants who took part in the same interview session. [00:01:26] IME8a: OK, um, uh, let me introduce myself first. My name is ***. And see you at gyroscope. Ohh, where we developed disturb monitoring solution for thyroid disease. Especially what we are doing is we develop an app for patients to monitor their disease by themselves outside of the hospital. At the same time the data collected in the app will be transferred to the doctor's web so that we our group made goal is to enable the remote monitoring between patients and doctors through our technologies. The before our solution is doctors and patients have no idea about the did you status when they are outside of the hospital because the only way to cheque their status is to take a blood test at the hospital. So that's what our company do and then. My brief background is I'm I studied business and computer science in my bachelor degree and I I completed my message degree in industrial engineering with the research focused on AI modelling part. So and I met. The Co Founders 3 cofounders and started this companies like three years ago. [00:02:50] Researcher: Thank you. [00:02:50] IME8a: Thank you. [00:02:52] IME8b: Hello I'm a telescopes UIT designer and I studied at a university about the UI UX design. So in this company I work as a all of the UI UX design here now. [00:03:12] Researcher: Thank you. [00:03:12] IME8b: And. Hmm. Ohh. OK, no. [00:03:17] Researcher: No, if you want. If you have anything to add, please go. [00:03:21] IME8b: Okay. Ohh. The personal and negative. [00:03:38] Researcher: OK. [00:03:30] IME8b: Ohh yeah, actually I'm a thyroid cancer patient and so this my experience is really helpful about our business model. So to me making our UI UX design at here is. Sometimes I feel this is my app because I will use this service. So yeah, it's really happy and funny work at here. [00:04:05] Researcher: Okay, I mean, I see that's a very strong motivation as well. When you work, that's that's really, I mean, I do really appreciate that. It. Ohh. Yeah. Can you tell me more about, I mean you introduce yourself saying about the the background and actually you already answered this question because he is related to how you moved to working for healthcare and technology. So I would I would consider this an answer, I don't know if you Jamie or you as well have anything to add about it, what why you're interested is related to technology and healthcare basically. [00:04:49] IME8b: Ohh. Uh, actually. Ohh it is similar to her, but my mother has a a theory related disease. [00:04:59] Researcher: OK. Hmm. [00:04:59] IME8b: So like

I learned, the necessity of this kind of solutions from long time ago. So there's there's. While I was searching for the the the items for start-ups, I encountered our CQC who is on University Hospital professor. He worked in the universe, one of the biggest university aspire in Korea and he sees 14,000 thyroid patients a year. [00:05:35] Researcher: OK. [00:05:28] IME8b: At the same time, he's he used to be a patient with high thyroid disease as your. So he learned the necessity of this kind of solution and he invented the core technologies. Then I met him to start this companies. Hmm. [00:05:44] Researcher: OK. I mean from my little experience, because I'm started working on these topics, when your ago, but I see that the role of not only patients but all the people around them are really like very important not only bringing like knowledge of the disease, but also to like bringing personal experience related to other field that can help who they care for and what's your in your opinion the most challenging and interesting. Topics area in the nearest future related to what's the scenario you see related with the your your working area. [00:06:25] IME8b: Um, the biggest challenge. You right. Um from my side. Um. When he was the the point, I mean the. Ohh. By connecting a connecting patients and doctors through this healthcare solutions, especially through app and web. That means it brings about changes in the uh, previous treatment protocols. Into another. In other words, it it changed it had either it has to make a change in the way they interact each other previously. In the in uh before our solutions, they visit hospital in a routine based like 2 month interval or three months interval and has to visit two times of hospital visit. But with our solutions we want to eliminate such unnecessary has provided them below test. So this requires huge evidences. Not only evidences, but also it it has to prove the cost effectiveness as well cost effectiveness and treatment efficacy. So that we can change the the treatment protocols since diverse stakeholders like payers and the healthcare providers and patients and sometimes in the pharmaceutical companies, they are all involved in this area. So that that's the. Ohh kids, tell me that we have to tackle down. Yeah, I think showing a data in healthcare app service means. Ohh so making relationship with Doctor and we call this relationship as lappo so and when I construct a UX in our service I care about this concept most so because I thought that the more rapple formed between the relationship the more patient can believe their doctor and this belief can affect a lot of to a quality of the treatment. So for this reason. Providing a data in app, especially relating medical service, has a good influence to patient behaviour for their characteristic of patient and doctors relationships. So if the patient noticed that their recording habits is checked by their doctor, they have an observer. So our behaviour can be different depending on whether there is an observer or not, especially in Korea or one doctor treats 50 patients per day. At in means that a patient has only 30 seconds or two minutes with doctor in treatment. So for this reason in Korea, it is really hard to make a rough pole with their doctor. And it means that in Korea, it is really hard to make a pay about their doctor perfectly. So furthermore, when we go to the hospital, we just listen what our doctors saying and we noticed I'm okay or not. So however, by providing data with their test meaning, we can give a lower level medical knowledge to patient. So yeah. For instance, in our service we have uh glendy and at here we offer the meaning of the blood testing items such as TSB or pretty full. The by offering the meaning of the items patient can know about their symptoms more specifically. So as a result, patient can have a curious about their disease more than the treatment's quality will increase, I think. You just. [00:10:31] Researcher: OK, this is. I mean I think this is very, very interesting you you gave me all the overview from the patient point of view. Do you have any feedback on the other hand from Doctor sides? I mean, what's your? What's their attitude to have patients data collected or to have the chance to cheque from an app or website their patients information? [00:11:03] IME8b: The. Ohh for example we have a service called a congressman and we give A2 platforms. The users will use the app and Doctor will use the web and when the user checked their taking medicine habits then the doctor can see their habits immediately. So when the when the users go to the hospital to see a doctor. They can notice that the doctor used their data. The show watching days, I think. The users can have some responsibility over their behaviour checking their health. Condition I think. [00:11:52] Researcher: Hmm. So you, I mean from the point of view that you design the interface

and all the structure of of these services. Um. Do you have on the other side the do you think patients are happy to? To collect all their data and share them to the doctor. [00:12:20] IME8b: Hmm, if their data give some give some more high quality treatment when they see a doctor, then the checking the data is not hard to users I think. You didn't. [00:12:37] Researcher: Okay and regarding the data literacy of patients. Do you see any specific challenge in designing the way data are collected? The way you ask people to collect data and share data with doctors? How you face, let's say this this issue. [00:12:59] IME8b: Hmm. [00:13:00] Researcher: Maybe it's not even an issue for you. [00:13:06] IME8b: Ohh. Make sure. [00:13:08] Researcher: Maybe I not sorry. [00:13:10] IME8b: Yeah. Uh, in glendy the uh, checking the taking, the medicine is just used to give some motivation to users actually, because most of the thyroid patients have to eat their peel everyday. So when I construct the UX in Glendy, I'm really care about the. Motivation because I thought that only motivation can make users can cheque their. Medicine habits. So I always thought how can I make some motivation and how can how can I use that motivation to make some users have it? [00:14:03] Researcher: And is there anything specific that you use or refer to to build the motivation you are talking about? [00:14:12] IME8b: I'm sorry. [00:14:14] Researcher: I mean, if there is you say that you try to build motivation now so that people can go and cheque, they have the record and in answer questions is there any specific way that you try to build motivation like within the app you have any like is not a strategy but more related to the way you engage people probably within your your service. [00:14:43] IME8b: In Glendy, when the user checked their taking medicine habits, we give a really cute character or really we show the really good and cute UI and in the future scenario we will give some reward over their behaviour. [00:15:04] Researcher: Look. [00:15:04] IME8b: This is our strategy. [00:15:06] Researcher: Okay. [00:15:06] IME8b: OK. I don't know, Jimmy. [00:15:08] Researcher: I don't know, Jamie, if you have anything to add. [00:15:12] IME8b: Um. Ohh from uh. Ohh my. Ohh perspective the motivation, providing motivation to use the app is really crucial so. I am my job is my. Actually that's really important. Like the task to be successful in the real world area as a solution. So regarding the firstly, regarding the data literacy. Uh, we were. We actually had to like a lot of concerns and discussions on how to. Display the risk level of the patient. Since we can predict our third hormone level itself, but it's really in might be difficult for most of the common patients to understand how the meaning. I will be. So what we. I trying to do currently is that. We show them the probability of being hyper being abnormal status where normal status. So that it's more like. Is it to understand there about their disease status? And. In case of the blood sugar level is quite well known currently for patients with diabetes, but in case of very dysfunction, the varied this is there was number such levels. Or portable from the portable devices. So that's, that's the uh, uh. So that they we we we decided to show it with the probability levels. No. [00:17:13] Researcher: But with probability level you mean like a stock bar or a number? What's the way? OK. [00:17:19] IME8b: Number with a collar. [00:17:21] Researcher: OK. Yeah. OK. [00:17:22] IME8b: Blue or red? And another. Ohh and regarding the motivation of providing motivation, what I'm mostly working on is that we make an like the partnership with the. The payer side. Once they so why do I what I'm what I'm wanna develop is that. Uh. Once they patients to use the app as we intended and then we once we calculate their points about their diseases management using the app. So like everyday they record it the medication intake and the follow the usual. They're the sentence survey that we can calculate their. This is management score and once they're score is. Oh oh, above 80 points then they are provided with the discount for their. Uh, uh insurance. Like this? That's what we are currently wanted to go. [00:18:40] Researcher: And do you have a? So from what you just said, you don't have any visualisation data visualisation in your app or do you? Good. [00:18:50] IME8b: We do, but we do not specifically show that they are. This is management score yet, but we are showing the. The medication compliance is level. [00:19:04] Researcher: Okay. [00:19:04] IME8b: So that they can be motivated. Motivated for that? You. [00:19:11] Researcher: OK. And you, do you have anything to add about the way data are visualised? [00:19:19] IME8b: Hmm. Uh, not really. [00:19:23] Researcher: Lovely. OK. Um. Sorry, I'm checking my questions. Um, have something related to participation because from

my understanding your app service description you consider people. The engaged by themselves. So because of course the the disease, have you ever consider or is there any link between patients or people in your service or they just work on themselves by themselves and they just interact and the interaction is mainly with the doctor? Is the question clear? [00:20:11] IME8b: Would you repeat the the? Hmm. [00:20:13] Researcher: Yes, sure. And my question is related to interaction among people themselves. So I see you trying to build a relationship between the patient and the doctor. I'm just asking if you also consider to build, I don't know if any community or interaction between patients or caregivers and the patients or is just the relationship between the patient and the doctor. That you design. [00:20:47] IME8b: Hmm. In service? Uh. When the users gave their blood testing result, the Doctor can comment about the result, and in the app the users can cheque the doctor's mention. And from this I think we can make a deeper relationship than just not giving them. Ohh yeah. Additionally we let we have uh. The. The community forums are for patient themselves. [00:21:31] Researcher: Okay. [00:21:33] IME8b: And we provide. Ohh the the the counselling services from nurses to patients as well. So that we want to activate this kind of the interactions between page among patients, doctors and nurses. [00:21:56] Researcher: And do you see nurses and doctors willing to participate and help in this direction? [00:22:03] IME8b: We actually. [00:22:03] Researcher: What's your attitude? OK. OK. [00:22:05] IME8b: We actually hire nurses by ourself. [00:22:09] Researcher: Okay. [00:22:09] IME8b: And then our nurses provide counselling to the patients through the app. [00:22:15] Researcher: OK. [00:22:16] IME8b: Which is basically supporting doctors job. [00:22:21] Researcher: OK, I see. That's very interesting actually. Would be very interesting to to see and know these nurses point of view as well in their role because it it's kind of a new role. Can I say that? [00:22:35] IME8b: Very very sure. [00:22:37] Researcher: OK, um and on the other hand, do you see any problem related to engaging people and ask people to participate in the process and he limit or like? Problem related to attitude or the trustability of data information they provide. [00:22:59] IME8b: Uh. Actually, once they conduct. Ohh. The blood test in the hospital and the. The lab test result are automatically transferred to our server so so there is no data integrity issues regarding the blood test but. They are a diverse information which is provided by patient themselves. Like medication compliance is and their weight and their symptoms. Ohh. Since medication compliance is one of the most important factors when they when doctor assess patients disease status. So because once the lab test results are bad then doctor should cheque whether the poor lab test results were originated by the poor medication compliance or they have to change the dosage of the medications. So the patient reported outcome, especially the medication compliance, that's the the key things we need to like. Um confirmed at this point, since we are lunch, we are going to launching the the. Um. Um, how can I say not better test after better test we launch our services. [00:24:30] Researcher: Trials. [00:24:32] IME8b: Right, right. Well, our. [00:24:33] Researcher: I'm OK. [00:24:35] IME8b: Ohh services from next month, so we'll cheque that result. [00:24:44] Researcher: And the role of data privacy and security in this scenario is the is that something that you face? I know that also depend on of on the country where you you base. Of course that might be different from here, but is there any like specific Cally issue or problem or maybe like a challenge that you see in this direction? [00:25:16] IME8b: Hmm. Actually, um. [00:25:29] Researcher: OK. [00:25:23] IME8b: Korea is quite Korea's data purpose law is quite similar to GDPR, so recently Korean Korea is. [00:25:41] Researcher: Hmm. [00:25:32] IME8b: Ohh like Ohh acknowledged for GDPR compliant countries, especially the the low perspective. So but. But one thing one bit different is that opt in opt out. The like once we want to receive information about the patients once we want to ask information about the patients, then we have to ask their permission every time. That's the GDPR. But in case of of Korea, where us, we don't have to do that, we can receive comprehensive agreements when they sign in the services, so that that's the pick big difference. So in this kind of. Privacy law. Ohh hinders significantly about the US user experience. That everything they want to do, some functions that patience has to cheque, agree, agree, agree. So there's the key difference. Who? But. [00:26:35] Researcher: So they do have to agree when you're saying that when they have

to run specific, OK. [00:26:40] IME8b: You miss me formation. [00:26:42] Researcher: OK. And you have any like formal specific way to explain this to to the user app to the user of the app or you you just write all the texts and ask for their agreement? [00:26:58] IME8b: Ohh we have to follow the law like the the law specified the the statements. Ohh. We have to show it and then receive their permissions. [00:27:14] Researcher: And I see you specifically designing for people like patients already. Do you consider prevention in any way in your within your service? Like also engaging people who are not already familiar with the disease. [00:27:38] IME8b: Ohh. [00:27:39] Researcher: Providing them some information as well or is a very is a more focused service that have a more like specific goal and. Activity to to to ask people for. Okay. [00:27:57] IME8b: Actually, uh, our solutions is targeting uh patient patients who are diagnosed with thyroid disease. So they are mostly familiar about their disease. But in case of AM R this the key challenge actually since. Um. In order to in order for the solutions to be, uh, widely spread out. [00:28:23] Researcher: Hmm. [00:28:24] IME8b: The necessity or the problem definition are. I I sympathise by the patients that users, but in case of a Mrs patients have have like less like. The pieces are less likely to feel the necessity of. Are monitoring a risk levels, so there's there's a difference actually. When I think about the proposals for AMR, the spearhead project, that's the key. Uh points, how can we like spread out the necessity to the citizens? That's the. Uh. Yeah, keep the keep difficulty. But usual cases. Of your cases where they where certain agenda where the campaign is was spread out to the citizens or the people around the world was. Actually, my thyroid, why? Very, this is one of the keys. Cases where uh. The. Umm where? Hmm, a through the campaign, the necessity of carrying various disease is spread out. Like from the uh associations like Korean serialisation American Third Association, this kind of association is conduct each campaign in each country. [00:30:07] Researcher: How actually you got involved with the AM R with the antimicrobial resistance? Because it's. Something that can be related to what you doing there in gyroscope. [00:30:21] IME8b: Um, actually we are. Uh, we've been searching for. Ohh text disease which we need to target and then. [00:30:31] Researcher: OK. [00:30:33] IME8b: Um, as you create one of the um. One of the worst area regarding over use or misuse of AMR. [00:30:47] Researcher: Umm OK. [00:30:48] IME8b: Then type already ohh so ohh one when when we hear about this project we thought of. This would be the game changer for the global markets. [00:31:01] Researcher: Good. [00:31:01] IME8b: That's how we like. We suggest what we can do for this consortium. [00:31:08] Researcher: OK. OK. Thank you. I mean I've I'm done with the question. I don't know if you have anything to add or if you have any questions for me. [00:31:19] IME8b: Ohh, actually uh. I'm just curious about Ohh. Ohh, your perspective on the interactions between patients and doctors since their diverse kinds of healthcare. But in case of the Disaster Health Act application and the web where the any other means of interactions. I'm just. [00:31:49] Researcher: Yeah, I mean I am, I'm I'm being researching during the past year. I was, let's say, positively surprised about the solution you mentioned before speaking about the the nurses that are actually employed by you to face this problem and the reason also why I was so let's say investigating on the other hand, the attitude of doctors, physician and nurses is because here for example in Switzerland what we found is that. That. They because of time mainly as you already mentioned, they don't, they not really engage in answering or interacting through application. So or we try to suggest them, propose them away to cut the time they spend visiting their patients. So we propose the application of the service as like you can do this instead of physically visit your patient. For some disease that allow this protocol. [00:33:03] IME8b: Hmm. [00:33:04] Researcher: They are very interested and willing in see how the application might work, because of course also have the data from different patient or like the track of all the patients data is additional extra point that can help them. On the other hand if we just ask them to cheque records or interact with patients as an extra time that have to to. Added to the procedure is something that they're not interested about, let's say. So they it's we need to. Just. Move the interaction. From like physical to. [00:33:52] IME8b: Hmm. [00:33:51] Researcher: To the app when, where is when is possible on the other hand, from a patient point of view. And I'm speaking about patients, not like citizens, as you mentioned for Amar, because it's something different. We are targeting a more

specifically patient with the urinary tract infection diseases because it's one of the leading cause to AM R. Um, on the other hand, they are very I mean happy and they demonstrate interest in gathering their data and trying to interact, improving their relationship with Doctor because most of the time what we observe is that. They know a lot. A. And because the disease can be recurrent or have like a different way to to treat it, some of those also use natural product or like prevention preventive activities and they are happy to first ever way to to gather the information they can properly use to the doctor. Uh, because one of the problem I'm I'm facing is that maybe they have the knowledge because of the experience of the disease. I don't. I'm not saying that is more than what physicians know, but because of experience, of course, the way they observe themselves. Is is very deep, no, but most of the time they have not. The way to, let's say, translate the the knowledge they have the the feeling they have in a way that can they can. Explain an interact to the doctor. So that's why thinking about a way to gather this kind of information and organise them. [00:35:51] IME8b: Hmm. [00:35:52] Researcher: Might be useful. I mean this is that the direction of the research? But I'm at the beginning, might be used to. Help during the communication between patients and doctors. [00:36:08] IME8b: OK. Hmm. [00:36:10] Researcher: I didn't know if you have any any comment or. If you see the the thing differently. [00:36:19] IME8b: Ohh I I agree. Oh oh, to most of your company, your opinions and thoughts actually the. Interaction in order. It's it's. It's quite similar in Korea as well, like in Korea. The average minute for inpatient session like it when patient leaves hospital and take patients is treated in the room by doctor. It's usually about 2:00 to 4:00 minutes. You're very short, so it's really difficult to incentivise doctors to be involved in the the the interactions, especially virtual interactions. It unless it gives a economic incentives like that additional payments for the doctors so. So that's why we focus on the, the the remote monitoring which can provide payment for doctors so that they can. Ohh that's great since most of the country they adopt. Ohh it's similar or higher payment for virtual treatment. That so? Yeah, still is so difficult to incentivise or provide motivation to doctors. Ohh. [00:37:53] Researcher: Yeah, that's true also because we are organising workshop related also to engage people, the other targets. So people who maybe face the problem once they don't know about antimicrobial resistance and the way we're trying to engage them is also trying to. [00:38:34] IME8b: Right. [00:38:13] Researcher: Motivate them in asking question and interact with the with the doctor during consultation. But of course then there is the problem of time because here in Switzerland were specifically you pay for the time you stay to the to the in the doctor room. So of course the more you ask, the more the more you pay. And that's something that's needed to to balance the let's say. [00:38:40] IME8b: Right, right. Any questions or comments? What is is your best method to make a motivation to patient to cheque their health condition? [00:38:56] Researcher: There's a very big question I'm not working on a like I mean the way we try to build engagement now. Uh is more related to um. Knowing the disease and then change behaviour. Of antibiotic consumption. Um, they way we try to to engage people and keep them engaged, especially during the activity is trying to of course give them something. So the idea of. Build and work on data literacy skills is because in the project idea we try to, let's say, empower people being able to read and better understand and use their own data and information to better interact with doctors. So we start asking them their stories, their experience, that that can of course can be helpful in understanding the disease. But and in exchange, let's say if we wanna see in. In this way we try to and enhance them in in in reading. A. Their data and and information. This is something that I didn't start yet designing this phase but. Because of my my background in information design and communication design, I will be focused on data visualisation and physicalisation, so having something like that I think is the parallel way you as a UX using character you mentioned before. So something like physical in this case or something like. Think. That you can use while explaining your stories or trying to understand and motivate your symptoms. That can help you thinking about your experience, but in the same time to make it tangible, let's say, to interact with someone else that's needed to understand what you're saying. I mean, I really thank you for for this chat. I hope to to see you again within the spirit project, but maybe we'll be also interesting to to keep in touch and if there is like anything regarding the project that maybe can do.

A.3 Transcripts of the workshop conversations

To ensure consistency and maintain focus on the substantive content of the conversations, the transcripts include only the sections of the activities where participants were primarily intervening. Moments in which I was describing the method or the activities are excluded, as these descriptions are already provided in the Methodology section (Chapter 3 of this thesis). To keep the reading smooth yet clear, timestamps are provided only at the introduction of new activities, while the alternation of speakers is indicated with "/" to signal that a new participant is speaking.

All transcripts preserve the language of the original recordings and conversations. All activities were conducted in English, except for the first workshop [WS1], the pilot workshop medical expert interview [P1] and two of the medical experts' final interviews [ME1 and ME11], which were conducted in Italian. These transcriptions are provided here in the appendix in the original Italian, reflecting the language used by the participants during the workshop. However, in the main body of the thesis, excerpts have been translated into English to facilitate readability.

Workshops 4 and 5 [WS4 and WS5] had a slightly different structure compared to the workshop sessions 1, 2, and 3, which are considered the core of the methodology because they repeated the same activities with the same target group and topic. Because their different structure, only final phases of WS4 and WS5 have been recorded, corresponding to the moment in which participants were asked to share and present the artefacts they had created to the other groups.

Abbreviations are used in the text. [WS] stands for Workshop Session. This research includes a total of five workshop sessions, which are numbered according to the order in which they took place. [P] stands for Participant, who is identified by a specific number for reference purposes. [G] stands for Group, which consists of three to five participants of mixed genders.

WS1: 24 October 2023 - SUPSI, Mendrisio (Switzerland)

[00:00:03] **[Symptoms definition]** P7: ...qualcosa sta succedendo all'interno del mio corpo che o che eventualmente qualcosa non va. Dipende poi dalle situazioni e che in molti casi comunque mi permette di riconoscere effettivamente cosa sta cambiando all'interno del mio corpo e cosa magari non va. /Researcher: Grazie. /P1: Io sono **, sono infermiera da sei anni e adesso ho appena finito un master in scienze infermieristiche e lavoro da sei anni. Ho lavorato sia in ambulatorio di ginecologia, quindi partorienti, sia ragazze, quindi diciamo è un tema che conosco bene. Poi va beh, io che io adesso lavoro in casa anziani, quindi di infezioni del tratto urinario non dico tutti i giorni, ma quasi, quindi diciamo che ecco, e fortunatamente non ho mai sofferto personalmente del problema. Se non ecco altre tipo di infezioni, ecco in quella zona, ma non del tratto urinario. E quindi ecco. /Researcher: Va bene, grazie mille./ P1: Eh, allora io ho scritto che sono delle sensazioni positive o negative, soggettive, che non sono visibili agli altri e che spesso possono manifestarsi come segni visibili, ma che rimangano prettamente soggettive al paziente, che spesso sono difficili da mostrare o quantificare, sia in senso fisico o psicologico. / P5: Ciao a tutti, io sono ** e realtà sono amica di **, però ho avuto anche purtroppo un periodo in cui ho sofferto di malattia al tratto urinario. Per fortuna, per il momento non più, e sono service designer. Lavoro per un'agenzia di consulenza che ha sede a Torino e in Svizzera. E sono qui oggi perché sia mi interessa l'argomento, ma è molto interessante anche come viene applicato la metodologia del design anche a dei temi che non sono, apparentemente sono temi molto specifici e apparentemente lontani. Dunque io non sono esperta su questo fronte. Eh, però la mia lettura personale di cos'è un sintomo per me la manifestazione soggettiva. Possibile malattia, disturbo, disagio che può essere fisico o anche percepito a livello mentale, più psicologico. Che in realtà, anche a mio avviso può essere vista come aspetto positivo, oggi lo vedo come qualcosa di negativo, però non c'è. Non è necessariamente un sito, a mio avviso, è sintomo di qualcosa di negativo. In questo contesto lo interpreto come qualcosa che si manifesta quando legato a un problema./P3: Sono **, vengo

da **e lavoro in un'agenzia che si occupa di esperienza digitali, si chiama ** però sono molto interessata all'ambito dell'information design. Ho studiato con ** che era la mia, una delle mie professoresse e **, che era la mia assistente al ** di ** e collaboro con ** nell'Università italiana che diceva prima e quindi il progetto mi interessa sia perché appunto sono molto interessata all'ambito dei dati, sia perché ho sofferto quest'anno per un periodo molto prolungato di malattie del tratto urinario. Quindi ecco, sono proprio fresca del dolore, del sintomo per me quello che ha scritto, che è il sintomo è sicuramente una traccia, un indizio di qualcosa che sta cambiando nel mio corpo. Quindi lo vedo in maniera negativa, sicuramente perché quel sintomo, la maggior parte delle volte ha degli effetti negativi su di me, ma lo vivo anche in una maniera positiva perché mi aiuta poi a comunicare con delle persone che mi possono aiutare a risolvere quel dolore, quel disagio effettivamente, Che tipo di dolore, che tipo di disagio ho. Quindi è come se fosse in qualche modo un linguaggio con il quale io posso comunicare il quello che mi sta succedendo e quindi aiutare una persona ad aiutarmi. Quindi per per quello lo vivo quasi più ormai, non maniera positiva che negativa, grazie. /P6: Ciao, io sono **, lavoro **, dove sono responsabile del l**. Sono coinvolta sul progetto, so qualcosa sulla resistenza antibiotica ma non tanto. Allora secondo me il sintomo, non so, ho detto che il sintomo è qualcosa di strano, cioè dal mio corpo che è qualcosa di diverso dal normale, che appare all'improvviso perché è solo appunto fatto che appare ma non c'è che non è una cosa così, qualcosa che riesco a vedere come continua attivare il tempo no, vedo sempre come un momento specifico perché appunto prima non non avevo né percezione quando riuscivo a vederlo, magari era lì, c'è sempre stato il sintomo. Intanto no che non riesco a vederlo, quindi è molto legato, forse anche ai sensi, alla percezione che abbiamo nel corpo, perché possiamo avere. Comunque ci sono sintomi di qualche disturbo però di cui non siamo coscienti. Che facevano un un'analisi dal neurologo, una visita veloce dall'urologo e mi ha detto hai le palpebre basse, ci hai mai fatto caso. Io non era, non avevo capito che quello poteva essere un sintomo di una malattia neurologica che non ho. Però era appunto che quando mi fa me l'hanno fatto notare, ho capito che anche certe cose possono essere dei sintomi, ma la nostra conoscenza non ci permette di, o percezione fisica, non ci permette di riconoscere, riconoscerlo, descriverlo. /P2: E ciao io sono ** e lavoro come assegnista di ricerca al ** e sono anche docente di visualizzazione dati che diciamo che il mio, il mio ambito è quello un po della visualizzazione dati. Infatti **, ** e **, insomma (...) sono molto contenta di essere qua. E ovviamente sono anche perché io soffro da tantissimo di malattie del tratto urinario. Credo che sia la diciamo, la malattia di cui soffro di più in modo costante da tanti, tanti anni e per me quello che ho scritto è secondo me un sintomo, è un segno proprio anche a livello di fonetica, mi sembrava che questa era la cosa più simile e. Inteso come una manifestazione tangibile o visibile di una condizione, questo tangibile, visibile, ovviamente può essere tangibile, visibile a noi oppure tangibile, visibile attraverso degli strumenti che ci permettono di una TAC o qualcos'altro. E poi mi sono ricordata, non so quanti centri, quanto sia accurato, però mi sono ricordata di questo esame che dovevano dare le mie amiche che facevano medicina che si chiamava semeiotica che studiava i sintomi e le patologie, quindi niente è venuto in mente anche ah sì, loro studiavano i sintomi, quindi esistono esami all'università di medicina in cui studiano sintomi. E un'altra cosa che ho scritto è stato che un sintomo non è soltanto negativo, cioè nel senso che un sintomo può paradossalmente, anche se non c'entra con la malattia. Se sorrido così, forse un sintomo che c'è qualcosa di bello, che sta succedendo è molto di meno, quindi un po come riflesso di qualcosa che succede dentro, segno. /Researcher: Questo è molto interessante perché io ho approcciato i sintomi sicuramente da un punto di vista del del progetto e quindi anche trovo curioso. Sicuramente, cioè positivo, comunque, che non siano emerse solo il lato negativo del del sintomo, ma invece anche proprio come, nonostante contestualizzato in questa ricerca, come segno anche effettivamente di qualcosa di positivo. Eh, non so, allora io mi sono, cioè in generale un po le cose che sono emerse riprenderei da quello che è stato detto. Ora ditemi se mi manca qualcosa o se o non siete d'accordo su tutto, però il fatto che sia un fattore sia fisico che mentale è stata una cosa che mi sembrato di correre un po in tutte le le descrizioni e non tutti hanno citato però ritengo.

Molto rilevante il fatto che sia legato anche al tema della soggettività, quindi nel senso effettivamente magari può essere un fattore di avere un determinato significato. Come avete detto segno avviso traccia è però la la percezione, forse che si ha è comunque un soggettiva può essere soggettiva. Ehm, mi sono piaciute tutte questi queste parole che alla fine, appunto, come segno, avviso, traccia, indizio che vedo un po sinonimi all'interno della definizione di sintomi legati al cambiamento del corpo. Quindi anche il fatto di riconoscere qualcosa che sia diverso dal "normale", nel senso di rispetto a quella che è la norma che può avvenire e quindi posso riconoscerlo sia all'improvviso, sia invece rispetto qualcosa che già c'era, di cui mi accorgo all'improvviso. Quindi anche il la non tempestività, ma il l'approccio che io ho nel riconoscere qualcosa nell'essere attento può essere importante nel percepirlo. Più in generale, poi andarlo comunicare e poi una cosa che è stata citata, quindi tu hai detto non l'ho, non non sapevo fosse un sintomo di qualcosa, quindi c'è effettivamente anche noi nell'andare ora la definizione di sintomo. Diamo per scontato che conosciamo quella cosa come portatrice di determinati significati o eventi, e non è detto che invece non siano già presenti dei sintomi che invece io, proprio per mancanza di conoscenza riguardo al tema posso interpretare. [00:10:09] P4: secondo me questa cosa è definibile come, cioè bisogna fare una differenza tra il sintomo intenso come percezione, che appunto tutti quelli che abbiamo detto noi erano, derivavano dall'idea di sintomo come qualcosa che io devo spiegare a chi mi deve aiutare a risolvere la malattia, dal punto di vista di ** che era molto interessante e che sintomo un sintomo scientifico, quasi medico, nel senso che qualcosa proprio di una malattia che ovviamente si esatto che si manifesta Eh, come ad esempio avere quando.. Le palpebre basse... oppure il fatto che magari non lo so se il dito lascia il bianco sulla gamba e perché hai problemi di circolazione. Però una stupidaggine però non lo so, finché qualcuno, magari un medico o una persona esperta non me lo dice e quindi al momento anch'io imparo a dire vedi, lascio il segno bianco e questo è un segno del fatto che ho problemi di circolazione. L'ho banalizzo da molto, però non è la differenza tra il sintomo, quello proprio scientifico, medico proprio di una malattia o di un problema. E quello invece tipo ho mal di pancia, ho mal di ventre, basso, mi stanno arrivando le mie cose oppure... forse legato al dolore, l'altro a una condizione, uno Stato. /P2: è vero però una cosa è vero, però comunque insomma, c'è anche un fattore di quanto ne sappiamo dei sintomi... Certo sì, cioè nel senso anche dolore al basso ventre, magari per una persona che non ha idea che per una ragazzina che non ha idea, che le sta arrivando, le sta arrivando la mestruazioni? Magari boh, non è una cosa a cui assocerebbe quello, non lo so... /P4: No no, intendo che quello che percepisci come tuo dolore o comunque che senti che rientra nei tuoi sensi, le tue percezioni. È un sintomo che, come quello che noi abbiamo descritto noi tutte tranne **, quando ha portato l'altro punto di vista e ha detto, il sintomo è qualcosa che puoi avere ma non riconoscere perché non senti perché non vedi, non lo vedi. Non lo percepisci. /P2: Ah perché non lo vedi, ok. /P4: È una cosa legata a un sintomo proprio di una malattia, quindi la magari poi tu non te l'avevi **, però ti ha visto che le palpebre basse era un sintomo di un problema neurologico. /P2: però lei magari da domani lo guarderà, quindi c'è tutta una forma di [not clear]. /P4: Infatti, quando io ho fatto l'esempio del dito, ho detto da domani, da quando il medico mi dice, lo guardo e lo comunico come un sintomo. No, non legato al dolore ma alla percezione, una cosa che vedi e senti tu, che ti dice qualcosa. /P2: Anche senza dolore. /P4: sì. Puoi anche vederla, vedi una palla e dici ok sarà qualcosa. /P6: Un'anomalia. /P4: Un'anomalia /P6: Un'anomalia, capire che le palpebre abbassate è un'anomalia. **[Symptoms identification]** [00:15:54] P2: Li giriamo direttamente... Come la gestiamo? /P4: io ho il primo... dolore quando si fa pipì. /P7: mi hai anticipata... /P2: dolore lombare? io sì. /4: necessità di fare pipì. /P3: si forse quella più di tutto, di tutto. Non so è, per me... /P2: no io no. / P4: abbiamo due etichette... fastidio e dolore? Ne abbiamo due, abbiamo duplicato fastidio, dolore diverso, mettiamole vicine. È diverso? / Researcher: io ne avevo pensati due diversi, fastidio qualcosa che sento... dolore è forse lo step successivo, nel senso che è proprio male fisico. /P4: Il sangue... urina con sangue. /5: crampi basso addome, io sì. /P2: Crampi basso addome... /P6: Urina maleodorante... /P4: Urina torbida. /P5: qui c'è brividi... /P4: brividi insieme con sangue? /P2: io sì. /P4: vedi che bella sta cosa? Perché io tipo le sto dividendo, ma perché

sto tipo monopolizzando la situazione con i dolori tipo all'addome, al ventre, tutte le cose che riguardano la pipì, anche questo cioè c'è... / P6: Nausea? /P4: ce l'hai? /P6: no, io no/ P2: no. / P4: incapacità di svuotare sempre la vescica? /P5: tipo incontinenza... però secondo me è una percezione, che tu percepisci di essere incontinente. Mettiamo incapacità di svuotare completamente la vescica e metti percezione che tu percepisci di essere in contatto. /Researcher: Ci sono delle etichette vuote, quindi se avete delle variabili su switch no a quella che dobbiamo fare sempre la pipi, poi decidiamo dopo. /P4: per me possiamo metterla vicino a quella che devi sempre fare la pipi poi decidiamo dopo. /P3: io ho avuto anche vomito. /P6: ah cavolo, per la malattia al tratto urinario? /P3: ero arrivata a un momento che m'ha fatto venire febbre alta e vomito, infatti sembra una prima data di emissione. /P5: quando è venuta l'infezione, anche a me è venuto il vomito. / Researcher: Ma come malattie renali ora ci rivediamo tutti alla cistite o c'è qualcosa di diverso a cui ci siamo riferendo nel senso? Mi sembra di capire che nella maggior parte dei casi spesso sia cistite, però non è detto, nel senso che ci sono altre. /P4: io anche la candida. /Researcher: però la candida, qui mi correggerà l'esperta, non sono infezioni... /P1: eh no, la candida sono infezioni dei genitali. /P5: però a me, almeno quello che mi è successo, mi hanno detto che se tu trascuri la cistite, può diventare una infezione anche alle vie urinarie. / Researcher: E infatti per questo dico, siccome infezioni vie urinarie e tipo un macro gruppo all'interno del quale c'è la cistite ma ci sono anche varie altre tipi di infezioni, no? E anche di riferimento, se è alto o basso, addome, oltre questo... /P1: esatto. /P4: io non lo so, non lo so cosa ho avuto. /P5: se dobbiamo considerarle tutte, tipo il vomito, anch'io l'ho avuto. / Researcher: no ok, era solo per capire se stessimo anche parlando di qualcosa di diverso dalla cistite. Invece stiamo parlando tutte di cistite, ok. /P6: No, mi chiedo se cioè stiamo parlando anche di candida, che sono infezioni dei genitali, che comunque sono trattata con gli antibiotici, quindi comunque sono batteriche. / P1: no però con il tratto urinario si intende praticamente dal rene fino la via urinaria, tutte le infezioni vaginale dei genitali sono un'altra categoria. /P6: però comunque sono malattie che vengono trattate con antibiotici. Quindi possiamo estendere anche a quelle? /P1: se è vie urinarie, non sono considerata. /Researcher: penso che anche i sintomi possono essere molto diversi, nel senso anche immaginando la candida, forse ci sono dei sintomi simili... /P4: Io queste le ho tutte, però io le tranne il vomito. / P2: come le perdite bianche che solitamente non ci sono durante la cistite. /Researcher: però la candida la identificherei con altri sintomi, tipo perdite bianche... Non so, anche il la pipì si, hai sempre difficoltà, ma forse non è lo stesso modo della cistite, no? /P4: Ho difficoltà, ho difficoltà però non non è il primo problema che ho ne ho altri scala più forti./ Researcher: si no però sempre di infezione del tratto urinario per identificare meglio i sintomi. /P1: si perché comunque, a meno che una persona ha delle lesioni, diciamo nel genitali, è difficile che lì si annidano dei batteri proprio nei genitali esterni, più che altro sono funghi o muffe o parassiti, ecco. /P2: Si no perché io tipo ho avuto una volta una infezione da *Escherichia coli* potentissima che alla fine cioè i sintomi erano quelli, molti una cestite molto forte però in realtà le avevo fatto una cura completamente diversa da una cistite normale, quindi boh, ma quella che una malattia diversa, il fatto di avere l'*escherichia coli* nelle urine a livelli altissimi...? /P1: Allora, l'*escherichia coli* noi, se facciamo adesso un tampone te l'abbiamo tutte perché sono i batteri fecali, quindi sono siamo contaminate completamente il nostro corpo da l'echerichia coli. Il problema è che quando c'è un deficit diciamo del sistema immunitario, c'è un tratto urinario debole. L'escherichia risale nel tratto urinario e poi ti farà cistite che se non curata, va su poi sopra il rene e fa la peronefrite. /P3: eccomi. Io ho sempre avuto problemi con l'*escherichia coli*. /P1: ma il 99% delle infezioni che si riscontrano comunque nelle donne avvengono proprio perché proprio perché, quando anche ci si pulisce bisognerebbe sempre fare poi il bidet perché le *escherichia coli*, quando si va di corpo va poi insomma.../ P6: quindi dovrebbe essere di piu nei paesi senza bidet? / P1: Eh sì, però è vero che noi, con tutto il discorso dell'igiene, super igiene eccetera, noi siamo un po più delicati rispetto in quei paesi. / Researcher: perché sviluppiamo meno anticorpi? /P6: ci laviamo di piu e quindi... /P1: eh si.../ P4: Io ho una domanda pratica in questo momento che trascende dalle etichette, se io cioè io sono il caso studio in questo momento,

non sono come sempre non sono, non ho problemi di cistite ma relativi alla candida che abbiamo capito che non fa parte delle malattie a cui tu sei interessata nel workshop... come si posiziona il mio contributo in questo workshop, nel senso anche quando devo plasmare il mio oggetto, io descriverò una cosa che non è la cistite ma che ma no, ma sono c'è anche in questo momento delle etichette io posso portare un contributo che... /Researcher: ma non siamo ancora arrivati a quella fase. /P6: prendi le note. /P4: no, perché magari non partecipo alla definizione dell'etichettatura, capito? / Researcher: io rimarrei concentrata sulle infezioni del tratto uriario proprio perché come diceva anche lei, i sintomi si differenziano, anche se non sono completamente diversi. /P1: oddio, se poi ho avuto una candidosi bruttissima che ti è salita anche quella nel perché poi è vero che anche i le spugne tutte, quelle i parassiti, così le si possono formare nei genitali possono anche risalire. Però, è chiaro che tu ti accorgi con la candida e le perdite dovresti in teoria già curarti così, ed è raro le muffe le micosi etc, è raro che risalgono nel nel tratto urinario, perché anche il PH è diverso rispetto ai genitali, chiaro? /P6: chiaro, però comunque le curi sempre con l'antibiotico. /P4: Semplicemente era quello, che poi la curi comunque con l'antibiotico, ora non la curo piu con l'antibiotico però... /P3: No, io volevo aggiungere anche il gonfiore di stomaco che in realtà io non so se nel mio caso e cioè è stato un sintomo sempre presente, ma non so se era legato alla malattia o è un effetto dei farmaci che prendevo, perché per tutto il tempo ho preso anche dei probiotici che lo hanno come effetto collaterale, quindi non so bene definire. Però è stato un sintomo. /Researcher: questa cosa è interessante per la definizione, rispetto ai sintomi effettivamente legati alla malattia oppure quelli causati poi dall'assunzione di farmaci, anche in riferimento agli antibiotici, se penso effettivamente, come dicevi e come ha portato ** la candida può essere un effetto dell'assunzione degli antibiotici, quindi quello poi non sarebbe più un sintomo effettivo delle malattie del tratto urinario. A meno che, come hai detto, posso sfociare, ma più un effetto del trattamento che sto svolgendo. Riusciamo un attimo a fare un punto veloce in due minuti per riordinare quello che è emerso e se avete aggiunto i punti che volevate aggiungere? /P5: Quindi rimane fuori nausea, pressione inguinale e temperatura bassa. /Researcher: ok, gonfiore basso ventre... lo stomaco lo teniamo o è più basso ventre il dolore? /P2: io ho messo basso ventre, cioè quasi gonfiore alla vescica, praticamente cioè senza che sia così gonfia di niente. Mentre dolore di stomaco era quello di **. /P3: si io l'ho avuto... /Researcher: OK, invece rispetto all'importanza mi avete ordinato da questo lato... no. Non c'è un vero ordine, quanto un raggruppamento? /P4: qua c'era l'urina... cose relative all'urina e alla pipi, qua stomaco, poi qua c'è basso ventre, stomaco, dolore lombare, poi qua brividi, vomito, basso ventre. Basso addome. /2: però crampi. Non gonfiore. /P4: si, e poi di là c'era stanchezza, fatica durante la pipi. Incontinenza... /Researcher: dolori locali. /P4: Sì, esatto, OK. Sono presi, brividi, pipì, febbre, stanchezza, scusami quelli. **[Intro to physical representation]** [00:30:45] P2: Non so se ho capito bene. /Researcher: Sì, allora l'idea è quello di utilizzare quello che un po' per gli spari tutti i materiali sicuramente non ci stanno tutti, nel senso che anche un po' a fasi esplorativa ho cercato di portare diversi materiali per poi capire anche quali voi effettivamente ritenete più opportuni in base ai sintomi che sono stati scelti. Quindi non so se volete aiutarmi a disporne alcuni poi possiamo tenerne altri da parte. /P5: Quelli no, aspetta ora. Quindi manca le piramidi, arrivo? /P2: Li lascio nelle buste questi. /Researcher: si, quelli li conviene, perché non. (rumore e conversazione tra i partecipanti che dispongono il materiale). **[Physical variables definition]** P6: lo facciamo insieme? /Researcher: L'idea di mettere il materiale sul tavolo già da ora, che possiate effettivamente iniziare proprio a guardarlo, toccarlo e vedere se invece, anche in questo caso rispetto le etichette già definite, trovate delle caratteristiche delle delle variabili, quindi delle proprietà dei materiali che non sono elencate, ma che invece pensate possano essere interessanti per descrivere questi sintomi...**[Participants explore the labels]** Someone: non riesco a leggerli... /P4: schema di superficie, texture e ruvidità. /P2: OK, qua abbiamo condizione, opacità, curvatura, brightness, peso, forma, dimensione standard. / P6: da dove iniziamo? /P2: dai sintomi? O da una variabile. Ho iniziamo dai sintomi o da un sintomo? /P6: forse da un sintomo. Dai che è che aveva il sintomo più grave. /P3: la febbre forse, il vomito.../ Researcher: Anche magari guardando i materiali, nel senso non per forza partendo dalle

etichette... o se c'è un tipo di ehm caratteristica in generale è riferimento sia al materiale, alla forma, alla dimensione, eccetera che... /P6: Magari pensa quando l'ultima volta che l'ha avuto... /P3: volevo riguardare le variabili. /pausa. Ma io la cioè non riesco però per la pesantezza del momento e di quello che sentivo sceglierei un materiale pesante. Sicuramente quindi non lo so, quella quella variabile lì mi porta a scegliere legno e anche perché può sembrerà banale, però mi riporta un materiale caldo che era non quella sensazione del momento, perché sentivo cioè il caldo è legato alla temperatura corporea, ma anche il bruciore della cistite e quindi cioè cercavo in tutti i modi il freddo. Mi ricordo tipo, stavo molte, molto tempo nel bidet o fai la doccia perché volevo una sensazione di fresco, la cercavo, quindi forse queste due sono le cose che mi portano a scegliere il il materiale esame legno e fra tutti scegliere quello più squadrato, il blocco grande di legno. /P5: lo dobbiamo prendere? /Researcher: No, io allora procederei associando proprio... Vedete che le etichette hanno una forma componibile? Quindi lei ha parlato di telefono e di peso, forma... Allora l'idea sempre tutti in questo contesto sperimentale, è quello di associare per ogni sintomo una variabile in modo che poi, andando a cercare di ripercorrere la storia che mi avete condiviso, possiamo utilizzare quello che stiamo definendo ora come vocabolario per esprimere la vostra storia. Quindi saprà che nel momento in cui vai a rappresentare la storia avevi la febbre, sceglierai un materiale con un determinato peso, oltre la febbre c'era un sintomo di gonfiore e invece, invece del peso è legata ad una forma. Adesso immagino dal mio lato, e l'idea è quello proprio di comporre tramite tutte queste variabili, quella che era quello che è stata la tua esperienza. Ripeto, essendo tutto molto sperimentale, possiamo un po' variare anche gli elementi sul tavolo, forse procederei un po' anche per step, per cercare di andare per ordine e capire come potrebbero essere associati. Soprattutto giustificando perché come hai fatto tu ora ad esempio il fatto della temperatura, che tra l'altro non so neanche se c'è nelle variabili non credo, è una cosa super interessante. Adesso ti do l'etichetta è è vero. Rispetto a questi materiali la temperatura non la fissiamo a noi comunicare, però anche questa cosa è interessante nell'ottica di ridisegnare o riprogettare il workshop e ripensare ai materiali disponibili mettere a disposizione non so come, però materiale, (persone ridono) qualche modo anche magari non so, a livello tattile... /P2: io avrei scelto il freddo, il freddo per esempio, per questa cosa di freddo caldo OK, era tra questi, mi sembrava il materiale che più potesse trasmettere queste due, cioè il freddo che caldo si è scaldato. /Researcher: Nel senso di temperatura quindi? [0:41:30] **[Symptom-physical variable association]** Researcher: Se dovesse scegliere tra peso del materiale e temperatura del materiale che cosa sceglierebbe per rappresentare la febbre? Magari per il momento possiamo tenerli entrambi qua, magari per ora, andiamo su quelli che sono i sintomi maggiori nel senso principali, associandoli alle altre variabili e poi magari li ritorniamo indietro su questa fase. /P2: Temperatura un po' didascalico. /Researcher: Temperatura magari pensato anche tipo al velluto, che nel senso mi dà una percezione diversa rispetto effettivamente, come dici tu. / P4: quindi un materiale pesante? Un materiale che fa, che dà calore. /Researcher: anche tipo... / P2: pelliccia /P4: la lana! /Researcher: Una forma diversa, però, che fosse in un materiale di lana, magari potrebbe esprimere il concetto di temperatura senza effettivamente avere una sfera che scotta all'interno, sul sul tavolo potrebbe avere senso. In riferimento stiamo procedendo per quelli più gravi, diciamo giusto, mi sembra di aver capito. /P2: c'era il sangue... / P5: anche il vomito... /P2: Esatto, anche il vomito. /Researcher: Sì, qua OK, vogliamo provare a pensare per per il vomito? /P1: Ma diciamo il vomito a me. Non lo so, io adesso mi sono fissata con le palline che sto guardando e sinceramente boh. Il vomito comunque, cioè è caldo anche quello, cioè quando vomiti non è che vomiti freddo. Quindi andrei sul legno e su queste qua. Perché comunque il vomito, cioè comunque quando vomiti non è che fai un rigurgito come neonato, ma di solito è una cosa un po importante e poi calda. Ecco. /Reseacher: OK quindi il riferimento sempre a quello che è lo successe alla forma? /P1: si, io lo associo alla forma, alla dimensione. /Researcher: OK alla dimensione, alla dimensione e alla forma. OK, perché non ha portata diciamo di di quello che effettivamente viene, quindi anche magari in un'ottica di tenere traccia di quella cioè sì in forma? /P1: Eh sì, la quantità, non non la pesantezza ma la la massa per... /Researcher: OK

quindi dice anche in termini magari in futuro ipotetico, di tenere traccia di quelli che sono i sintomi. Potrebbe anche essere utile, magari Eh. Quanto riguarda il vomito, capire effettivamente quanto una persona ha vomitato a livello di sintomo, o non necessariamente la quantità? Piuttosto la presenza o meno di questo sintomo. /P1: più che altro se una ragazza comunque vomita tantissimo rischia poi di disidratarsi, quindi la sequenza magari la quantità effettiva rispetto, cioè se comunque la persona vomita tre giorni, 3, 4 volte al giorno, è pericoloso per la disidratazione. Ecco, OK, quindi a me viene becco questa cosa qua, OK? /Researcher: ecco allora forse invece che la forma potrebbe essere spostato su la frequenza di qualcosa, nel senso di avere, nel caso in cui lo so, con la sfera però, invece che magari le dimensioni sarebbe la quantità di sfere raccogli e che mette insieme perché questo invece, anche dal punto di vista medico potrebbe, Eh. Avere rilevanza per descrivere la malattia alla gravi e capire la gravità, se… /P1: cioè diciamo che comunque sia la persona vomita tantissimo e tante volte è altrettanto grave rispetto a ecco due episodi di vomito e poi soltanto con atti di vomito, senza senza liquido. [00:44:01] /P2: Però posso dire una cosina, cioè tipo, anche se parliamo di frequenza va bene avere una palla sola?! Io penso alla frequenza, penso alle palline, le palline. Boh, non lo so. Stavo riflettendo su perché effettivamente dimensione si sta secondo me la fa da sola, però se invece parliamo di un ritmo prenderei una roba che forse fa ritmo. /P5: magari tante palline, o non si puo? /Researcher: Sì, sì, ah, si può tutto. È come se stessimo cercando di definire noi le le regole no? quindi mhm va bene, non non c'è un giusto o sbagliato, è solo capire come potrebbe essere la migliore delle delle regole, delle idee per per rappresentare quel determinato sintomo. Quindi si è più quindi proprio una frequenza e una quantità, se vogliamo, rispetto rispetto alla dimensione, la frequenza che implica anche il tempo, quindi non solo quantità. Tipo quante volte, ma come hai detto prima in tre giorni qua mi determina rispetto al tempo, è propriamente la frequenza OK, magari specifico solo sotto timing. Il fatto della frequenza anche. / P2: magari potrebbero essere anche tante grosse. /Researcher: E poi, esatto, a questo punto magari possiamo lavorare al contrario e vedere se tante grosse possiamo cercare di associare la dimensione a qualcosa? Detto che la frequenza è data da le volte in cui vomito, se devo pensare al contrario, magari ragionare in termini di dimensione, quali di questi sintomi? / P4: il gonfiore? /Tutti - il gonfiore di stomaco. / Researcher: forse in questo modo è più facile. Infatti siamo vostre idee, più completa. /P2: è più facile variabile-sintomo. /Researcher: Sì, è vero, è più facile forse partire dalla variabile e poi vedere che cosa si può associare, come come sintomo, OK. /P1: ma il bruciore non lo abbiamo… che è quelle secondo me più /P2: classico. /P4: c'era il dolore quando si fa la pipi. Non c'era anche il fastidio. /Researcher: però il bruciore non era stato identificato? C'è il bruciore tra le etichette? P4: no, non c'è / Researcher: aggiungiamolo/ P4: però secondo me fastidio e dolore sono un po… /P6: però bruciore è iù specifico. /P2: Lo scrivo sopra, OK. [bussano alla porta, entra una partecipante P8 che è arrivata in ritardo] Researcher: in realtà siamo già ad un punto delle attività… ma ti riassumo quello che stiamo facendo. /P1: Comunque, premettendo che non ho mai avuto la cistite… in teoria quando urini, non senti che urini, cioè non dovresti sentire niente, invece quando quando la senti è proprio come se se fosse… /P2: gocce di fuoco. /P1: eh si, è quasi calda no? O fredda comunque che fa attrito con la parete quindi, ah no? /P2: beh se facesse pipi, questi mi farebbero male (si riferiscono alle forme in polistirolo e agli angoli) /P6: una cassa di legno con gli spigoli dopo così… spigoloso. / P2: Sì, quelle calde un po potrebbe essere la sensazione di questi spilli.. Spilli sull'uretra, caldissimi si. Quindi, che cosa mettiamo… bruciore quando si fa pipi? /P4: io metterei rogo… ruvidità. /P3: Eh sì, sì, perché forse non è solo la forma, ma anche la… /P4: Senti qualcosa di solido che ti passa tramite… /P2: perché qua c'è anche viscosità, però è un po diverso, forse viscosità è più no. /P4: Io penso proprio una sola superficie questa sera immane, quel pezzo di polistirolo e io ho guardato gli angoli da quando abbiamo iniziato questa attività continuavo a pensare pipì, bruciore, quel materiale [polistirolo] proprio nella forma di triangolo, da proprio già fastidio anche solo a sentirlo, capito? /P2: anche il rumore. Non sta facendo traccia delle forme? /Researcher: No, perché secondo me in questa fase il focus è sul ragionamento in generale rispetto l'associazione specifica, che riguarderà una fase successiva. Allora magari abbiniamoli… Mi sono un attimo persa sul

bruciore, per qualcuno è ruvidità, invece tu cosa dicevi? /P5: eh no, io dicevo anche la forma. /P3: Esatto, mettiamola accanto. /Researcher: teniamola accanto e poi vediamo se qualcuno lo associa qualcuna a qualcos'altro P5: lei diceva anche le palline di metallo... quindi ritornare sul materiale o sul il fatto che quelli fossero visto il fatto che quelle siano piccole forse non si lega un po' all'effetto ruvido sempre si potrebbe essere espresso dalla ruvidità? Ce n'è qualcun altro oppure invece vogliamo ritornare a...? Tipo, anche la parte di rumore, non c'è tra le etichette e anch'io l'ho pensata in relazione al polistirolo. Non c'è tra le variabili, perché il riferimento ai materiali non non era stata considerata, ma potrebbe essere interessante portarla dentro se pensate possa essere associata a uno dei sintomi che sono qua, quindi? /P2: ...perché il rumore, cioè il rumore, lo associo all'attrito, cioè è un pò il rumore dell'attrito. Questa cosa qua secondo me che mi fa sentire questa sensazione di fastidio e l'attrito in realtà lo potrei associare al fastidio e cioè a tutto ciò che comunque ha a che fare con i fastidi/dolore o bruciore durante la pipì. Attrito molto simile, forse è una conseguenza di questo è. /Researcher: Forse anche il riferimento alla difficoltà a urinare? /P2: Ah forse sì, brava, attrito nel senso di difficoltà. / Researcher: nel senso di mancanza di fluidità, cioè il contrario di fluidità rispetto a quello che potrebbe essere l'azione di Urinare. /P5: Anche la magari boh, non so, a me viene in mente la permeabilità della superficie, cioè. /Researcher: OK, OK, questa anche non è considerata, però più andiamo nel dettaglio, in fase di poi non so, mi sento queste cose non sono direttamente trovabili in questi materiali specifici. /P5: sisi, però per esempio se tu hai una rete, cadono le gocce, se tu hai una rete piu stretta ne cadono di meno. /Researcher: quindi forse anche un po' la trama? La texture? /P3: comunque nella gomma piuma penso passerebbero dei liquindi, mentre nel legno no...quindi /P2: esatto. Pattern/ texture e parlavamo di... /P7: incapacità a svutare completamente la vescica? Difficoltà a urinare? Con pattern parlavamo di incapacità di svuotare completamente la vescica, intendevamo questo difficoltà. /P3: No, no, c'è anche fastidio durante la pipì. Fastidio e dolore. Quindi fastidio è il nostro bruciore? /P2: Magari si può far bruciore, fastidio, dolore, possiamo capire se c'è n'è uno che è più "SHAPE", l'altro che è più ruvidità, cioè tipo ruvidità, è più bruciore, magari la forma è piu fastidio/dolore. /Researcher: si perché magari il bruciore è anche piu specifico no? Quindi magari lavorare sulla ruvidità della superficie e questo riprenderebbe un ** ti ritrovi con il dolore quando si fa pipì con la forma, quindi riprendere un po gli spigoli che ci si citavano prima mhm, sì. /P2: me venuto in mente un'altro, quello sul sangue. Perchè quella è una roba che per me è abbastanza comune e ho pensato alla brightness - più e luminoso più e boh, rosso forse. Però nel senso ho pensato alla brightness, come possibile variabile da associare al sangue che però potrebbe anche essere l'urina torbida credo. /P4: Io invece la mettevo nell'opacità, l'urina torbida. /P2: ah si mi piace, / P4: quindi c'è un contrasto in realtà perché appunto se c'è il colore, tu lo associ alla brightness e del sangue, quando è torbida. Io prima la associavo, cioè lo volevo dirvelo dopo, le associavo a una questione di opacità. /P3: forse urina con sangue direttamente colore, allora sì, infatti allora. /P2: Allora sì. Poi penso sempre che il colore sia una, è una variabile molto importante perché uno vede subito e quindi se i sintomi cioè non so se dobbiamo procedere, nel senso che i sintomi più gravi prendiamo le variabili più importanti, colore, forma? Non lo so e quindi magari c'è il sangue è abbastanza importante, così come dire la febbre, che è la dimensione secondo me... /P5: si perché poi a livello più peso scientifico, cioè quando c'è sangue vuol dire che è più grave e quindi forse se uno l'ha avuta tante volte anche da un punto di vista del paziente, sai che quello è un indice che vuol dire che c'è qualcosa di un po più grave. Se forse è la prima volta che che ti succede non sai cosa succede, quindi magari non conosci, però magari qualcosa che anche dal punto di vista medico è molto oggettivo, cioè nel senso che c'è qualcosa di un po più grave. /P1: Però non so però perché solo il sangue, cioè se arriva una persona e dice che c'è tanto sangue però è una personalità fertile e non ha nessun altro disturbo. Cioè è difficile, potrebbe anche essere semplicemente vaginale dalle mestruazioni, il tipo di sangue, il colore soprattutto colore. /P2: Tipo io quando mi ricordo era un sangue che ho riconosciuto per la prima volta. Non essere il sangue della mestruazione mettere un sangue quasi come se mi fossi tagliata, cioè arancione, cioè era e quindi per quello che è stata la brightness perché per me era un sangue molto, molto acceso. No, però il colore è quello, cioè

quindi ci sta colore. /P4: Ma brightness potrebbe essere saturazione, cioè nel senso brightness la intende più come appunto, qualcosa di acceso, di saturo e quindi riconducibili al colore... /P2: brightness potrebbe essere anche bianco e nero. /P4: ok, tu pensi luminosità del colore, non saturazione. /P2: un rosso piu bianco o piu nero. /P3: forse poi se la luminosità non so, cioè che poi anche l'opacità e mi riporta a quella cosa lì mi riporta la sensazione tipo di di stanchezza, un po di senso di svenimento, un po quella cosa lì, no, quelle scintille, quella luce che vedi quando non lo so, ho pensato questo mentre lo parlavi adesso del bianco e del nero. /P2: tipo vedo bianco vedo nero... sto svenendo. /P5: c'è la sfumatura anche. /P3: è sfumatura allora. /P4: Quindi abbiamo sfumatura, colore, opacità, luminosità per stanchezza, urina torbida, urina con sangue abbiamo OK, allora più o meno, e qui si, il mondo è qui. /Researcher: forse brightness e opacity ci sono tutti e due, ma forse stanno su una stessa, stessa variabile in due direzioni diverse. Nel senso no, però brightness opposto potrebbe essere scuro, che chiaro e scuro. /P4: Per me brightness è chiaro, scuro. /P2: Eh no, però allora secondo me brightness o opacity, a meno che non sono due colori molto diversi, è un casino distinguerli. /P5: uno si riferisce al sangue, l'atro alla pipi. Se uno fa la pipi al sangue c'è un combo... il sangue ha la brighness e poi la pipi puo essere opaca o trasparente. Due assi con due estremi diversi, quindi sono riferiti a due cose diverse, solo che quello che esce. / Researcher: OK, potrebbero potrebbero combinarsi. Ok, quindi il riferimento all'unico con sangue e brightness... /P5: si però l'opposto di brightnss non so cos'è. Il sangue può essere chiaro o scuro. /P3: Mettiamo brighness e color nel sangue. Opacity nell'urina torbida. E la sfumatura nella stanchezza. /Tutti: ottimo. / Researcher: Allora come tempistiche mi muoverei, forse su effettivamente lo lo shaping non so se c'è qualcuno altro specifico o forse magari si possono anche finire di definire mentre iniziate effettivamente a lavorare con i materiali, nel senso che poi effettivamente durante la costruzione. /P4: Comunque abbiamo fuori fastidio della pipì, l'abbiamo messo nel bruciore più o meno necessità di fare la pipì è l'incontinenza, sono simili. /P7: fastidio era bruciore abbiamo detto? /P4: Sì, esatto. E poi necessità a fare pipi con incontinenza. Va con incontinenza che ho perso, eccolo qua, la continenza. P2: Poi abbiamo ancora posizione, curvatura dei contorni, viscosità. /P7: qua abbiamo ancora movimento e orientamento. / P4: Io movimento lo metto incontinenza perché quando sono... devo fare la pipi... /P3: e anche viscosità, nell'incontinenza. Che sia secondo me molto... /P2: si collega bene con la ruvidità, cioè questa sensazione sempre un po di... L'altro era in movimento e viscosità. Beh, che comunque insieme ci stanno, senza cioè... /Researcher: Ok e dai. Io lascerei così, poi nel senso può essere argomento di ridiscussione del della dell'associazione che abbiamo fatto. Ok, possiamo passare alla fase di Shaping [01:03:29] **[Shaping]** P4: ma deve essere una forma unica? / P3: deve essere una forma unica? /Researcher: No, questa azione è individuale, quindi prendete pure le forme. Come ho detto in riferimento alla storia che avete condiviso, cercate di ricostruire quelli che sono i vostri sintomi, per poi descrivere la vostra storia. /P3: anche nel l'attività individuale posso comunque comporre un oggetto scollegato, quindi più forme o deve essere uno? /Researcher: Sta a te. Vuoi utilizzare tutto questo vocabolario per avere un unico oggetto che personalizzi con i materiali, oppure vedi un oggetto per ogni sintomo che hai avuto e quindi vuoi mettere insieme varie componenti. Puoi servirti come preferisci di queste componenti tenendo poi presente che l'oggetti ti servirà per descrivere quella che è stata la tua esperienza. Ben venga tutto, nel senso che l'idea, appunto, cosa di utilizzarli per raccontare meglio, poi è descrivere, mostrare come se dovesse mostrare la tua storia accompagnata da una spiegazione. /P2: Questa è l'ultima attività? / Researcher: Concludiamo verso le 6 PM, potete lavorare fino a magari alle 05:50, quindi un quarto d'ora /20 minuti su questa attività per poi usare gli ultimi 10 minuti per presentare. Ridescrivere la propria storia presentando l'artefatto o quello che è emerso. /P2: e io non devo seguire questo per forza (regole labels) oppure si? /Researcher: L'idea è quella di utilizzarlo come punto di partenza. Poi ogni tipo, come ho detto prima di personalizzazione è più che benvenuto, nel senso nel momento in cui poi io lo lo spiego no. E invece che partire da zero posso rifarmi a questo elenco. A questa lista e anche andando a prendere, abbiamo lavorato collettivamente, andando un po a recuperare quelli che sono gli ingredienti, se vogliamo, della della mia malattia, Eh. Partire da quelli o

comunque seleziono quelli che sono i più importanti, quelli che io ho avuto, di cui ho avuto esperienza, visto che ora si lavora individualmente e personalizzarli. /P2: Claro, thank you. /Researcher: L'ho detto anche agli altri, anche gli altri 15:20 più o meno per fare questa attività di shaping e poi concludiamo con con la presentazione finale e come dicevo, abbiamo costruito una questa sorta di vocabolario. Partite magari usatelo come punto di partenza, selezionando quelli che potrebbero essere i sintomi più. Importanti per voi o di cui avete più esperienza? E poi venga la personalizzazione sia di materiali che magari se non eravate d'accordo su alcune variabili o se avete dei ripensamenti rispetto alle variabili che sono state, pensa sì… /P1: cioè possiamo creare… costruire rispetto, assemblarli o invece magari al contrario, Researcher: si, scegliere un unico oggetto e agire su quell'oggetto. In riferimento a creare, ad esempio, la ruvidità, l'opacità dell'oggetto colorarlo rispetto a una determinata colore o luce che è il riferimento alla vostra malattia, eccetera. /P5: c'è la forbice? /P4: anche io volevo lo spago… /P2: sto cercando.. Il polistirolo! Hai mica uno stuzzicadenti? / Researcher: no, non c'è, c'è la colla… /P1: posso chiederti la forbice? /Researcher: Tipo questo rumore… (rumore di sfregamento su polistirolo) non so se lo abbiamo associato ma era da associare a qualcosa… /P3: scusate lo rifaccio. / Researcher: ne vado a recuperare un'altra. /P1: abbiamo avuto la stessa idea-- ma questo va bene per questo materiale? /P6: avere gli spilli… poteva essere… /P4: eh si gli spilli/ Researcher: si riesce a utilizzare il fil di ferro infilzandolo? / P2: Perché non riesco a infilare questa roba? C'è per caso del fil di ferro? Magari riesco a infilare, usare tipo ago. /Researcher: cos'è che non riesci a fare? /P4: bucare. Fatto. /P8: mi passeresti il fil di ferro per favore? /P1: posso scusa rubarti al volo solo la forbice? /P4: devi. /P6: mi dai il fili? (rumore materiali e sfregamento) /EP4: c'è il filo di ferro? /P7: Ti rubo ancora il filo di ferro. /P3: ti posso chiedere le forbici?/ P2: Posso associarne, posso fare una roba così perché ci sono due gonfiori, li metto entrambi. /P4: Voglio qualcosa per la puzza… /P5: è vero! L'odore non l'abbiamo messo. /P4: prendo un coso di vinavil, che puzza… /P5: usa un pennarello uniposca, ce lo abbiamo? Però ad alcuni piace. /P2: cosa puzza, cosa puzza, elastici, puzzano. /P4: bastanza perfetto. Plastica. Gomma. /P5: potresti dar fuoco… Researcher: posso aggiungere odore come variabile? /P2: si… /P4: Come è vero che puzzano si. /Researcher: Odore in riferimento a… A cos'è che lo stai associando? /P4: Ah agli elastici alla gomma. /Researcher: Allora al materiale no? In riferimento all'odore che senti proprio quando vai in bagno, all'urina. /P2: Com'era quella sensazione di dover urinare… incapacità di svuotare la vescica. /Researcher: Può andare se vi lascio ancora 5 minuti. Tutti – nooo. /Reserchер: L'unica cosa cioè non voglio, no, no, nel senso per me possiamo andare anche avanti, è giusto, magari andiamo 10 minuti dopo le sei non so se queste per qualcuno può essere un problema o possiamo considerare magari 10 minuti in più, cosi vi lascio ancora 5 minuti abbondanti per finire poi poco e poi passiamo adesso. /Tutti: no nessun problema. /P2: ho fatto un dramma io… /P7: Ma ti infili o mi prendi in giro il difficile. /P4: è difficile è? Un botto. E l'ultima cosa va, poi ho finito. /P6: io ho finito. / P2: io apro anche lo scotch. /Researcher: li forse ti conviene usare l'attack. P4: tu non ti preoccupare. Dici che mi serve l'attack? / Researcher: dipende cosa vuoi fare. O le incastonati dentro tipo diamanti. /P4: se non funziona mi arrabbio perche mi ha rovinato tutta la struttura. /Researcher: forse servivano bucate? Tipo perline… /P4: eh si. La mia non è temporalità. /P6: la mia non reggerà mai. /P6: io scappo prima. /Researcher: dite che poi riuscite a muoverli? O no? /P4: devi aspettare che si asciughi tutta l'impalcatura… è un incubo incollare le palline, non stanno. Ora devi aspettare che si asciuga tutta l'impalcatura. /P2: avrei bisogno di colori! Il giallo… /P6: ma perché stai inserendo le palline? No va beh dopo lo vediamo. /P2: volevo metterle sopra in realtà… ma non c'erano gli spilli. /P4: (in riferimento all'oggetto di P7) Concisa, classica, non fa una piega. /P7: Io ho bisogno di essere diretta, precisa. /P4: VP hai fatto gli stadi? /P3: mi manca una cosa… /Researcher: se volete possiamo spostarli li [davanzale] cosi li vediamo tutti insieme. E forse, vista la non lo so, possiamo lasciarli lì, ognuno presenta, se volete si possono spostare lì se preferite e si presenta, cioè li presentiamo da lì, magari te li vediamo tutti. /P3: io scusate, ho fatto una cosa… troppo lunga? Eh però l'instabilità è un lato… [1:29:00] **[Artefact presentation]** Researcher: Ok, c'è qualcuno che vuole iniziare, magari a descrivere quello che ha fatto in relazione alla propria esperienza? /P6:

Posso iniziare velocemente io? Allora, io ho fatto questo... era per tenere insieme ma non tengono. Sono delle perdite, quindi le parti bianche sono il materiale, quindi la variabile del...va beh non era... quella lì, era forse la brillantezza. Però se la brillantezza, insomma il colore dell'urina vabbè non ricordo bene esattamente perché lo sento. Più che però ha alternato a questi che la mia condizione psicologica OK che ogni volta che compariva la prima volta poco e comunque avevo un ero molto preoccupata, poi aumentavano. Infatti, c'è il doppio triangolino e quindi c'era la preoccupazione che aumentava e poi sono aumentate le maggiormente e quindi questa era la mia esperienza di come visualizzare questo acquisto sintomo di perdite bianche, succedeva... Sì, sì, succedeva qualcosa di se, mi irrigidisco rispetto alla situazione. / Researcher: Grazie. P3 vuoi andare tu? /P3: No allora, sono 5 perché in realtà io non ho mai sofferto in maniera grave di malattie del tratto urinario. Ho avuto delle cistiti molto leggere che ho curato con integratori, mirtillo sempre è ma non è mai sfociata in una cosa che mi dessero veramente dei sintomi seri e gravi. Fino a Febbraio in cui ho avuto degli episodi conseguenti (consecutivi) che in realtà socio a un unico episodio. Per questo ho composto diverse forme che sono stati effettivamente 5 episodi diversi che però io vedo come un unico episodio, perché non sono mai stata bene in tutto in tutta la malattia. Quindi si inizia con la prima fase e come vedete nelle prime quattro fasi ho avuto dei sintomi simili tra di loro e aumentavano solamente diminuivano in base a appunto alla fase in cui ero e quello che è cambiato è che rispetto a la prima volta che l'ho avuta mi sono sentita sempre meno stabile. Infatti, più avanti, più le le sculture cadono perché appunto, con il ripetersi della malattia, con il ripetersi dei sintomi, il sintomo più grave alla fine era per me la l'ansia e la paura che avevo nel nei confronti della malattia, quindi quella è rappresentato dal cubo di legno che è sempre più grande, ma è sempre più grande perché aumenta l'ansia, ma è sempre meno stabile. Fino all'ultimo stadio che è stato quello più grave, che ha provocato un'infezione molto grave con vomito, febbre appunto. La necessità di un intervento urgente e che appunto, come vedete è zero stabile ed è rappresentato appunto da più cubi di legno, più più legno e quindi più più ansia da parte mia è l'ultima forma, è quello che è rimasto perché ancora ho dei sintomi legati a questi episodi che sono principalmente legati a la paura e a come questi episodi hanno influenzato la mia vita, causandomi ansia soprattutto verso i rapporti sessuali e a ha tutto quello che per me poteva provocare quella malattia lì e quindi quello che è rimasto sono delle palline pesanti di metallo. Basta. /P4: Ah l'ultimo non lo avevo visto. /P2: Ah perché c'è un ultimo (blocco di artefatto)? /P3: si. /Researcher: Grazie, grazie. /P3: Era più semplice /P4: Bello. P2 dai, vai tu? /P2: io? Me lo ricordo? /P3: ti sei fatta... la leggenda? (rif. allo scherma sulla tovaglietta). /P2: Questa forma, diciamo che la forma in primis vuole rappresentare un flusso che in realtà è sia temporale che metaforico della della pipi. Poi forse questo giallino torbido aiuta. In realtà qua ho cercato di rappresentare quelli che più o meno sono i soliti sintomi delle mie cistiti, io la cistite, adesso meno di una volta al mese, quindi ogni due mesi almeno una volta, non gravissima. L'ultimo episodio molto grave di cistite in sale a quest'estate ho avuto la febbre e tutto il resto, c'è molto grave... nel senso che mi ha veramente destabilizzato. E però vabbè, questo più o meno è un tentativo di rappresentare temporalmente che cosa succede al mio corpo come se fosse un totemino che tengo lì e mi ricordo dove sono, cioè quindi all'inizio quello che succede è che noto una minzione frequente, sempre più scura, non si vede (dall'artefatto) però l'idea più o meno era quella, che è seguita da un gonfiore e al basso ventre, il gonfiore al basso ventre diventa poi un fastidio. Una difficoltà nel nel appunto, nel nell'andare in bagno. Quindi una prima difficoltà, unità da spilli e palline che rappresentano la ruvidità di quella sensazione di spilli nel due nell'uretra che è quello che per me questa cosa, in seguito gonfiore ancora di più, cioè per me sento proprio questo dolore qua fortissimo di gonfiore dietro la vescica e per me, cioè è quello che mi stai anche dicendo. Arriverà il peggio deve ancora venire e infatti il peggio e questa carta vetro che è sottile però è rossa e quindi niente boh poi questo questo un po troppo lungo (rif. Filo), però era più per dare l'idea di questa cosa e l'ho pensato più che altro perché a volte lui magari guardarlo così no? Cioè pensare OK, questo è da dove parto, cioè questo è il sintomo peggiore che mi è capitato. Come cioè, ed è un percorso che ho anche provato a fare nel tempo, come come se n'è arrivata questo senso, ma c'è sempre questo gonfiore prima

quindi poi nel tempo ho imparato un pochino a riconoscere i pre-pre-sintomi e quindi in realtà dopo che ho preso un sacco di antibiotici e ho bevuto cranberries a volontà, ho scoperto che l'alimentazione volta che mi aiuta di più, cioè appena sento che potrebbe succedere qualcosa per tre giorni, mangio riso integrale e cose... una dieta quanto povera di grassi, di cose infiammanti e niente basta, questo è il mio storia e ricordo non so come farlo qua, olaf, con la coda. /Tutti: grazie. /P2: Grazie a voi. /P4: Bene, vado allora io, Eh? Io ho già ammesso che non so se parlo di cistite o di candida, non l'ho ancora capito. Il fatto comunque è che tratto con l'antibiotico, i sintomi sono quelli che sono sul tavolo. Dolore e nausea non li ho mai avuti, magari qualche volta nausea ma non so se la riconducibile a quello al fatto che prendessi l'antibiotico. Detto ciò, anche a me, un po un iter intertemporale, ma non proprio, nel senso che sicuramente, il punto da cui parto è l'incontinenza. Cioè c'è l'ho già di mio, (tu lo sai che sono sempre lì, ogni volta in bagno) però, è un'incontinenza diversa perché mi da dolore. Quindi il fatto di mettere in realtà dentro questa gommapiuma è dovuto al fatto che è un materiale che assorbe, cioè mi sembra un materiale che contenga dei liquidi più degli altri presenti sul tavolo e quindi assorbe, assorbe, assorbe, ma al tempo stesso ha questa sorta di catena intorno che ho simulato con lo spago che cerca di contenerla e crea queste bubble che diventano dolenti. Quando diciamo da dal, dalla pipi che resta ancora, scusatemi, il mio termine letterario, che è ancora lì, tutta dentro, contenuta dentro il materiale morbido che è il mio apparato genitale, arriva fuori e fa male, diventa spigolosa e diventa fastidioso urinare e queste che ho messo le palline che in realtà avevamo associato al timing, io le ho associate a la sensazione che era una cosa che mi da super fastidio ed è messa che durante il workshop delle perdite, queste perdite che mi rendono invalidante anche socialmente, perché scaturiscono anche il maleodore, cioè io sento il mio maleodore quando la candida mi percepisco avere un odore diverso e penso che gli altri intorno a me lo percepiscano, quindi non è soltanto un dolore fisico ma è anche qualcosa che per me è debilitante dal punto di vista sociale nel rapporto con gli altri e in realtà gli elastici poi tornavano anche bene come concetto, oltre che per l'odore, li usati per quello, perché ho detto, ah questo puzza, tieni, perché mi chiudono e mi ingabbiano socialmente. Quindi il ritorno un po anche alla mia descrizione iniziale di sintomo, che però relativa a quella per me è una questione molto di chiusura verso gli altri, perché quando sono sotto, esposta e ultimamente ogni mese /mese e mezzo, infatti ho smesso di parlare con gli antibiotici che sto passando ai probiotici che mi sono stati consigliati e che in realtà un po mi stanno calmando, la situazione, riesco a, questa non ancora perché è ancora il sintomo che c'ho sempre, ma riesco a risolvere, a non arrivare a quello stadio per cui ho sono dolente, cioè sento che metto un cattivo odore o ho delle perdite fortissime che mi mi rendono anche difficile anche la giornata al lavoro perché mi sento sporca continuamente, però ecco, diciamo che ho imparato, cioè sto sperimentando queste nuove cure che mi aiutano, nuove cure, che mi aiutano a restare nel primo stadio, che comunque è costante perché o comunque l'infezione sempre in essere al momento, ma è un'infezione che riesco a gestire semplicemente un poco come anche BG, con un'alimentazione particolare e con per esempio eliminato il glutine da poco e mi si è attutita la voracità con cui questa infezione si presenta. E poi con ovviamente pulizia, vabbè, quella c'è sempre però insomma, quando c'è questo tipo di problema si è cerca di avere un'attenzione in più. Basta grazie. /Tutti: grazie. /P7: Allora io deciso di rappresentare in realtà l'unico sintomo che è quello che io ho e che è quello più debilitante in realtà per me, come me lo immagino io nella testa, cioè per me il bruciore addirittura poi si arriva ad un dolore nel momento in cui si fa la pipi è come se qualcosa di appuntito e di molto ruvido mi attraversasse e quindi immaginatevi questa cosa in movimento (artefatto) che passa attraverso me ed è assolutamente fastidiosissima e sgradevole. Niente, molto semplicemente. / Researcher: Grazie. /P5: Allora non so se riesco. È un po' un mostriciattolo. È questo l'ho fatto anch'io con il filo, perché anche per me ho pensato subito a qualcosa di temporale, come se fosse un processo. E diciamo che per l'esperienza che ho avuto io in realtà è passato tanto tempo, quindi ho un po la tensione, ma penso un po a tutti che più passa il tempo, più sembra qualcosa di più piccolo, però in realtà ero stata molto male e io ho sofferto abbastanza di cistite, poi anche ho avuto un'infezione, ma da

quello, cioè diciamo che io ricordi più forti che ho, che abbiamo visto anche oggi erano all'inizio dei crampi associati anche al bruciore, quindi ho messo due palline uguali perché per me i due i due fastidi un po erano quasi interscambiabili, quindi per me hanno un po, possono essere un po scambiati in ordine temporale la ruvidità, perché comunque ti senti scomodo. Lo so certo qualcosa che ti fa sentire scomodo anche banalmente uscire, cioè hai già dei sintomi che devi andare in bagno o magari ci sono persone e quindi per me associola vita qualcosa di scomodo. Poi, andando avanti nel tempo, arrivo al momento in cui appunto ti senti come ti dente, non si capisce se devi andare in bagno, però poi non devi andare in bagno e ricordare il momento in cui non puoi uscire di casa, quindi ho deciso di fare un cubotto anche e mi sono diventata una texture con gli spilli. Perché secondo me è una combinazione di più cose che un po, come dicevamo prima, la permeabilità del materiale che ti dice effettivamente una percezione che hai che in realtà fisicamente non è. La texture, perché filtra poco liquido e poi questi spilli perché davvero fastidioso e c'è sempre bruciore. E poi questo nodo è un po grosso, venuto male per me è come se fosse una biforcazione, perché io qui avviso la dottoressa e succede qualcosa, cioè quello che era successo a me era che si venivo anche da un pregresso di trascuratezza, non consapevolezza che fosse cistite e quindi magari l'ho avvisate troppo tardi. Lei però, al momento in cui ho bisogno non mi ha risposto, quindi in questa via è il macigno, quindi il peso, la associato a qualcosa di chi lo addormento più grave che diventa l'infezione e lì diventa davvero debilitante. Perché, per dovuta andare al pronto soccorso perché non sapevo più come fare e poi invece qui per me è vuoto perché prendo un antibiotico e ti passano i sintomi. Solo che poi io da qui in poi quando viaggio perché non mi era successo anche quando viaggio diventa una cosa circolare, perché si chiude e ritorna, io non ti piaccio che me lo porto sempre dietro. /P2: anche io. /P5: E quindi niente. È una specie di processo che si può anche chiudere, oppure può avere una biforcazione, cioè per me questa è la cosa più più, non so piu pazzesca di questa di questa esperienza che sembra che non finisce mai. / Researcher: È interessante come forse è stata la prima che ha citato il dottore. /Tutti – eh...si. /P5: per me è stato... cioè a me hanno detto che era sfociata in una infezione proprio perché l'avevo trascurata. Un po ovviamente mia negligenza che sicuramente è associato al fatto di avere un occhio di riguardo, se hai sintomi chiamare subito il dottore o comunque io sono, a prescindere, un disastro in quello però, anche il fatto di non avere subito un rimedio, cioè ha fatto sì che questa cosa era già trascurata da parte mia, ulteriormente trascurata, probabilmente era già arrivata al limite. / Researcher: Però nel tuo caso, ad esempio con antibiotico sei riuscita a risolvere questo problema? /P5: No beh in quel caso mi hanno dato l'antibiotico proprio in vena. E quindi poi mi è passato e poi invece di solito, con l'antibiotico, si, se mi succede poi mi passa. / Researcher: e quindi te lo porti. Invece, tu e P4 forse, no P2, avete citato l'alimentazione, oltre al cranberry, anche proprio cosa mangiate, che può aiutare, in supporto all'antibiotico o... /P2: Non ho preso l'antibiotico, cioè nel senso se, perché dopo che c'è l'ho detto tante volte, riesco a riconoscere quand'è che ci siamo. Quindi se la riesco a prevenire, in quel momento mangio bene, mi faccio le tisane alla malva... / Researcher: e in riferimento a quei, micro-sintomi, come li hai chiamati tu, qualcosa del genere, prima... ce ne sono alcuni di quelli? ce ne sono alcuni, che sono diversi o sono prima di quelli? C'è ne sono alcuni specifici che sapresti citare? /P2: Intanto ho identificato, ma penso più per abitudine quello che succede a me è che questa cosa mi avviene sempre prima del ciclo, prima delle mestruazioni, questa cosa tendenzialmente mi accade. E la settimana dopo se devo avere il mio male al fegato ce l'ho una settimana dopo. Quindi c'è tutto un ciclo di disagi quindi già so a livello tempistico quando questa qua può succedere e micro sintomi di solito sono voci... cioè l'unico sintomo è gonfiore che non è gonfiore di pancia, ma è proprio gonfia la vescica, cioè non so se esiste però mi sento proprio un peso e gonfio basso molto più basso. /Researcher: Ho capito, diverso da tutti gli altri e lì capisci che... /P2: che è l'inizio di quello poi forte che sento quando c'ho sempre e quindi è un po un po quello lì però adesso ho imparato quasi a riconoscerlo prima ancora che diventi un problemi problema di minzione, cioè riesco a prenderla prima e allora mangio diverso e bevo... /Researcher: e il dottore, se posso chiederti, in tutto questo? /P2: il dottore c'è stato all'inizio una prima volta che sono stata così così prima

cistite che avevo avuto tipo a 15 anni prima volta, tipo 16 avevo sentito la ginecologa però all'epoca lo associavo tanto all'attività sessuale qua di là vivevo come una vergogna no perché per la cistite per cui non ne parlavo con mia madre non ne parlavo, anche coi dottori, mi vergognavo perché c'è magari, faccio troppo sesso. No cioè perché per me era quello, e la dottoressa, ginecologa mi aveva dato delle bustine di cranberry, a me sta cosa però non è che mi avesse dato un sollievo immediato, ma non non lo so un po basta... No poi vabbè c'ho avuto un episodio forte quello delle febbri, del sangue eccetera allora lì no sono andato dal dottore ho fatto la visita molto... ho fatto gli esami no esami urine, sangue, tutto e poi allora io faccio una cura di quasi un mese tra antibiotico, lavande, ovuli. E poi da quella volta lì ho capito che non era solo perché facevo troppo sesso. Ma C'erano anche altre 1000 cose. Ovviamente è cambiata la mia vita sessuale, cioè in ogni caso, cioè io non posso più pensare di avere un rapporto e non andare a fare pipì e di non lavarmi perché viene l'ansia che il giorno dopo possa avere la cistite e mi possa fregare tutta la settimana di vacanza... / P3: eh si... Per me c'è un'altra questione che magari non vi ho raccontato adesso, ma io purtroppo abito a Milano, non avevo ancora cambiato dottore, quindi il mio dottore era a distanza, quindi tutte le mie prime quattro cestiti sono state curate con degli antibiotici dati a distanza senza una visita e senza degli esami che quindi non erano mirati per il tipo di infezione che avevo. Solamente nell'ultima infezione, sono andata dalla ginecologa, per fortuna avevo appuntamento quel giorno e quel giorno è stato l'episodio della febbre del vomito. Quindi c'è stata questa casualità. E solo da lì, con le cure, proprio con i probiotici di sei mesi più l'antibiotico sono guarita. Però tutti gli antibiotici che ho preso prima praticamente non hanno fatto, o almeno la prima volta stavo meglio, ma dalla prima volta in poi non... no. Solo con i probiotici sto bene. /P2: ma a che distanza sono stati gli episodi? /P3: collegati. Io avevo la cistite, prendevo l'antibiotico. Dopo una settimana mi ritornava la cistite, si, mi sembra. / Researcher: Lasciamo l'ultimo... /P1: il mio bellissimo, bellissimo. /P4: proprio dall'unica non designer... /P1: Allora vabbè, come sapete io non ho mai avuto esperienza personale, però curo, ho curato tante pazienti, quindi ho messo la carta ruvida sotto per dimostrare il fatto che comunque il mondo non è liscio, nel senso che capitano sempre e comunque dei delle venature. Insomma, quindi è una cosa che comunque c'è a chi capitano certi problemi a chi invece questi qua... eh ormai è così. I colori perché vabbè, io non ho, cioè non nel senso, non vedo mai la vita soltanto con colori spenti, ma comunque con colori vivi e volevo dire che comunque in tutto questo problema qua alla fine, comunque non è che non c'è rimedio anche se son comunque cose croniche che comunque, anche con il passare del tempo, anche con l'invecchiamento comunque meno male passano comunque o si trasformano. E poi ecco, ho messo la pallina con il filo di ferro non per darti un senso di costrizione di gabbia, ma semplicemente che comunque ogni situazione è complessa e va presa singolarmente. Quindi, anche se qua abbiamo cercato di trovare una definizione comune, alla fine ognuno comunque ha una sua definizione e purtroppo lo ammetto, è che nel mondo sanitario questa cosa qua, se ci si cerca sempre di standardizzare, ma alla fine non... ogni situazione è a sé e poi alla fine quella più leggera di pallina per comunque. Ecco come avete anche citato alcuni di voi che alla fine diciamo gli antibiotici o comunque delle terapie forti, così non sono sempre a soluzione tante volte basta... Io ho amiche che hanno portato la cistite con l'agopuntura e vabbè c'è chi ci crede effettivamente. Poi ci sono tantissime cose, anche più leggere. Ecco, e niente dai grazie. / Tutti: grazie. /Researcher: Va bene, non so se avete qualcosa da aggiungere o più in generale volevo ringraziarvi tantissimo non solo nel tempo, ma anche per aver condiviso questo tipo di esperienze e storie perché un conto è partecipare a un'attività, un altro conto è basare queste attività su comunque un'esperienza che è molto dolorosa in sé è anche il ricordo comunque, la la narrazione che ne consegue può essere faticosa, quindi davvero grazie. Spero che in qualche modo comunque possa essere stato utile anche questo scambio e la conversazione che si è che si è generata e poi anche magari nei prossimi giorni qualsiasi tipo di feedback o che volete lasciarli scritto o risponde, cioè anche per mail rispetto alla mail con cui vi ho contattato, sono molto ben accetti, in riferimento sia al contesto di lavoro, quindi il processo e il l'attività, ma anche all'argomento o più in generale. /Tutti: Grazie, grazie.

WS2: 2 May 2024 - Brunel University, London (UK)

[00:00:00] **[Symptom definition]** P10: ...of our naturally condition that of our natural condition of feeling good, and symptoms happen when the balance of health is broken and you have to change your habits. /Researcher: OK, sorry. I just started the recording. I will use the recording just for myself. I mean to. Yes, to go back on data. /P13: There's a backup recording as well. / Researcher: OK. Thank you. /P11: Hello everyone I'm **. I'm from ** too. I work as a service designer and, for me, a symptom is a sort of ring bell that help you to understand something that is going to happen. I see it like this. I think it could be something that is better to listen if it's like tangible or not tangible, but it's not so easy to see, and perceive. Also, in my opinion, as I see it in my language, probably maybe in English is very different. A symptoms is something that can refer to health but also to other topics. So maybe environment or something different. / Others: Oh that's true. /P12: Hello, I'm **, third year PhD student so I think a symptom is something happened when you got sick. And maybe it happened during daily life, but you didn't notice. Is like when you wake up in the morning, you find it's like you got cold and also symptoms come from your voice or your skin or your face. So people will notice it. But it's also come from the inside your body or behind your clothes. People can't see it. /P13: Hi everyone, my name is **. **. And for me symptoms are something unusual and anything that feels outside our day-to-day normal behaviour. I left to find them as symptom. It's... It can refer to a lot of different things, as she said, a lot of things could be internal as well. So I've said a pain. Sometimes it can be blood loss. It can feel tired. Feeling tired of the day it's very different from feeling tired all the time. Certain symptoms could mean many different things. Sometimes you could, it's sometimes it's the way it's going to tell something is happening and you need to pay attention and sometimes it could be a way of feeling better as well. You need to feel symptoms in order to feel better. As as if you have a cold, there's no point in taking a lot of medication. You do need to let your body go through the process, so it could be seen as sometimes your body wants your attention on need to let those symptoms take you. Take the course and that's to say. /P14: Hi, everyone. I'm **. I was very kindly invited to, I guess give my opinion from a professional aspect, as I am doing my PhD on AMR. My definition of symptom is therefore very clinical. It states that physical or mental side effects from your condition that you're facing. / Researcher: OK. Thank you. Thank you again for attending. I think all the time is very surprising that I ask what symptoms is within in the healthcare scenario, but all the times from someone it emerges that might be also something positive, even for like a like healthcare condition, but not only pointing to something that being worse but after like a disease, a sign or anything that you are recovering. That's might be a symptoms as well or something that cannot be seen. OK. Thank you. And so. Based on this definition, this idea we have about symptoms and I would like to ask you now what symptoms do you suffer from and what are the most relevant to define the disease. So in this case we're working on, originally, urinary tract infection that might lead to antibiotic resistance. But in case you have any other information that you want to share, or a condition that you want to share and that are related to intimate healthcare data, please share those. To do this activity, I have a set of labels. **[Symptom labels introduction]** These labels are actually reporting symptoms from the literature or like, the most common symptoms of urine tractive infection. So you might find some of those that are not known based on your experience, your case. As you maybe you find that there are some other that are missing, so there are empty labels so you can write your symptoms on. What I would like to ask you now is like maybe select with all the others, the symptoms that you find more important to define the disease and to speak about your pain and condition in case of the intimate care healthcare data that you have in mind. So, maybe you can start reading some of those and select what might be completely like out of... There are some empty ones, if you needed to add some other symptoms, please feel free to write with pens on the labels. (people moving to take labels and read them, moving labels around ---silence no one is speaking) [00:06:22] **[Symptom description, selection and organisation]** / Participant (not recognizable from recording): What do you want us to do? /Researcher: OK, so the idea is to select some of those that you.. /

Participants: Together? /Researcher: Yes. Together, to let you consider the most representing or like the one you suffered the most in terms of... urinary tract infections. If there is any of these symptoms that you were affected maybe and you feel more difficult to or like stronger let's say to report... /Participants: OK. /Researcher: There are some of those that are really related to urinary tract infection, while some other might be more like a general. / Participants: OK. /P10: Maybe we can put it **[labels]** in this way. /P13: Yeah, we can say that's fair and we can all see it. Yeah. /P11: We both selected incontinence, I don't know if you agree... and discomfort when pee. /P14: I guess that's (unrecognizable word) /P11: Ok. /P10: Yes. / P13: I think that could also be for other symptoms as well and other conditions. /P12: What incontinence mean? /P11: When you... when you need to go to the bathroom and then... Ginevra can explain it (laugh). /P14: Like when you can't control it. P12: I see. Ah ok. (Participant was writing on the wrong side of label so it will not match the shape of the others, so I turned the label to make her writing on the right side). / Researcher: Actually, the label was done with a translation on the back because the set is from the original Swiss activity, where they have three languages. Yeah. So we have a translation on on the back. /P11: I don't know how to say in Italian when you feel like... full. /P13: Bloated/P11: Yeah, exactly. /P9: Yes, you might need this **[a new empty label]**. I don't think there is. I mean, yes. We have swollen. Yeah. /Researcher: OK. But if you, I mean, I think might be good also to have another term in case you might... /P11: Yep. /P13: What would this mean? Do you know anything? Yeah, or it's just side... /Researcher: I would consider some of them **[symptoms]** more general, like side pain. Would you link it to any specific condition or disease? /P13: No, I don't know. I can't think of anything. I'm just just. Yeah, it's to general to link to anything. But OK, yes. Yeah /P14: I guess when the UTI travels upwards to the kidneys... /P13: That's that's right. OK. /P14: So then I guess he's come with a more worsened UTI when you get a temporary. / Researcher: Yeah, because all the times we, I mean very often we talk about cystitis the most. I mean we refer to cystitis the most because it's the most common version of UTI. But yes, those symptoms come also from different urinary tract infections. So it might be the case of... /P14: Yeah. /P11: I got fever once, but it was like infection. I don't. /Researcher: OK. /P13: Temperature seems to come a couple of times now. /Researcher: Maybe just consider the other side of the label, sorry, because otherwise we cannot match with the others... but it's not bad. You can just write on the other side. OK, so for example others as cloudy urine or vomiting. /Participants: Yeah. / Researcher: ...unable to empty your bladder fully or lower back pain are not like... so important?/ P13: Yeah. /Researcher: OK, those are the main. So we have incontinence and need for [noise], bloody urine, swelling stomach and fever. /P14: Bloody urine is the first sign...That's one of the first signs. /Researcher: OK, OK. But have you ever? /P13: You need to clarify... I think that information that we get generally, whether are we collecting symptoms that we feel... / Researcher: I will keep the focus on the symptoms that you have felt and what is good from your side to provide feedback and for example, I didn't know that cloudy urine is the one of the first symptoms, but if you never experienced that, I would not consider it for the activity to be honest, maybe it's something that it's really... let's say important from expert point of view and people just don't, or maybe don't even know, because if it is one of the first sign would be good to to know, but they don't. So in case of like even knowing that might be good for occasion of the disease happening, maybe. OK, so now I think we can like just remove or put back those labels that you did not consider. And focus on those at the center. (noise of people moving labels on the table) /P9: Do you want us to take a photo? /Researcher: Yes, I mean, I am taking some, but I would avoid to have face... but maybe like their activity or other stuff, I will, I will keep that. Yeah. OK. /Researcher: And so... then the focus of the activity is to Shape Your Symptoms. So once we have clarified what symptoms are for us or what we do consider symptoms and we have tried to focus on what might be more relevant for us... I don't know if you have any feedback on the symptoms selected or you want to share anything. I mean just as a personal opinion of the symptoms selected or... [00:14:18] /P14: It looks like they've been ordered in when they first occur and then down here is when it gets more severe, which is really interesting because those are the ones that you went to first, which means that you guys are experiencing things in the and treating them

and noticing them before it gets to the point where it's your experience with shivering and everything, which is really great. /Researcher: OK. /P9: I've never have this kind of... illness, but many of these are very similar to other things that I've experienced before. For example, after I gave birth, I have nearly all (laugh) /Researcher: Yeah, it's something that I was discussing with Arthi before because we were saying, even if you haven't never experienced UTI, many of those symptoms are really like quite common for women in general. Yes. So it's not only related to to UTI, but more about... female feeling of like body sometimes. /Participants: Yeah. / Researcher: So thank you and the idea is to now trying to make them more tangible. So we said that sometimes symptoms are visible but sometimes are not even visible. So it is to trying to make them completely visible, maybe even more visible than visible, like physically existing through the help of some materials, so physical material to create some what they call artefacts, based on your experience and your data of the experience. How to do that, I took some inspiration and some ideas from this method called data physicalization. So the idea of making data physical. [00:20:21] **[Introduction to materials]** /Researcher: I prepared the materials there already, but I have some labels. Yeah, I have some labels so would be maybe nice if you wanted to assign the labels to all the group of materials so you can start also exploring those materials and see what is available, how maybe you can then use it or or not. I mean I don't want to assign let's say. If you have like a couple of labels and then you can... You can go there and... Touch and move materials... I mean I tried to organise it as everyone can access it. Yeah, but then we were saying there are more chairs than space. So it's not so easy. /Researcher: So there should be one label for each of the group of material, which should report material first and then shape, and the size. I put the spheres in little bags just because otherwise they would not stop to go around... (laugh). /Researcher: Foam and polyesther. /P10: Ahhh... /P13: This is foam? / Researcher: Oh, OK. I didn't know this is considered foam (what is called polystyrene on the label), but I can see that this might be considered foam as well. I didn't consider it because I translated from Italian, and that's polyester and the other I would call it "schiuma". /P10: "Polistirolo" /P11: Polyester is general plastic. /Researcher: That's my fault. I am sorry. **[Physical variable identification]** /Participant: I consider this foam /Others: Yeah! /Researcher: So, how do you call the other? /P11: Spongy thing... (laugh) /Researcher: You can touch them to see. /P9: Can I touch how it feels? Oh really softly... /Researcher: Hey, I mean, I prepared some of those. It was not easy to find all of the available things. What I would ask now is that... The idea of like material property. So I think you can go back to your seat and we will be back to the material later. So the idea of introducing the material is to also introduce the idea variables. Those properties of materials that can be used to translate somehow you're feeling your experience, your symptoms into something tangible. As you've seen from the kit, I focus on the shape, dimension and the material of the units, but there are actually many other properties that can be used and are already in the units that are on the table and that you can take advantage of when trying to describe and represent your symptoms, such as the orientation of the material or even the position, the texture or the way that are kind of secondary elements that still can be useful to define some important information that you might want to communicate, so try to focus on the on the material and you are absolutely free and more than welcome to come back to the kit, I have prepared an other set of label, this time reporting physical variables. And and I would ask you this time to go through these labels and you did already with the other set but select the variables or in general what are material properties that you see in those materials. So for example, here we have movement, brightness, viscosity and many others that I leave to you. So is there any of those that you find in the materials? So please select them while discharge the one that you think might not be associated with the materials that we have there. /P13: Are we linking with this or are we... /Researcher: Not now I would now focus on selecting the one that you might find in the material and then later on work with it /Participants: Ok /P9: It is colour... and weight. Maybe the roughness. Mm hmm. / Participants: Size. Movement? /Others: Could be, mmm ya. /P13: I don't see this yet, but I'm feeling this is very important /P9: Definitely. Interesting. /P10: Orientation... /P11: Texture / Participants: Yeah. Yeah, yeah, yeah, yeah, actually, yeah. /P9: Orientation... 3-D form...?/

P13: I am not sure. /Researcher: That [3-D form] describes... It's similar to shape, but not like... cube is a cube. If you consider the contour... it is considered the line or external line that you see of the shapes. So even if that's a cube, it might be different because like 3D shape, make it different so. Maybe is something extra that you might consider once you start assembling... / Participants: mm hmm. /Researcher: It's not just a cube or anything else, but maybe something longer or something like different and unique. / P13: Yeah, the position here, yeah. /P9: So are we having this as part or?/P11: I would add it. /P9: Viscosity /P13: Yeah /Researcher: And there are some empty label as well as before. So if you like, uh, perceived or want to touch the material again to see. Yeah, if there are any feelings or perceptions or a future of the units that might be useful. /P13: I think the contour is quite interesting. I don't know if that's consciously made, but especially if you cut the polyester in an angle, it exposes a lot of contours. That's others have a very smooth finish and they have a contour which would be interesting to express certain symptoms in, yeah. /Participants: Yeah. / Researcher: I mean, that doesn't mean that you have to use it. Let's say later on, so just about the the way you might consider translating, let's say, your symptoms. OK? /P11: Yep, I don't know how to say it in English, but maybe something that... "durabilità" [Italian] /Researcher: Ok, so how long... durability? /P9: Yeah yeah! /Researcher: How long it might persist, existing. No, I think you can write it down here. Yes. /P12: We include a temperature, so different materials... / Participants: Yeah! Yeah! That's very good. /P12: Someone are cold and some others are not. Researcher: OK, OK, good. So we might remove all the others if they do not work. Thank you. (People moving labels) [00:30:10] **[Symptom-physical variable association]** /Researcher: And what I would ask now is to actually trying to associate them so it doesn't have to be one to one, but you might consider different variables for symptoms and kind of not justify but explaining how and why would you associate like some of those feeling and symptoms with specific material futures and variables. / Researcher: So I would suggest maybe start with the first symptoms that you selected and see if there are... based on your feeling, because this is not like there is not any right or wrong answer, what would you associate in terms of material futures. /P10: ...like "Need to pee" with "timing"? /Participants: Ah [laugh] that's true. /P14: Temperature and fever? /Participants: Yeah, yeah, yeah. /P13: Does it link (referring to the labels)? /P11: Yes, need to be with timing you said. /P11: How long... (not recognizable)? / Participants: Yes, could be. /P9: Let's be together and. /P14: I am not sure I totally understood this one but... [not recognizable] with swollen stomach?/P11: Yeah, could be. /P11: And maybe also incontinence with... timing /P9: mmm /P11: I do this [putting labels one closer to the other, as two symptoms have been associated with the same variable] /P9: Would it go with size at all... or... /P13: I think size, might be good, yeah. Sometimes is how you feel as well... /P10: Also (not recognizable) ... what do you think? /P9: Or might it be the roughness? /Researcher: Is there anything that might be helpful for you, maybe trying to describe the... the feeling maybe you think about how would you describe the feeling? /P13: Yeah. I think for me, definitely the textures would associated with the pain. /P11: It's comforting and [not recognisible] /P10: Maybe pain... Something that you can... /P14: Orientation as well /P11: Also cramping, maybe / Researcher: I mean you do not have to find the combination. If you have more than one that, even if you have different opinion... /P9: ...with emotions? (undistinguished chatting – very low voice) /P13: To emphasize the significance./ Researcher: There are some of those that I remember were quite similar, like... Discomfort when peeing. Yes. And when peeing with that might be a different level of weight. No. Mm hmm. Maybe starting with discomfort and then going to pain. /P9: Yeah, they go together. /P11: Durability and [not recognised] because... / Researcher: Or even maybe something new that you now consider as the symptom of, like, maybe how long? Yeah, because how long it last... /P9: Exactly. /P10: Or something that causes pain /P11: Or cramping /Researcher: I mean, we can add /P11: Or incontinence or cramping... I think it's like this is because you have something that is really fast and then go away and something is like long-lasting. /Researcher: Do we have cramping. Would you like to add it or? Yeah, you want it? Yes. /P9: Is it not in there? /P13: Or maybe is it? Yeah. /Researcher: I mean, we can even reconsider some of those. (checking labels to see if cramping is already available or not) / Researcher: I do not think so. No. Lower

abdomen. /P9: I think we can move that there, yeah. [00:40:23] **[New symptoms]** /P9: Because at the moment all the symptom, are the physical ones. Do you want me to think about the mental one too? As I mentioned when I gave birth, I have a lot of these and it's almost like you feel anxious. /Researcher: Ok /P9: Every time you have to go to the toilet because you've been experienced again. OK? You don't like it, OK, every time you kind of, as long as you can prolong it. Yeah. It would be better. Yeah. You almost like consciously kind of. I don't know. I don't think fear is quite the word, but probably anxious. /Researcher: Yeah. And that's very good, actually. And we might add it as symptoms. And this is very helpful in terms of like, understanding from the bottom, let's say what people really perceive related to the disease in general. Because again, as I said at the very beginning, those are from literature. So there are a list of symptoms but the fact that those psychological feeling are not considered from associated with this kind of symptoms is relevant as well. So I think, I mean, some other kind of literature for sure will speak about the psychological symptoms, but would be very useful, I think if we consider them also to open up the idea, the perspective on what symptoms are and what might be useful for mentioning them. /P9: mm yeah. /P13: Does it belong to...(not recognizable) /P9: I am wondering if it is something to do with that. Because it's almost like you anticP10ate the pain that come with it, ok. It feel like dropping so on the wound. /P13: Does it not sound very pleasant. /Researcher: Yeah, I mean, I don't know if you have like. Wanted to start from one specific symptoms that you have in mind and start exploring the material and collect units to to try to to represent. /P13: How long do we have? / Researcher: I would say like 20 minutes or less, 20/25 minutes it depends if you need more time or not. (P9 leaves for another meeting and will come back later) [00:44:30] **[Shaping]** Researcher: I mean, the vocabulary wants to help you, let's say, but doesn't have to be followed to produce something that has to be the same for all of you, yeah. /P14: We just link them back? /Researcher: I would say everyone build their own based on the personal experience. [00:54:11] **[While participants are working to the Shaping, the Researcher ask some questions to P14 who is the medical expert]** Researcher: I don't know if you have any personal experience in this direction, otherwise if you want to share someone else's story or maybe from a medical perspective how these symptoms relate to each other. /P14: You mean related to AMR? / Researcher: Yes. In case of like, I mean the reason for introducing AMR at the beginning and then yeah of working on the UTI is because it's one of the main diseases that we can lead to AMR and also the fact that sometimes in many specific cases (not recognizable). Researcher: Would you ask them (patients) to report any specific information? Imagine to ask people suffering from or reporting any of these diseases, would you ask them any specific question or data or information to report to you? In case you need them to prescribe or decide to prescribe an antibiotic or not. /Researcher (to the expert P14): Would you ask them (patients) to report any specific information? Imagine to ask people suffering from or reporting any of these diseases, would you ask them any specific question or data or information to report to you? In case you need them to prescribe or decide to prescribe an antibiotic or not. /P14: So that's not my field, but I have some knowledge on it in terms of the first time experience and experience with people. So what they tend to go by is, where they first ask your basic symptoms and run through your list. So fever, temperature, all these things, and then they kind of go backwards to what we did. So how we started. Whether you have like bloody urine, et cetera. They start with temperature, shivering, because those are the key indicators for infection and then require immediate action. And I guess the knowledge that you're providing in this whole workshop where you're able to, if the button is and key information we want to say and how to communicate these symptoms of what would take the diagnosis from, OK, you need antibiotics to OK, maybe you need to treat these other symptoms, etc. /Researcher: I would say 5 minutes and then we can start sharing with some of you. /P9: I will be back in half an hour. Yeah. /Researcher: Maybe you want to share with others [your artefact before leaving] and if others need 5 need 5 minutes extra they can keep going with their work after your presentation. / P9: Yes. So, I have tried to have all the, kind of triangle shapes because I'm trying to avoid any sphere, I feel like when it's smooth surface, it doesn't quite explain the pain. I prefer the sharp

edge as the way to describe all these sharp edge that I feel. I would like to create something asymmetric. Anything relatively unstable, still too stable for me [laugh]. But it's kind of trying to explain that it's not safe or stable. It's this feeling anxious and you know, kind of feel scared every time you go to the bathroom. I used the wood rather than other the material because I feel like it's quite heavy and it does suggest this pain, I guess, that is quite important. It is quite significant for me, but I don't want it to be all one material because, the feeling is different and it's by having a mixed material it does make it feel like yes, it's more complex than just, you know, like the same all the time. I try to avoid anything that relatively smooth. OK, so that's why it end up looking like this. Yeah, OK. / Researcher: And is there, if I might ask, as you were mentioning before some psychological feelings. Is then something that you find in your artefact at the end that might refer to not physical condition but psychological conditions? /P9: I think when we start talking about the material, you know when we start talking about the roughness and stuff like that and it's not just the roughness from the physical side of things, it's roughness from the mental side of things too. So actually talk about it. That's give me an idea of, you know, the mental side of things, because if you remember when I described the symptom, it's very simple. I just think about how the body reacts to it. I didn't think about psychological things like the other, and I feel like, oh, that's really important too, you know? OK. /Researcher: Yeah. OK. Thank you. Thank you. If you would like I would say 5 extra minutes. It's like 28, let's say 35. We wrap up and everyone will describe the artefacts. (Silence, everyone works on the artifact) [01:05:13] **[Artefact presentations]** /Researcher: OK, if you have done, I would maybe ask you to present your artifact, sharing your experiences. So use the artefact to tell your story. Maybe you can close the session, let's say if you have any feedback on how people report the symptoms or even describe the symptoms or any other things you observed during the activity would be, I think, nice to hear. Anyone wants to start? /P11: Ok, let me take my notes. I've tried to represent my experience. I start from below. In my case, in my experience is such a journey. So I start from the lower part. Still... something that is ok to manage still OK to manage as symptoms, so kind of discomfort but not so high. And while going up is a kind of climax, so I also add material that is more solid, but also something that in terms of size and edges and also weight is higher. I added also these spheres, smaller ones, because I'm thinking something also that is not stable. I wanted it not stable because you don't know where this is going to go. So you start from some discomfort and then you don't know if it's going to go away or transforming into something else. And also because in my journey it depends if I'm going to call the doctor or if I manage by myself or maybe it depends on the kind of multiple direction, because it can be like horizontal. And actually I choose this material because it's something that you can destroy with your hand. So it's kind of something that you could spread, but it's not going away. So when I got the cystitis, maybe it's going to go back and you never know like plastic... that you cannot cancel it. And going up, I added a cube made of wood because I wanted also to represent the weight or something that is going to be worst. So like burning or the sensation that you will feel maybe tired. And you feel like that is not going away. So it's getting worse and also the sensation to... we said oh, sorry. We said "bloded", so I added this. I added this just because it has multP1ole edges there. So it's getting worse and then the last one, that happened in my case just once, that it's fever. So it becomes infection and I tried to represent with this I think I need it more like because it was really, really painful and it's not stable because you never know that is the going to going to go away or getting worse also depending on the doctor, because if you not find the doctor right away and you don't get the antibiotics. In my case, you have to wait and it's getting worse. But yeah, it was difficult to represent all the symptoms in one. Sorry, I got you confused [eheh] but yeah, this is my view. / Researcher: Thank you. And maybe you're gonna go next. /P12: Yes, I want to share the only one experience before when I had the UTI problem. But at that time I was just 22 years old and I was at university. I didn't go to see the doctors. I just searched some information on wP11site and tried to buy some medicines from pharmacy. I bought around two to three kind of medicines and tried different one during two or three days, but I'm very I was very lucky. After that the the symptom is disappear. So my model is look like the symptom is inside your body. So you can't

feel it. It's it's like a when I go to university no one know I have this problem but I know it and I suffer from it. If you have the good or right treatment you'll have a good body. But if you didn't take the right medicine maybe you will have the long time problem and you will got seek. So that's why I'm going to become like this. And I also want to mention the education for girls. If the girl can't know enough knowledge from the schools, and if their parents didn't tell them enough knowledge is very normal for girl to feel very scared and stressful when they face this problem. If they search the information online if they search the right information is fine. If they didn't search, search the good information, they will most scared about it and they will feel, oh, I'm nearly to die. Why? Why I have this problem and If you have a older sister or some or some sister-in-law, maybe you can ask advice. But if you only tell and if you have nothing you can ask is it will become more stressful. I think this is my feelings. /Researcher: OK. That's very interesting. The fact also to where to look for information. So you said that difficult to reach the doctor, you mentioned Internet that you really say all the times that you're gonna die. You always like to feel you have all the things you read, and then nothing like properly to fix the problem. But having as you said, I mean you mentioned the sister or sister-in-law or I don't know if you, I mean also like pharmacist usually are very good in giving you feedback but of course you have to... talk with them, exactly. So it's not sometimes not so easy. /P12: I think it is hard to open your mouth to talk about it, especially with strangers or with doctors or with your parents. If you have a sister, it's better. /P13: I think even in the UK, the first point of contact is pharmacists. Yeah, I think when I had it, the pharmacist gave me medication. It went away in what? Maybe like a week or so. A few days anyway. So I didn't have to go to the doctor. It's always useful first before to go to doctors. In the end it always make the things worst [referring to looking for info online]. They only talk about things that tend to be bad. Yeah. You're going to die… /Others: Yeah (laugh) /Researcher: OK. Thank you. Next, you wanna go? You can go. /P10: I can go. Ok. I had one time cystitis, so I had one experience. I started with the cube, the wood cube to represent the weigh so the pain of peeing and I associate the ball [sphere] for timing, so the urgency to go to the bathroom, so it is biggest one. And the time that is not that urgent, it's happened the time that the feeling advanced it went away, so it didn't become a cystitis. It's out, but I have also put over the ball so, the idea of the need of peeing, the triangle to represent the anxious. So the pattern and the texture, because when you need to pee, sometimes you just start to be anxious because you don't want to feel the pain. I've also associated the wood for the pain in general, so there's more cube is for durability for suffering of cramping and the triangle is also for lower abdominal cramp. Also the orientation and the position that all the angles of the triangle can represent the pain of the situation. That's it. /Researcher: Alright. /P14: Mine is the simplest. It's just to represent both sides in terms of both extremes, so I've got the small polyester ball, which is my representing the lighter symptoms. So the first symptoms that you get, first symptoms that you notice and then symptoms that you treat yourself, and then I've used the short wooden peg to join the two, because going from these light symptoms to going to worse ones can happen in a matter of hours. So it's a very short bridge between the two. And also on the positive side of that, it can take a very short amount of time to get better. For example, there's a three day antibiotic course that you can take now. Which happens when you get the worst symptoms. And then the worst symptoms of represented by the big wooden sphere. And this is the more serious symptoms, fever, et cetera, that require more medical attention so antibiotics. /Researcher: Ok, Thank you once again. Do you want to share? /P13: Yes, yes sure. Just did not want to bias... yeah. Right. So I did have UTI but I chose not to show that just because one of the most painful experience of my life - having said that, I've never had a child before, so I'm sure that's more painful than what I'm describing now - was when I was given Mirena coil (IUS) because I had severe Polycystic ovary syndrome - PCOS [a very common hormone problem for women of childbearing age. Women with PCOS may not ovulate, have high levels of androgens, and have many small cysts on the ovaries. PCOS can cause missed or irregular menstrual periods, excess hair growth, acne, infertility, and weight gain]. So the GP is suggested as a way of controlling the [not recognizable] because maybe can very severe [not recognizable]. So the coil was one

like one of the thing that she [not recognizable]. But when I did have it, I had the most excruciating pain for three weeks and that went on and off, probably like every hour or every two minutes. You can never tell when it comes and how it goes. When it comes the pain, lasts for about somewhere between 10 seconds to 20 seconds. So it's always that anxious as ** (other participants) was saying, you don't know when is going to come, but when it happens I can't do anything. I have to stop what I do, crawl into this little baby position and just hold for it to go back. And this is kind of affecting a lot including my work because I'm standing and giving a lecture and if I get these twenty seconds of unbearable pain, what do I do? So it's a constant anxiousness and fear as well. So I kind of bookended this with like slightly different to what you are doing. So this [the artefact] for me represents normality. Because after 10 or 15 seconds, just feels the frustrating part is just goes away and it keeps as if nothing has ever happened and everything feels so normal. Like, why is this happening? So this this for me, it represents normality and a lot of kind of shapes and as others have said as well, I wanted to show the sharp edges around the (not recognizable) and represent the severity of the pain and little pegs... I wanted to do more about how (I was infect – not sure)... but it's kind of show that the sharp edges around (not recognisable). Yes, that was sort of my mostly representation of what? Around the the use of texture and patterns and aching, sub abdominal cramps. It didn't feel like cramp. It wasn't cramp. It definitely felt more painful than that. I've had cramps in the past, but that wasn't cramps. Yeah. So I think it was definitely kind of more in representation of the pain, abdominal pain. But I'm trying to play around with the textures to show it. /Researcher: OK. Thank you. So first of all, thank you all of you to speak about this kind of stuff, because I suppose, I mean, imagine that it's not easy also to try to make them understandable from for others. I would not like to invite you if you have any feedback or general comments on what emerged during the activity, even from like the experiences... /P14: The most it is what I was repeating to you before but... Even for me, when I came in and saw that we will label them on severity, it was really interesting to see how most of the symptoms are generalized to other things. But from a clinical point of view, that's not going to help in your diagnosis. So I guess identifying the first symptoms and knowing what to do when you treat yourself one not only simply from going down and regret gets worse. Where you potentially need antibiotic intervention should be a whole can of worms. Leading to resistance and everything but to... because you're able to deal with it yourself, you're even able to overcome it yourself and get rid of this old dread of when it first comes on, oh I have to deal with this, etcetera. So it's a big mental wave on your shoulders. But from this whole workshop it's really great because you're able to identify the symptoms and actually realize that, yeah, this is actually normal. I know I'm sort of doing this kind of thing. /Researcher: OK, OK. OK. I don't know if what other of you have any like comments. Please feel free. Otherwise I will leave you 5 minutes if you want to fill in this little cloth that will help me in having feedback on the activity even on materials themselves, because actually this was the second session, the first for the first session I used raw material that say so there was no pegs, there was no holes in the units. This time I tried to facilitate, let's say the assembles of the units, but maybe you can tell that were better to have like raw materials and I think might be also interesting. I mean next step I would like to explore different materials. So if there are other materials that you might suggest in term of familiarity or in term of even feeling no, because these are different materials in terms of weight and texture, but I think different way than texture can be found in other different material. For example working with fabric or other stuff. So even if when you think about your symptoms having mind or even next days might feel or touch any other shape materials or see other stuff that you would think like oh, I would use this instead. Or this really remind me that feeling. I'm happy to to have feedback about it, yeah. /P10: No, that's like... when I was building this, I have like I needed a connection from two different sides but I couldn't... like something more. Yes, flexible that can connect different situations. /Researcher: Yes, they are not like straight, yes, but still needs to be somehow linked to each other. /P10: Yeah, maybe I was needed to connect this two pieces but it was difficult. /Researcher: Yes there was no way to do that. Ok that's very useful actually. /P11: I was thinking that maybe she said about the lengthiness of this one. Hmm, if you like,

representing in a linear way or something. That's like ** (other participant) says. Like, maybe you have some symptoms. If it were like connection that can be another dimension to say something. /Researcher: Yeah, or even to connect, yes. Or make relation between different feelings or symptoms. /P11: And also, but maybe this is just my opinion, you use like material that is completely not like the surface is like not transparent. So you see like we have pattern or texture but then, as I see there are symptoms that maybe are common or sharable with some other kind of illness, or disease. But then when you know if it's like urinary infection and when is something else? Maybe it is the first time? You don't know, so something maybe can be quite difficult, like a bottle of water made of plastic, you can see and then you know yourself because maybe it happened 10 times, so you learnt how your body works so you know how you like how to treat yourself, by yourself or you need to go to the doctor. But if it is the first time it is something that you don't know at the beginning. So maybe it's good here in case. /Researcher: OK, thank you. OK, thank you all. /P13: I think I think for me was the colours, very important. I mean I would have brighter colours could have probably meant something for people as well. And again this is might be by my subjective opinion here, so some things like play doh, might be very interesting because it's something very moldable and you can moudle into something. Yeah, it doesn't have to be. Don't have to be sculpture or not sort of designers do it, but something that can again shows the different symptoms that you are going though. / Researcher: Yeah, you are more free in expressing yourself on one hand, on the other sometimes it go on, skills, I mean, it's like in between, but with play doh everyone should be able to do something. No, you're not the request to… /P13: Yeah, a bit more common and I just like the translucent, transparent kind of flavor, the materials as well, so that would have a different meaning to. /Researcher: Yeah, I think with play doh you then go back to the decoding phase, which is still not possible here. I mean if you work on units and then try to associate the units to a specific meaning, then in theory reading the artefact that should be able to link the ideals spheres the idea of triangle et cetera. But probably if you, I mean probably you can do with play doh as well, but you need to create classes of shapes let's say. But yes, I would like to explore play doh as well. /P13: Yeah, something to we can we can talk about that.

WS3: 24 May 2024 - SUPSI, Mendrisio (Switzerland)

[0:20:24] **[Symptom definition]** P17: Ok, so, I am ** (name), my definition is very long, while I was waiting for you… so, what I wrote is a symptom is a sign - I tried to find the word for that. This term is mostly used to talk about medical conditions, for example, if you have a cold as signs or symptom of, that can be a running nose or a cough. It's a clue to understand the problem, and usually a combination of signs correspond to a specific medical condition. / Researcher: OK. /Others: Wow (laugh) /P15: I am ** (name).. I wrote that symptom is an effect that the disorder has on your well being. It is a feeling that makes you think that something is wrong with your health. /P16: I am ** (name).. I wrote the a symptom is a common experience that one feels when not feeling well. This experience could pain, sore numbness, or any kind of uncomfort discomfort in the body. /Researcher: Ok, so you said "common", so, like something that make people understand like a common point of view or share, recognise, let's say the the feeling. /P20: I said symptoms can be what you feel and experience as a result of illness. /P18: I wrote the symptom is very uncomfortable feeling, sometimes painful feeling in some organs or part of my body. It might be itching, pain or this discharge. /Researcher: Ok, I missed your name /P18: ** (name). My name is ** (name). /P19: And I'm **. So for me as symptom is something that I feel or have and that makes me feel that I'm not in my usual normal state and symptoms can have a negative or or something positive effect on me. /Researcher: OK, so it's interesting because all of you put it in like in the negative sphere, you mentioned the positive one. So something not like strictly related maybe with the healthcare it might be no? Do you see symptoms that might be also something assigned as you mentioned of and if you were positive… like? Maybe because here we're talking about healthcare, so… /P18: Symptoms of pregnancy. /Researcher: Yes, for example, so something not related with the diseases /P19: Also maybe when we drink alcohol, we feel more… /Researcher: Yeah (laugh)

/P19: Not in our usual state, but it's not… / Researcher: Ok ok, it's always and nice to hear the first like run of definition of symptoms because it's always emerges something like interesting that is really related with the personal ideas, of course the context where we are affects a lot the the definition that everyone provide, but there is always like a word or a different interpretation of the way people perceive symptoms. **[Symptom identification]** Researcher: Ok, so now I have this set of label which reports the most common symptoms, they were built on bacteria infections, but what emerged, and in confrontation with the expert as well, is that they are kind of common symptoms to most of the infections in women. But you might find that something is missing, for example and so, what I would like to ask you now is to identify symptoms that are more relevant in your opinion based on your experience. This is a common activity, a group activity. So I ask you maybe to point to the symptoms that are more relevant and maybe justify how they were relevant for you, why you mentioned the symptoms. If you cannot find anything that is here, we have like empty labels, so you can just use them to add the symptoms that are missing and then at the end when you have all the symptoms that are relevant to you, I will ask you and list them from the most relevant to the one that maybe you sometimes perceive or that are not so important or like serious when you experience the disease. I don't know if some of you want to start reading the labels, while putting them on the table, which I think might be helpful to start understanding which kind of symptoms we have here. Thank you. I remove stuff from the table. /P18: I need a translator. / Researcher: There are actually on the back we have Italian, French and German (laugh) /P18: Thank you so much that thank you so much. / Researcher: I'm sorry, but because we are basing Switzerland, there are already a lot of languages and I know, I mean you can use the phone of course. And if you actually want, I can look for post it and then if you want to add the post it on on the on the label as well, maybe it is useful. / P20: Are these symptoms related only to UTIs or just general symptoms? /Researcher: No, I started collecting them from the literature and speaking with expert related to UTI, but then during the last workshop I had London, there was this person who is doing a PhD on urinary tract infection and antibiotic resistance, so very like close to my topic and what she was saying is that the these kind of symptoms are usually the ones that are common within infection diseases. /Participants: Ah, ok. /Researcher: And so, this is the point where I started considering to open the topic a little, so also to understand and then define which kind of antimicrobials should be prescribed instead of like going with like general ones or wrong ones which again increase the chances of of resistance. But, as I said, it is something that maybe is not here maybe because you mentioned in your story a specific infection which is not so common as the others that have been considered before, so, I am happy if you actually, I have others [labels] so if you actually bring on the table different kind of symptoms. For example, here we have hatching, I read in English and then up to you if you want to flip them as you prefer, then we have foul smelling urine, vomiting, need to pee, incontinence… /P17: We need to classify them according to what's most important for us to communicate to the doctor or… /Researcher: Yes, yes, based on like your experience or the feeling in general you have… Shivering. Then we have a swollen stomach. Pain when peeing. Disconcert when peeing, so some of them are like different shadows of maybe the same kind of feeling. But as I said, I leave to you say maybe like discharging some and say this is more relevant, or I never felt any discomfort, but it was definitely pain, for example. This is why I bring them on the table and try to start a conversation on symptoms first. Then we have bloody urine, cloudy urine, lower abdomen cramping. Side pain. Then we have lower back pain. Inability to empty the bladder fully. Nausea, pressure in the groin. Low temperature below 36 degrees, and tiredness. So I just leave you some minutes if you want to flip them to read the translation or just start thinking about the symptoms, you perceive, and then maybe we can start listing them if anyone want to share what's maybe the first one that identified as the most relevant or even the less relevant, maybe saying like this is definitely nothing important in my opinion. /P20: So I I just want to clarify one more time like, are we considering symptoms within like urinary tract infections or / Researcher: like general infection/P20: or also other diseases? /Researcher: I would keep the focus on intimate infections. So not like I would

say, if not vaginal infections, but maybe like for example urinary tract infections are not strictly related to vagina, but it also affect like and is related to intimate healthcare and intimate parts of the body. /Participants: Sure /Researcher: I would keep the focus there, it is more or less the related to the introduction I gave at the beginning, so it might be for example like Candida, it might be cystitis which is a UTI, but from the previous workshop we had someone who experienced infection after giving birth. So that's not recurring, that is not because of any disease, but was more than specific occasion when she this person felt similar symptoms and similar problems. I mean, I didn't read your story, but I read from your when you sign in that many of you had experiences of at least one of your urinary tract infections or any kind of intimate infection. Right? (Particiapnts: mmm (Yes) [00:31:33] **[Symptoms organisation]** / Researcher: Ok, so maybe we can we can start from there. /P15: This would be the first for me [referring to a label and symptom] /Others: Umm. /P19: Yes, also vomiting, if you don't know why, it's really no… I would say also near this one…/P17: This one? /P19: Yeah. /P20: For me, aching was like the first thing, with the like kidney and here, lowe abdomen cramping I guess. /Others: Yeah. /P20: So here, they come together. /Researcher: You put them [the labels] on the same line… /P17: When you need to pee, a lot… I don't understand this. /P18: It feels like I think it's an enabler for anything you can not empty your bladder fully you like always, always want… /Others: Ahh /P18: And you and it's usually it's outside pain /P20: Ah discomfort when peeing and pain when peeing. I guess this is more severe and then maybe this is more like… /P19: I was saying… this one is also and. / P17: Sorry again because I miss a part which you told me. What do we need to do? /Researcher: I ask you just to like select the ones you felt within your experience with history and the beginning. If there are any like specific symptoms that are relevant… and discharge what is not relevant or maybe what you never have the feeling of… And then if you have any other which are not there, because maybe you say I also have this feeling or this symptoms which is maybe not there… /P18: Where is panic attack? I mean… /Others: yeah, yeah (laugh) /P20: Write it down. /Researcher: Yeah, that's a good, very good point /P18: Because like usually ohh my goodness, what happen? Should I, maybe… (participant feel uncomfortable in writing on the label and look for a post it or paper where to write the symptom and then attach on the label) / Researcher: If you wanna put stickers on the labels as well /P18: It is not make it dirty… / Researcher: But you can, do not worry. /P16: Do we have to use all? /Researcher: No. This is what I was saying if there are some of them that you don't feel or you never experienced or even like experience but was very marginal in your opinion just do not take them. /P17: What is this for? /Researcher: Umm, that's the lower… let me check for you, we can… /P16: That could be misleading guys /P19: Even in French, we don't understand. We don't know. (participants look for picture on their phone to understand what part of the body the symptom refers to – goring) /P20: This is the groing. /P16: You know when you guys say the kick in the groin, but you say you got kicked in the groin? So that's the groin. It is there basically. /Others: Ok /P20: For me, I don't experience all of this. Not all of them, I mean only in certain parts. /Some other participants: Mee too /Researcher: Ok. Is there anything like specifically that you would pick up [remove] from here? /P20: Pick up? /Researcher: Like select and say these are the… what is relevant or like… /P20: Based on my experience it was like aching and like I felt it was swollen, my kidney and my bladder was swollen. So I was walking like this, Ok? And that was like the biggest and I guess that like relates to like… / Researcher: So is that the swollen stomach or is there any any other part instead of stomach that you would add on the label? /P20: It feels like my bladder and my kidney is swollen. /Researcher: Ok. Would you like to add it? Maybe. /P20: Yeah, sure /Researcher: But just go on the label, do not worry /P20: I am very worried. /Researcher: I mean, if you prefer the post it /P18: We can save it /Researcher: I mean, I mean, they are to be written, but this is a problem of design actually because it happened already. And what they were saying is that if you design a kit for people to be used, the people have to, like, feel they can use it. No? But it's not so polished, guys. /P17: Yeah, but for us… /Researcher: Because you know you know what that means to prepare it. That's probably because of like sharing pain in preparing material, no? /P18: I do not feel that all of these symptoms are related to my experience. /Researcher: Ok. I mean the idea of having this

parts like participatory, so having one label kit only and discuss around it is also to try to ask you to not justify as you have to justify to someone but ask you to provide details and explaining more than justify why you are selecting some of those instead of others. So to have a conversation and maybe trying to improve the list as she was saying with her specific ones or understand how they can affect like your life in general. So maybe if you also have question about experience of others are more than welcome. Sorry, you were referring to UTI, right? /P20: Yes /Researcher: Ok. And if you want to answer, if you suffer from UTI like chronically, or was just once or twice in your life /P20: Once, maybe twice, but I'm only referring to like the most severe ones /Researcher: Yeah. Ok, ok. And you were saying as well that you don't experience all these symptoms, would you like to select some of those and say why they are the most relevant for you? /P18: Yes. For example, like according to my experience, can I share it or not? /Researcher: Yeah, sure. /P18: For example, I have like weak urinary system and the cystitis is like super classical disease for me, like at least once per year I will I will have it and usually what I have is like pain when peeing, number one, pain when peeing and then. Where is it? [She is looking for a label with a specific symptom] Yes, of course, because like first question, Ok, I have to work. I have to work and like the whole day is crashed. So this one like you have I have to, but it's so right now it's super rear because I have first aid kit with me always like I know how to deal with it without drags. / Researcher: You have to use with you, sorry? / P18: I have a first aid package. /Researcher: Ok Ok /P18: I know how to fix it. I usually have one or, so antibiotics with me. /Researcher: Ok, so when you have first symptoms, you just start taking antibiotics. /P18: I mean before of course I will call my doctor like and try to avoid using antibiotics because I know some like traditional way, maybe like to make like to heat the place. Maybe it's just because I sit on the cold. Because usually it's having, like you sit on the cold stone, tomorrow, just for sure laugh) /P18: Like wait and wait for tomorrow. You'll be surprised in the morning. /Researcher: Ok, so you know /P18: Unable to empty your bladder fully. Umm, it's like the most and need to pee. You cannot leave the the restroom. /Researcher: And does this… I mean, as I said at the beginning, you can answer question you want if you don't want to answer like specific questions, just don't worry. Is there any umm, I forgot the question. Sorry I forgot what I was going to say, what I was going to ask. / P17: I'm going to understand is why this one is so important. /P20: Aching? /P17: Aching, oh, maybe no, I mix it up with itching./Others: Nooo /P20: Aching is something is paining. Yeah, like you know when someone say you're backaches, you know, you know that kind of. /P17: Ok, thank you /P20: Yeah, I I've been taking pictures of what we're doing so that we can share it back to our group. /Researcher: Yeah, sure. It's OK. Yeah. I am taking picture as well with I will use it within my research so none of you will be recognizable. Just to like report about the the activities. Ok, yes, I remember now the question, sorry, if any of those symptoms affect your day. You said yes, but it means that you for example do not go to work or you change your routine or anything like that? /P18: And yes, like I know, like if I wake up in the morning and I feel like so the day will be surprisingly good (sarcastic). Like, good! /P17: But you will do what you have to do. /P18: I mean, I will stay at home. Like usually I prefer to stay in bed and try to keep everything like like for example I I take a warm shower because sometimes it might help, like, because maybe maybe this symptoms happen because of the not because of the cystitis. Like you don't know, but if it's like three or four days, probably something went wrong like and especially if you are in, you are not in your country like and you don't have possibility to visit doctors or because you are traveling a lot. Like, OK, so I have it before I have it toolkit and it's completely same, completely same symptoms and they start being strongly and strongly – "foreggin" [name of antibiotic] my favorite like my antibiotic like which I have like called my doctor hello. /P17: So it's me again / P18: It's me again. Hello. Like it… [name] do you have? /Researcher: Ok, so you have you call your family doctor and yes, the general practitioner who knows already your recurrency let's say yes and just give you the antibiotic. /P18: Yes. / Researcher: Ok, is there anyone else that want to share this personal experience selecting the symptoms most relevant? I would also like to ask why you put those in lines [referring to labels], for example, is because they are… (laugh) / Researcher: No, no, it isn't like a very easy question, like is because they are somehow related or because they have the same relevance

in your opinion? /P19: Same level of… / Researcher: Ok /P16: And also they kind of group. Some of them are like grouped pain. / Researcher: Ok, so based on and part of body? / P20: More about the kind of activity? So for example this is all like kind of cramping pain to like this part. I feel like and this is all about peeing. /Researcher: Mm-hmm. /P18: But this is the most /Researcher: Yeah, but that one is there because it's like, yeah /P20: It's the scary one. / Researcher: Yeah /P20: On the top, yeah. The the ones that seem to most severe, I guess. OK. / Researcher: More severe, but also maybe that one is the very first one that appear, which is the first symptoms that you experience when you in that case going to urinary tract infection, that's pain where do you peeing no? Ok /P16: For me it was those two ones (referring to the first symptoms that appear). Yeah. /Researcher: So you get the red the blood in your urine when you start feeling the pain. /P15: But for me this is just for UTI. Other stuff I don't find… /P18: For me, it's almost like the most digusting the the most disgusting feeling is like you of course firstly, you have pain when you are peeing, but the point is that it's you feel like you always have to pee / P17: And is that always painful? /P18: It's always even when you are like finishing in your like, wait like stand up and ohh my goodness, no /P17: You need to pee again. /Researcher: I'm sorry we were saying about these symptoms related to UTI, have you [talking to AF] shared an experience related to UTI or any other kind of experience within your story you filled at the beginning? /P15: I am sorry, I did not understand /Researcher: The story I asked you to share the beginning, was that related to an experience of UTI or any other infections? /P15: Yes an experience of UTI. These seems correct (referring to some symptoms) /Researcher: Ok, but if you think about different infections, you think that these are different from the other kind of infection /P15: Yeah /Researcher: Ok. Is there any other like specific group? If not all the symptoms but group of symptoms or like way too recognize them. Or would you like to share them some of them? /P15: mmm what is the word? So, like this discharges? /Researcher: Mm-hmm. /P15: And different smells on your body that feel wrong. Itching. Pain even. / Researcher: Yeah. Ok. So discharge, the swollen stomach, the low temperature, side pain and cloudy urine, we can put them like aside and we move forward but of course, if you have anything to to share, we have like next step as well. And so the idea of the activity is then identified the symptoms and then move to shape them. What does shaping symptoms mean? [00:55:28] **[Intro to materials and variables]** / (People moving around and touching the material) /Participant: They also have foam. /Participant: This is foam. / Another participant: Ah that is foam? / Participant: Ah yes. This is also foam, kind of… This one is SpongeBob. /Participant: Oh my god, this is cute /Participant: [touching units of material] I feel like a baby. I wanna go back at this time /Researcher: Have you assigned the labels? Yes. Ok, there are some other labels, similar to the one with symptoms you have worked with before, but this time related to properties, which are the variables of materials. So, I would like to ask you to try to explore these variables and start to see how you can associate them to symptoms. How can you use them to represent the symptoms you have selected the and you have experienced personally. So there are… /P17: So we need to link those to their materials? /Researcher: Yes, I mean, so trying to understand the if from those material from the materials there, if you recognize, let's say this kind of variables, if you think they are there, if there is something that is missing or something that you would like to have instead of or additionally to that material to represent the kind of symptoms that we mentioned before. So if there is anything that maybe it's not like this first kind of and feature of material that you perceive at the beginning, but maybe something related to any other way of perception that you might have. So here we have… We're gonna move them maybe later on [referring to the symptom labes which stand in the middle of the table so to have space for the new set of labels]. We have weight, position and orientation which I already mentioned before, we have the size, color. Then we have timing. We have 3-D form contour which is the kind of shape you see as a 3D shape, so they kind of sorry like border of the shape. It is the border of the 3D shape /Participant: Which is empty inside? /Researcher: It's not empty, exactly they outline. That's good way to describe it as I always have a problem in that. So the object is 3D, but you see the outline from like your perspective. /P17: That's so for example, here they don't have any complaints. / Researcher: I would say yes, but exactly… /P17:

Can you see the shape? /Researcher: I mean, it's not this shape itself, but from your perspective, the outline you see, the shape you see from your perspective, why this shape, you mean like a cube? Everyone has like the idea of cube is more about the idea of cube. While with the 3D form, which I would say correspond to the outline, it's just from my personal perspective, I see like the specific border of of the shape itself. I mean, it's something like not as a primary property of the of the material it self, but I consider it from a what is sort of vocabulary of physical variables. And I think it might be interesting at least to put it on the table. Maybe you're gonna say, like, I don't want consider it, but something that might be worth to explore. Then we have roughnesses, pattern, texture, fuzziness, viscosity, brightness and opacity. /Participant: What is fuzziness? / Researcher: It's like when you like foggy. / Others: Exactly. /Participant: Viscosity is like… / P18: Viscosity? /P20: Like, the viscosity of the water is different from the viscosity of the Maple syrup /P17: Kind of liquid, kind of solid. /P18: Jelly… /P17: So yes, maybe I don't… I always start by saying that I have never have infections, but I was thinking that maybe what can be missing is for example the temperature. Yes, something feels cold, or really want to… /Researcher: Definitely. /Others: mmmh, temperature /P17: Because for example, to explain that thing, I can say that it's it's a burning pain. /Others: Mm-hmm. /Researcher: That's a good I mean point, if you wanna add it /Participant: You got to write it on top of... (laugh, referring to the act of writing on the new labels, as emerged before because they do not want to ruin the set) /Other participant: Yes you can use check notes. / Researcher: I mean, yeah, I don't want to force you, if you want to use the note post it, go ahed with the post it. As you are confortable. I would say like starting from the material, is there anything that is not here or when you think about the symptoms you mentioned the very beginning like pain when peeing if you would like to express it through like materials like objects even like maybe try to think about objects already existing. So not something that you have to build with units, but if you have to think maybe about an object that really exsist represent what kind of symptoms on that kind of feeling that you perceive at the moment is there is anything like to add. I mean you don't have to… /P17: You mean adding a shape? /Researcher: Am.. more than shape, I would say I would… I mean shape is already a variable ok? but if there is any specific shape we would like to add and you would like to mention, definitely. Otherwise, I'm speaking more broadly about variables, so as you said, the temperature, you know, but it's not like you're not, let's say, forced. It's not mandatory to to add different ones. I just leave you, maybe a couple of minutes if you wanna think about this activity. /P20: Sorry, I don't know if this is bearable, but like elasticity, something that is able to like stretch [01:03:16] **[New physical variables]** /Participant: What is the spelling, sorry? /Participants: "El-as-ti-ci-ty", elasticity, yeah /Participant: All right / Researcher: Ok, maybe something can also come up during the the next activity. I would like to ask you now to try to match them with the symptoms, so it's not like one-to-one combination, but maybe starting from the the most relevant symptom you listed before. What do you would like to or what your experience would suggest to a match with them? Yeah, that would probably exactly (participants start turning the set of labels of symptoms in the same direction as the one of variables so to make the reading and association easier) I was saying like we can move this. /Participant: Yeah, it doesn't matter. /Researcher: I was trying to keep the order. /Participant: Yeah, we all have pictures./Researcher: Ok, ok. I mean, maybe you can start again selecting what you mentioned the very beginning was pain when peeing, was that? /Participants: Yeah /Researcher: Ok, maybe you can start from pain. Exactly. [01:04:51] **[Symptom-physical variable association]** /P17: What do you want to match it with? /P18: Roughness /P17: Wow /P20: Where is it? Ah ok / P17: Something else? /P19: Maybe temperature, no? Also… /P18: I mean, all of them are, a little bit lighter, neutral, compared with pain when peeing. I would add here sharpness (as a physical variable)Participant: Shape?/P18: Sharpness, sharp, sharp-ness [ephasis on the word] / Researcher: Ok! That's a good one /P20: It falls under pain, is it related to the shape / Researcher: But I would add sharpness, because… I mean leave the shape [label] but I see sharpness as something more specific than shape, but you can tell me what you think as you mentioned that /P17: By the way, when we did the activity in the class, and we had to choose the shape (referring to a presentation the

researcher run in the class three day before to present her doctoral research. In the end of the presentation she asked students to quickly answer some real-time questions to associate shapes and materials to specific symptoms). For me, I was choosing the shapes according to the sharpness. For example, if the pain was thingy, I would choose a cone like it wasn't, but maybe the shape was also the actual shape. If it feels like a stone, I would take a sphere, but not because it's soft. Just because it's a stone. / Researcher: Ok, trying to differentiate those two elements (shape and sharpness?) would be interesting. Ok, so you mean the number of edges, to the shape. But how we would you consider like a sphere with a lot of like spikes? / P17: Spikes, yes. I think this shape was missing. / Researcher: Ok. That's, you know, I didn't have time to check results, I mean results, your answers but I'm very keen to do that because I'm very curious and I will actually report the feedback if you're interested. It was the first experiment in that direction, and so it's it's a very good feedback. I would consider that. But I I mean, as I said, it is about shape, but that's kind of specification that might be interesting to keep in mind and considered in terms of designing like units to build symptoms. /P18: So for me like usually even like when I, when the doctor asked me what kind of… sorry it's my way to do it. It's when usually the doctor asks me what kind of pain you have. It's usually like associated with an angles. It might be sharp or tuned /Researcher: Ok /P18: For me is like I usually answer like ohh I tuned [not sure about this word] pain like here which is why I like it usually associated with sharpness. /Researcher: Ok, so there is no pain like a sphere [silence]. Might it be? /P17: Might be, but I would associate it to something else. For example, you told me to sharing story of intimate infections, I had once infections on the board of my toe and the pain was like a stone. / Researcher: Ok /P17: But if I hit my toe, it's like there was a cone on the corner of the stone. That was something inside, ok? (laugh) /P17: It is my description/P18: For me the sphere is about aching… that's what I did was I understand from. /P20: You mean aching? /P17: And for me for example, itching, it would not be 3D because the flatter it goes /Researcher: Because you probably think about the action. /P20: For me it should be like tiny little like red spots /Researcher: Yeah, yeah. /Others: Yeah. /P20: Like uh, sphere maybe very tiny little, just like /Researcher: Ok, so also numbers of units might be a variable / Participants: Yes, yes. Yeah, actually, yeah. / Researcher: Because if you already thinking about itching as spots… That's about quantity. Might we add it? /P20: Sure. Anyone want to write it? /Participant: Is it ok if I go to the bathroom? /Researcher: Yes, sure! [door opens and closes] So, inability to empty the bladder fully, is there any anything… /P19: I would say timing, it could be… /Researcher: Ok, related to… /P18: For me colour, like really for me call or like blood blood. /Researcher: OK OK yeah. /P18: Need to pee… eh. Timing, you just have to wait. I like, I mean the time... What? Where? Where is this call is finished like. /P20: I like elasticity [unrocognised word] there, but for me… / Researcher: Elasticity to swollen bladder? Ok… / P20: Maybe, what I'm thinking /Researcher: But you… /P20: Color? Participant: It is there (the variable colour was already associated to an other symptom) /Researcher: I mean we you can move it or just consider that. But when you think about elasticity related to swollen stomach, do you think about something very elastic or not elastic at all. /P20: Uh /Researcher: Or something that might change, maybe like conditions during the perception. /P20: I think the the way I'm considering it is because when you're in a normal state, you don't feel it feel your organs and they're there. But like during an infection, you feel it and like you feel something's there. So in my head it's like it's bigger now. /Researcher: Ok /P20: So in that sense, like something has stretched, something has like in just coupled in size, but like it has mass to it, it's not something that's just like transparent or like something that you can go through it, it like the swell in size and like volume. /P17: So maybe the size and weight is also here /P18: For me like "discomfort when peeing" is connected to the blurriness because you feel something but you don't understand what is that. Peeing or not peeing… /P19: I would say maybe for this one, pressure would be also another variable /P20: Uuuuh… pressure. / Researcher: Yeah /P20: You see, I've write it down. /P19: We have no more /referring to empty labels to add new variables) /Participant: On a post it or… /Researcher: I have this one… /P19: or post it? /Researcher: Or even with post it, yeah [01:11:49] /Researcher: Or if you can put it here, has you prefer /P20: Brightness, this is

interesting. /P15: Brightness maybe with this one… /P20: I was also thinking like nausea or pressure, pressure would be more like… /P18: For me brightness is vomiting because when you vomit, it's already means that something went wrong. Like, ok, so I clearly understand that maybe I have to fix it. Participants: eh (probably not agree) /P20: For me is like… nausea, then you vomit, that is bright (laugh) /P20: Kinda connected. /P19: This is… incontinence? What is it? /P18: When you when you cannot keep your… keep it inside. /P19: Yes, OK I am. /P18: I don't know this one. It's like really in my head. It's like speed /Researcher: Ok, because probably you're having mind like running to the bathroom or. /P19: In my opinion is like kind of pressure. /P17: Incontinence? /P19: Yeah. /Researcher: Would you… add /P19: You don't have any pressure, like you cannot. /P20: I feel like what I notice is we need multiple of these (referring to the same label with symptoms so to match it with different variables). /Researcher: So you can match more than one. Yeah, I see the point and I see that. That's probably become more difficult later on because if you assign a variable to different symptoms when you have to represent those symptoms, maybe the variables have different meaning you know. So the idea is to try to understand what's worth the most in them of association. But as there is no right or wrong direction is it's something that we can we can keep open. /P18: I found like I don't know how to explain it, but panic attack for me it's like 3D form /Participant: You have to explain me /P18: I will explain you what. So it's a kind of problem from in my head since childhood, because usually I catch a panic attack when you have a higher temperature, for example, on your body like. And I in my head like kind of drawings happening. It's happened like I see, like small pieces of something. I don't understand what is that because you see the the shape but it's empty like it's just something I don't know how to explain it like it's something… /P17: Visually you see something? /P18: Yes, and it's in in like I don't know how to like points in your eyes, for example. /P17: Yeah, ok /P18: And you know, it's not real, it's kind of shape, but it's not like it's it's /P17: From my experience it is like a symptoms before you've… faint, faint? /Researcher: Yes [01:14:52] /Researcher: Yeah. /P17: It's induced by the panic. Like for example black dots everywhere or stars or whatever /P18: In my case it's figures, I notice it, I recognize since childhood I was five years old with… /P15: What do you mean by figures? /P17: Shapes. Fundamental shapes, like spheres. /P18: Yes, yes, but it's empty. /P18: But it's like it's not. It's you see, like like cube. But it's not a cube. /P17: It's and it's not even real. /Researcher: And is that moving? Or it's just like /P18: It's moving and it's it's moving and the more moreover, it's not just moving. It's like continuously duplicate and duplicate and it's like… /P17: It's like in the cartoons? /P15: Like a screen sharing, right? /P18: Yeah, usually once I I can't… when I was a child and I have a flue with very high temperature and this was like 40 degrees and like high temperature of your body and it's like, you know, it's insane when you're start sayin something… it is it's a symptom like even when you sleep you are you are speaking something is. /P17: How to size it? /P18: Random words, like something and yes. /Researcher: Ok, I think that a lot of interesting stuff emerged. So what I would like to, we already match them, and what do I would like to ask you now it's work individually, so everyone will build own artifact, how I call it **[Shaping]** /P19: Can I ask you something, so we need to… to chose many symptoms and then shape them? /Researcher: Maybe start listing on the symptoms from the your experience. So from there, or even others differently, and then start the thinking how they are related if they are somehow related, if there is an order or if… why some of them might be similar or very different. And I think this might be helpful. Then when you have all your symptoms listed to go there and take units to start building them, so then you can read like this specific symptoms - How would, how would I represent it? Go there. Take the units. Build the shapes you feel to represent it, and will be… /P19: On UTI or also on other infections… /Researcher: I would just stick on the story you shared at the beginning, the one you filled in before. So based on that, try to identify symptoms from there /P17: Sorry… /Researcher: Yeah, if you wanna shape the… have written the story before? Would you like to try to build that experience? /P17: I could, but there are not a lot of sympotms… I was thinking maybe some of the symptoms, even if I didn't have infection, I experienced /Researcher: Yes, yes. Yeah, you maybe you can select some of those. It might be worth for you know, like you take once, one time

that you experience them not together, but you know like related to it's not a disease but an occasion, because I think it's also interesting how you relate them and, for example, headache might be very different. So maybe relating it to others things. Those are short [referring to pegs for the assemblage], I have some longer here and see what we have… /Participant: …just create something… Other participant: mmh? Participant: Making an house (intistingueshed chatting). [01:21:23] /Researcher: That I got that give you 20 minutes to do this activity and then we're gonna present each other the arfects /P17: I thought of a context where I can relate well I I can link some of them but it's different from the story there. /Researcher: Ok, it's Ok.Participant: Where's the house? /P19: I am making a beautuful house. I tree house. I see your house [second recording starts] [00:00:14] /P17: I finished! (Participants start explaining their artifacts to others, informally) /P16: It is very poetic! /P18: Is it so serious? (laugh) /P18: Because I in my case, I'm trying to build something disgusting. Because it's it's it's a no… /P15: It's a little bit more than a little bit, then more… That's the idea /P17: How do we call? Is this and foam, foam plastic, you know? / Researcher: Yes, I had, I had the same problem last time. So when you say foam, they consider… both the polyester one, so that they call it foam, so sometimes, I know sometimes there are like misunderstanding, but how would you call it? Because I then checked even online and how they call it is still foam, but they say rather foam for the soft one and then polyester or something for the for the other one… /P20: I used to say, this as like memory foam… /Researcher: Ah ok, memory foam, like the pillow one or like mattress. /P20: Exactly, And then the other one Styrofoam /Researcher: Star foam, star like… / P20: No, I I kind of ok, sorry. Styrofoam /P18: Yes, but we can say sponge. [00:02:38] /P15: Why didn't see this… (referring to the flexible connectors on the table) /P18: Can we show when we have finished? /Researcher: Yeah. /P18: Ok, good. It's it's a. It's a cherry on the top of my cake. /P16: Well, it seems like yeah… /P18: …to make it more unstable. /P16: Cool. /Participant: or plant /P18: It doesn't look like a disease. It's totally something cozy /P16: Cozy?! (surprised and disagreed) /P15: Is that what… like?/P15: You know what? You know like a restaurant when you get… /P16: The restaurant? /P15: Yeah, hospital (laugh) /P18: I have to put times in inside? Like to the explain my pain more /P19: It's like stepping… /P18: Yes, extactly… [00:04:09] / Researcher: Who needs to, like, keep going in building stuff? [00:05:50] /P18: Oh cute, it looks like a house. /P15: It's like a boat. /Participant: Hmm? /P15: It looks like a boat. /P17: Yes, but actually what causes this? Because I feel like I'm the one that's not normal /P16: No, no, no. /P18: If you don't have, you are sorry if you don't have kind of. /P17: Yes, I don't want it but I don't know why, like the rest of you have it /P19: Like the doctor told me that I don't drink a lot… water / P17: Ok… /P19: So, that's one of the reason. /P17: Ok. /P19: And also that after having sexual intercourse, you should go to toilet and this other one. /Participants: Mmm, yeah! /P19: And this works a lot. I never had it again. So yeah / P17: Yeah, yeah, yeah… /P19: But I don't live for every symptoms… you can solve it /P17: Not every symptoms, but just urinary infections, what causes… /P16: Sometimes the toilet bowl is not cleaned, and then when you wipe you as… umm yes it need to be backwards and not front. /P17: I guess that, yeah, yeah yeah. Ok. [00:07:17] **[Artefact presentations]** /Researcher: Ok, I think if you have done, if you like to share your story, the one you share the beginning by describing your artifact, so going through the artifacts and try to explain the choices, the design choices of your artifacts related to the story, trying to, like narrate and explain to other what happened during your experience, supported by the artifact and description of the artifact. I don't know if you. I think we can stay on the table and if anyone want to to start… /P18: Ok, so you see it's it looks a little bit, yeah. /Researcher: I was just taking a picture but you can start, yeah /P18: …one second I have to translate some words. So, this "artifact", or "installation", how to call it… it looks a little bit pathetic and weak for me and the same time it made it made with, disgusting for me, materials. I hate this kind of material [she is talking about polyester] for me is like, especially when it touched to each other it make a noise which like make a painful inside you and then also like unstable because if you touch it will… no… boy come on [she touch the artifact so to make it falling on the table, but it does not. Then, it falls]. Yeah, it destroys. So for me it's something which I hate a lot. Like all all in one at the same time, it's weak because it might be fixed, but it's pear (not sure about the word

"pear", but it might mean: "something has gone wrong" with me /Researcher: Ok and may I ask you what you have written there on the note the, I mean, on the post it /P18: It is most, but it's a because one part is missing. It's a piece of glass because it's something sharp. I wouldn't… I didn't add wood here because for me, wood is something cozy. Like it's warm, comfortable. That is why I wouldn't use, I wouldn't use the wood, but I will probably use the glass because it's something sharp and… /Researcher: You mentioned sharp, also glass, sorry also because of color and transparency or just because of like the feeling? /P18: Because of the feeling. Not because of the transparency. /Researcher: Ok, might be… metal? /P17: Yeah, actually I was thinking something sharp was missing, but I was thinking more about metal rather than glass. / P18: Yes, but for me, like you know, metal is more strong than glass. /P17: Yeah, it's heavy also and that's what I needed. /P18: Yes, I at the same time I found this disease disgusting and the pathetic… /P17: That cannot be heavy. /Researcher: Ok, so the fact that it has those features for you is more something light in terms of weight. /P18: No. Uh, no. /Researcher: Maybe I misunderstood. Ok / P17: Light means not heavy. Not heavy. Yeah, not heavy is light /Researcher: Ok, ok, thank you. Do you want to go? /P20: Yes, sure. For me, I experienced… it's sort of like pain when peeing. So for me these objects sort of like represented like spikiness, irregular shapes and all these things are associated to like the pain that I felt during peeing. And then I just wrote, I would want to color them. /Researcher: Ok /P20: Yeah, because these neutral color doesn't describe like the pain for me. And so that was the first item that I experienced and then I experienced like the swollen kidney and bladder. And for me, I just sort of representative with like smaller cubes that are like more rubbery and stretchy and the bigger cube that's connected with the very short clear tube because and I was like, hunched over like not being able to be, like, flexible and expand and myself. So I just felt very constricted. And here I just said I wanted to change this to more like organic shape and rather than something like rigid with sharp edges. So… /Researcher: So you are saying the opposite of having somethin like super sharp. / P20: Yes. So for some reason, like when I think of something getting swollen, it's not sharp, it's more like round and regular. /Researcher: Ok, thank you /P20: Thank you /Researcher: Anyone else? /P15: I can go. Umm for me I chose the wood because for me to depict pain, I think it has to be something heavy, be so the other material doesn't do it for me and also for me it was a process because I'm very sensitive to both fungal infections and UTIs. So, I think fungal infections last time it lasted a year, so it was… more discomfort, less discomfort, like iteration of intensity of symptoms. /Researcher: Ok, so it is a sort of timespan of… /P15: Yeah /Researcher: Of the whole experience. You not link like specific disease to any block, but more about the whole shape of… /P15: Yeah, how it felt / Researcher: And what about… If I may ask about like tubes... The way you connect those blocks... / P15: I just… (laugh – as she just added tube for aesthetic reason and because she wanted to have them in her artifact) /Researcher: Ok. You can say that. It's fine. Just to understand. Ok. And have you and took any notes about material? Or do you have post it? /P15: That I would like roughly textures maybe, because this is too cute. /Researcher: Ok, thank you and sorry I have a question regarding colors. I forget before. Do you see any specific color? Let's say that you can paint those units. What color would you paint them with? [this question address the previous participant who mentioned the desire of having colours] /P20: With [undistinguished] I would like paint more like with red colors like reds or like the shades of maybe pink, red. Not not like pretty colors, but maybe something to do with like blood and flesh. And like the organ colors / Researcher: Ok /P17: For me, when I think about color, maybe it can be linked to one of the other variables. For example, back to temperature, I would see blue for something cold, for example. /Researcher: Ok, ok /P20: We said color and temperature to bloody urine. Which makes sense. /Researcher: Ok, so what do you like to share yours? /P17: Yes, so mine is is linked to a epileptic seizure I had, so I don't know if you know all the symptoms, but I started with the pyramids because it's pointy, I need something pointy for the headache. Yeah, basically. And then I used the wood ball in the middle because of the heaviness of the pain. And I used the cube because of the nausea. And I see it as something very huge. I wanted something that could flow, but its shapes does not work, so I took something heavy that's on top. And I wanted a flat base and I forgot to note it, but because it

would be better if it was a cube but not a cube but a parallelogram, so flatter. /Researcher: Ok. As a base of all the structure? /P17: Yeah, because the base is stable. /Researcher: Ok /P17: The base is stable /Researcher: The base is stable because, you mean when you start building the artifact or because you are experiencing… /P17: No, the experience because everything happens in the head, but the rest of your body is really stable. And this because a lot of what's happening I don't understand [laugh] and and that's it / Researcher: Ok, have you took any note? What have you written there? /P17: Oh yeah, this one is for all the piramids. Ohh yeah and one of them is full, I don't remember why… oh because of tiredness. Because it needed to be another, another material, it needed to be lighter. And this one said says lots of pain because I associated to the pointiness. This one on the ball in the middle says heavy, and umm this one… not understanding as I explained /Researcher: Ok, you mentioned, you were mentioning metal before. So do you see any part, for example of this artifact built in metal instead of like wood, for example? /P17: Yes, those… all the wood pyramids would be would actually all they wood would be metal. /Researcher: …so you just went for wood because it's the heaviest there. /P17: Yeah /Researcher: Ok /P17: That's it. /Researcher: Ok. Thank you. /Researcher: Would you like to? / P19: Yeah. Yeah. So and so first I choose a shape. /Researcher: Sorry I was (undistinguished). Sorry, go ahead /P19: I was choosing a shape more like where most of it is, like on the bottom because the… I, yeah, for the fact to one thing to lie, lie down and also those to make it to represent the sharpness because it's like burning sensation when peeing. And also then those are for like, nausea and it's a lighter material than the one on the bottom then those are for more tiredness and to link to… to want to lie down. And yeah, also uh, yeah, it's all kind of messy in the middle and that's to represent that something is going wrong and… yeah / Researcher: Ok. And did you take any note? Would you like to have any different material or futures instead of… you. /P19: For me this is for sharpness, but also metal could also work to represent represent it. /Researcher: Ok /P19: To represent the pain, and also, I chose wood because it's the heavier material. /Researcher: Ok, thank you /P16: Ok, so uh, actually wanted to unbalance this, but I I don't know how to do physics [laugh], so just imagine it's balancing so… /Researcher: Sorry, I missed it. So, you want it need to be stable or not? /P16: No, no, not like the whole point is unstable /Researcher: Ok /P16: And also like well, that's why most of it is like on one side. The wood and this and the wood part is all about the pain when peeing, so it's the base of everything. That's where what hurts the most. So it's like sharp edges and stuff. UM, this is for the bloody urine, so to not very explainable why I chose this but I was hoping for fluid texture or something like Play-doh so that we can change the texture. So maybe possibly next time then for this was about the foul smelling urine. So it's same as she said, the sound was very like irritating, so it kind of… it's not something annoying, but it's just irritating to smell also. Yeah, so. That's all /Researcher: Ok /P16: And also spiky texture for this. /Researcher: Ok /P16: For some reason, I don't know /Researcher: For texture, you mean like… because it's like more visible let's say from others? Or because it's like bigger [undistinguished] or? P16: No, I just feel like I did something like this to express myself. / Researcher: Ok, so it is more about touching it and feeling the difference /P16: Yeah. / Researcher: It's interesting about sound actually, because one of like previous group identifies the proper variable to represent staff and even if you didn't it in, like the moment of identifying variables, in the end like came up from from the conversation and that material is mostly most used because the annoying like noise that that produces instead of like specific features of the of the material in se /P18: Imagine people who are working on the factories. You know what kind of headphones they have to… /Researcher: And is your notes on there that you would like to share or have you already…? /P16: Yeah / Researcher: Ok. So I think we have done.

WS4: 15 October 2024 - Universidad de Monterrey (México)

[00:00:58] Researcher: So what is this you work on? /G1: On the flu. Yeah. Also go with the go. Is the COVID like… flu? Yes. Like COVID. Yeah. It's the same symptoms. It's the snowing and intestine, yeah flu, the same symptoms that kept you from going to school when you were a kid, so. Actually this is, sort of like, like physical representation of the person and its state and this is the condition of block nose and running

nose that are alternating each other. Yes, exactly. /G2: I like that. Yeah. Yeah, exactly. That's a perfect representation of that. /G1: And this is the throat. We wanted to make like an itchy throat with the friction and so and also like it's sound enveloping because of the loss of voice. So we did like low language of friction (not clear) This is the pain. This is a the knee-join pain. Because we, we said kinesthetic friction and also, this represents like prisoner's ball that like you know, those iron balls, yeah. Like there's the prisoner is attached and yeah, and it also represents the impossibility to move a lot because of the weights. Like yeah, and inertia of like of the tired. [00:02:50] And this part since when you have a flu, usually you also feel like joint pain. This is like a twisted knee. So it gives it gives this uncomfortable. Let's say, but it could also be yes, it could also be constipation, yes. Also, because, because you have you have this cube in the middle. Yeah, and it's full wood. Exactly. That's basically. /Researcher: Thank you. I don't know if you have any feedback or like you want to share anything about the the activity or the way you feel. /G1: It was really funny. It was really interesting. I have never thought of associating symptoms with materials and their characteristics. So it was nice. I'm gonna think of it differently from now on. And also I I'm wondering if it could help to resemble a human shape in this because we working this way. So the human shape really helps diagnosing, you know, the kind of symptom, locate what's going exactly. For example, if I represent this thing somewhere else in this composition, I could not associate it with running noise, for example. So I I guess that it becomes like a doll and, like, a voodoo doll, you can relate the symptoms in the visualisation for the visualisation purpose I guess. [00:04:26] Researcher: And would you have like other sort of materials or shape to to represent stuff, I mean we cannot cover everything, but maybe by using stuff you have thought like, oh, it would be very useful to have this or that. /G1: Maybe like a rubbery. Like yes, because for example this one. If it was like proper like let's say for example some flexible rubber, I don't know if you're if you're like used to 3D printing like for example DPE, which is a very flexible material, and since it is printable, you could also imagine lots of new shapes and this kind of needs. I think the shapes are good. Yeah. Yes, I don't. I didn't think of like, oh, I need another shape. But yeah, maybe a rubbery material will be nice. /Researcher: OK, thank you very much guys. /G1: Maybe something more connections. Like we were saying that we wanted to put the triangles under play. Oh, yes. the throw. I passed a very, very strong situation with the body because I I had an ectopic pregnancy. Yeah, in Canada and in this moment I draw. I draw. In my body this is what is happening, and I feel... So I say because the this moment I I don't think I don't I say in my body is this happening. I feel in if if for you is with this this information. /Researcher: Yeah the drawing is another way of of course like communicate feelings and perception. There are something related to healthcare as well. For example, there is a narrative medicine. Is this sort of... I mean idea that takes also from anthropology and involve patients in finding a personal way to narrate what's going on. So something that might be related with symptoms but also personal life affected by disease usually is like they do that for cancer or long term diseases, chronic diseases, these sort of things that heavily affect your life. And they running studies, asking people to narrate what's going on and actually I have this confrontation with people in this hospital. In Switzerland we work with and they ask about, there were 93 people, asked them if they wanted to share the experience and try to narrate their experience for the purpose of providing doctors with more information to know them better when they have to operate or speak with them or not only in term of healthcare staff, but more human related things and all of the 93 people accepted voluntarily to do this kind of trial in this direction and most of them went for the drawing, some others writing, so they sort of write a sort of diary with the samples and stuff to add on. Some other with art. So they were using art that we communicate that symptoms in that direction. Yeah. Here. The idea is to try to bring more, let's say specific information not only perception, but to try to work on... focus on what's going on to then communicate that and material is another way to do that. But of course drawing is very useful. [00:09:01] Participant: So about the narrative medicine, what did the doctors want, though? Because doctors? Because I think that's interesting in a research context. But then if you link it back to how much time people have, then I think doctors going, I don't want to listen to

your podcast about any of your week was or whatever because they can't fit it in. /Researcher: I refer to this study particularly, and that feedback of people involved in the study, so it's not like it's generally speaking, but they will say that doctor was positively reporting feedback on the study because they were saying we actually had this chance to know more details I see. And instead of like going and ask people. So that moment of conversation or reading the documents and other stuff. They were just going through this sort of out of narratives that patients were doing about themselves, of course, the idea was to focus on the illness, binging in whatever is related, but focusing on the illness. So the goal was explain what you want your doctor to know about you and the situation, and they were saying that was very useful. And wew actually saving time instead of being time consuming /Participant: But that's interesting about the impact of it. We'll be sure that is again afterwards. You get the study, but I'm sure there are others. I know the feedback on this one because I participate in the presentation and other stuff, yeah. /Researcher: Please. [00:10:37] G2: So, it's not a person, it's lactose intolerance. At the bottom you don't know what was really messed... the fullness. Yeah, so the state of feeling full quite quickly with this little square. It's really because of the one thing that we variable that we added which is density density. OK. So like the wood squares are quite dense and squared, it's full and then we started with bloating because it starts going out of control, here's one of the big one. So I think we are well. I think this was quite cute. This is bloating in combination with the lower back pain, yeah, back pain so. The pain is sharp and set the shape. And then I think that's all.This is also nausea because it felt like a marble inside you, because the motion and these, well, that feels like, mental fog. Yeah. And the bloating, that's sound. The time of day in the day, so sometimes it's it's really. Sometimes it's really bad, sometimes is not that bad. Sometimes is OK-ish. Yeah. I think that's it. /Researcher: What does make it worst? Or better? You said that sometimes you feel bad. /G2: Sometimes it feels worse, like the wood. And the size. OK. So I mean in terms of when I listed it would be what what you paid? Normally, at the start of the day would be OK, but as the day... /Researcher:OK. So it's a sort of timeline as well, maybe maybe. OK. Yeah. I didn't need you guys as well I needing to provide this feedback or want to share. Participant: I wanted the foam sphere (the participants were compaining that the foam sphere is not made of the same material as the other foam components. This is due to material availability. It is true that the foam sphere is harder than the other foam available.) / Researcher: There's a big one for me. I completely agree. Soft, very soft, but no one cut the foam in sphere shape. That's like so difficult. I actually built all of them, but of course and cut some others, but the sphere was actually impossible to have the same. So I looked on Internet and found those, but not the sphere.... OK. Thank you all of you for your effort and being here today has been very interesting for me and and useful as well for you.

WS5: 25 October 2024 - Berner Fachhochschule (Switzerland)

[00:00:00] G3: It's our throat, I have this feeling of relativity, and, uh, composition is, uh, really linear to show the process of, of, like, uh, the whole condition and also the pain of, uh, um, swallowing. So this is kind of the throat, and this is our sort of pain that's also getting swollen. And it represents our issue paradigm, and we use the transparent clues to, uh, reflect on the, like the, um, a kind of flu fluidity, uh, that's associated with it. /Researcher:So you managed to make the connector longer, actually, with the wire. /G3: Yeah, with a paper clip. With a paper clip, yeah. And, um, I think it also shows the process in this kind of construction, between the flow There is actually something moving. Yeah, something disrupting the throat. Mm hmm. It's making one cough. Mm hmm. Something is, another material. /Researcher: Thank you. Uh, do you have any feedback related to how you use the material or any limits Something that you would want to have there instead of the material that were available? Or something that have been facilitated by the material? I mean, any kind of. /G3: Maybe just a paper clip, actually. Yeah, we can include in the so nicely made already or they seem like modular, you know? Yes, but maybe color. Yeah, I think we had a bit of trouble showing the temperature and this kind of conditions related to that. /Researcher: Yeah. Okay. Thank you. Thank you. would you like to share next? [00:02:25] G4: So those are our

three main symptoms. We think vomit, anxiety and bellyache. And also fever. Yeah. True. So, this is bellyache, stomachache. We wanted to show it, like, in a... [the first recording stops] [second recording starts] G5: We want to show it in a triangle, in a squishy triangle. Then, uh, yeah, this, this, uh, we connected this with the joint. And this we consider, this is an ice cube that, uh, determines the temperature. So ice means that's cold, like that, it has an opposite version that's hot. That means when we have temperature, we are not really good. So we symbolized it with the temperature. And why we connected these both is because when we are having a fever, we also have the body cramps or the joint pains. And, uh, yeah, we left this out because any other disease or fever or body pain or any other disease that connects have all these symptoms connected with it. Uh, we almost feel, um, not really good when we have headache, we have fever, or we have, uh, body pain. Everything comes together. So that's why we left this out so we can connect everything else. /Researcher: Thank you. Thanks. Thanks. I've seen you create yours [one of the participant (P21 worked by herself in the group and preferred not sharing her artefact] Would you like to share it or not? No. Okay. /Researcher: Would you like to go with the yours... bubble structure I would say... [00:04:08] P22 (One of the participants worked by himself to the probe): I would say first created and then I thought about what it could be. / Researcher: Okay, this is a very designer driven process. /P22: I'm going to say that it's the opposite of the other ones, meaning it's not when I'm ill, but when I'm not ill. Okay. Because everything is structured, everything is in its way, it all feels nice. When everthing fits into the place. So I'm going to say this is how it feels when you're healthy. When you're full of energy. /Researcher: You found a good interpretation of, yeah. Okay, thank you. /Do you have something more bad, let's say, in terms of conditions... to present? [00:04:08] G6: We had the fatigue and so we had the word sound envelope and fuzziness or blurring and because the feeling is overwhelming and it's all around and it keeps you in your bubble and it keeps Sometimes the sound, sound out or sound in, um, it isolates you and so it was, uh, hard to find a way to, uh, to maybe see, but inside there was a little piece and which, um... /Researcher: Okay. Yeah. I see now. Yeah. So it's all around, uh, Surrounded by? Yeah. Mm hmm. Okay. And say again, sorry, the symptoms you were working on? /G6: Fatigue, sound envelop and fuzziness. /Researcher: Ok, thank you. Is that part of... [00:05:49] P23: I was running out of material to be honest. / Researcher: Oh, no. Sorry about that. /P23: It would I kind of have a similar approach. Okay. Like you, but I always had this insomnia in mind. I missed longer I wasn't happy with the material to be honest with you. It would mean that it's like a center and it's like really, you know, like I would have made more cows. And, um, but I ended up here because the material was. Yes. /Researcher: So you want to something, let's say longer and more flexible to wrap it. /P23: To go with this again here and to make, you know, go around so that it's becoming maybe like a ball of made out of. Related to insomnia to represent the insomnia. I mean, it's something. like running all the time and it's something really transparent, but also like, um, not stopping, but all connected and cows, but I couldn't express it. /Researcher: Okay. Okay. So yes, I'm sorry. I mean, I was, I was saying to someone else, uh, the material, the very first session was run with raw materials. So there was no pools, there was no connectors, just pieces of. pieces. Um, and then I noticed people were focusing more on how to get units together. So the glue required time. The wires is not like well enough to keep different materials together. Uh, and the idea was to have this wall so to facilitate the process. Uh, then I suggest, I mean, they were available all the day, wooden pegs and someone during a workshop such as that to something longer and more flexible work were required. So that's why I, I had added that part / P23: Maybe (the connector) longer. So, so I can decide how long it is. /Researcher: Yeah. But as I was saying, not that I want to use the material, um, but as I was saying to someone, of course, I mean the kit can be improved till like. The infinitive and and that like beyond. Um, and that's something I wanted to do, collecting feedbacks from people who work with that, but what already works, even if the kit is very limited, as you notice, but I completely agree is the fact that people can relate to what what is available to say even what is not available. So to use it as like, this is good, but I would make it more longer in this case. Or on the other hand, there were people in the past saying, okay, this is what it is not the symptoms or my feelings. So

that's exactly the opposite because blah, blah, blah. So using that more as a prompt, let's say, to activate the conversation and the thinking of the symptoms, but I see. And thank you for the feedback. /P23: Yeah, no, maybe you can use something like this, for example (the flexible connector). Yes. Like some parts because this is also, yeah, yeah. That's another part. / Researcher: No, that's another problem of like the kit, but physicalization in general, it depends from what you use, but that's a consequence of course. Thank you. Would you like to go next? [00:09:13] G7: This is supposed to be a neck pain. And, um, it's like something that would be moving and it's also like it has its spikes and sometimes it's, um, a bit, it's a bit stronger and sometimes, uh, you would barely notice it. So that's, um, uh, what represents the material, materiality of the different materials. Um, and yeah, I, I had this, um, during creating it, I thought I should have something that's more spiky than what was available. But also like what was available was helping to form this to form this idea what it should look like. Um, yeah, so I found this. /Researcher: Thanks. More spiky. You mean like having a shape with more edges, for example, or about like the length of the edges. How would you envision that? /G5: Yeah, like something sharpness. Yeah, sharpness or like, uh, like a spear. Yeah. Yeah. /Researcher: Okay. Do you want to start? [00:10:29] G8:So this is like, fusion between so, uh, sculpture here that ** started but maybe you should say something about it still because I don't know what your idea is. P24: Oh, neck pain, sorry. Neck pain, yeah. It's so obvious. Um, Nack pain. /G8:That's why it's bigger than yours. But actually we all used um, this polar, uh, echiga Yeah. Triangles and no, uh, balls. So that's what we all have in common when we chose the objects. This was clear. Well, there is one little round shape hidden here that, um, (one of the participants) picked. Yeah, it's here (the polyester sphere they refer to is hidden in this picture but visible from others as it is one the other side of the artefact). I put it here. Um, but then we're also saying, um, like this one also just kind of like I chose this because That is the ideal state of my shoulder when it's like soft, which is like a distant memory. And this is like, kind of connecting, like, it also feels like, you know, when you're like, you're feeling this kind of strain. Um, but yeah, also memory connector to what that state could be like, um, and yeah, heaviness. /Researcher: So what's the ball stand for? Do we know? /P25: Oh yeah, I mean, the ball had kind of, where is the ball? Yeah, I mean, it was kind of already, like, marred and, and kind of, um, damaged. So this is what I feel my shoulder is coming in stages, to be fair. But I really missed some more expressive materials, to be fair. Like, something more amorphous, like a clay or something, that I can give a shape to. Instead of the sun being this kind of vast monology. Um, yeah, but this is maybe also professional information. /Researcher: No, no, no, no. That's another like things that emerge all the time. So having like clay or plasticine to mold. Um, and that's something I would like to try. Actually, uh, at the beginning I excluded the direction because I run something similar for another research, uh, and then, of course, there is this layer of being or feeling actually able or not being able to, like, uh, create something that satisfy you somehow. So you don't have to be able, but people, some people feel like they're not able, so don't even, like, approach the material to, to create something. Uh, but again, there, the, the, the focus, the goal is not to create a sculpture, like, So it's just about, like, making shapes and, and try to express with materials, but I would definitely want to try to... /P25: For me, it was very difficult to express pain. To be honest, I share your sentiment on the spikiness or just on something that is actually damaged somehow. I wanted to press your materials together. Okay. I hesitated because I thought I cannot mess up your kit. /Researcher: Okay. So that's okay. /G8: I think the connecting material were, were important. In case to even express, yeah. The pain which is connected. /Researcher: Okay. You mean not to, um, like, um, let's say connect pieces, but more about the meaning of like a something. /G8: That became only clear to us when we connected it, and then we're like, oh my God. Yeah. So yeah, these tubes are really cool. /Researcher:So about edges, for example, would you not consider to, uh, select a lot of like triangular shapes or squares, um, cubes and kind of create something new? Or do you want to identify already something that has different edges to then, uh, create a different shape? So that's something that you have not done. So that's because probably you were looking for something from the beginning. /G7:Ah, the assembly of the first layer, but I don't consider those very edgy. Okay. Okay. Okay. Okay. Okay.

They're not representative of the pain that I have here. /Researcher:More like a pincer or something like that. Okay. Okay. Yes. Okay. I don't know if you have any, like, General, I think I went through all of you, right? Yes. Uh, if there is any other like general feedback on the entire day about the process, the methods, or the kit itself as we were discussing. If you have any curiosity or something maybe was not clear, I don't know. **[Feedback on the workshop]** Participant: I'm just interested in color, because you guys want to color, right? Have you done any tests with that? Because that just adds another layer to it. Yeah, sure. And what makes me initially think of the clay, plasticine, Play Doh. It's colorful and you can mold it. /Researcher: Yeah, that was part of the first session as well. So the first one was very, let's say, wide and open to see what I can identify there then to, to focus on. And there was color as well, so I left some acrylic painting, paints for, for paintings. Um, so people were, tend more to use colors to represent one to one color of things. So because of urine, they were using yellow because of blood, they were using red, which is, I mean, still fine was more like representative, let's say, of things to, to, to communicate. Uh, the reason of avoiding colors there is because, uh, color are somehow already explored with visual variables. Of course, they might be use completely differently if combined with materials, but because I've been suggested because I was focusing on too many things. So I've been suggesting like, okay, select some that you want to go in like detail. Uh, and I selected shapes, materials and like texture, uh, to go through. So it was just about, um, as there is no like solid, solid, Uh, knowledge or proved knowledge in that direction, just selected some that I would like to investigate more out of my interest and where the research is, like, focused on. Uh, but of course, are all those layers that can be added or further investigated differently. I mean, for example, now, uh, I would, uh, I can ask, uh, or provide you with the colors and then add the layers of, of color. So maybe from an, in an ideal world, these all, all the units might be provided in all different colors. So you select units already in the material. Then there is a limit of like physical components also related with the, uh, waste as well. Uh, so it's always like finding the balance. [00:18:06] Participant:I just wanted, uh. I was curious about it because I really enjoyed that it was neutral. Yeah, exactly. It was not distracting. Mm hmm, mm hmm. Color also, yeah, distracting. Like, okay, what color do I choose now, too? Yeah. / Researcher: Um, I mean, colors influence a lot is one of the first visual variable that we are affected by. And that was the reason to try to make them neutral somehow, as you were saying. /Participant: But maybe you can use one color. I would, would you agree? Like red or grey? /Participant: Mm hmm. Yeah, but it's not good enough. /Participant:For whom? Or, I mean, in our society or country, but not, they are not universal, so. Yeah, I would agree with you, but me, so. /Participant:I was thinking about, like, For me, that's always the same thing, but, um, lighter color, and I also wrote, um, before, in the, in the previous workshop we did, a lighter color reminds me something peaceful or calm, so I would prefer something darker, or gray, or black, so it's, like, black and gray or shapes, uh, are, like, no colors, so it would be, um / Participant: Yeah. Yeah, I think it would be really interesting to have, like, maybe even more materials, like, for example, steel that would be darker. steel, it could represent the heaviness also. /Researcher: There was steel at the beginning when someone was suggesting glass as well or something see through that is not available at all. No one mentioned it. That's like I would say, uh, unusual. Uh, but yes, then about, it's also about like practical, having shapes and all this stuff in all the materials, but I completely agree. /Participant: Maybe next time either textiles and scissors to have something, because I was related to the body, the very thin layers. And this is also, also solid. /Researcher:Yeah, I would like to investigate different materials in this direction. So, uh, as clay or plasticine was mentioned before. So results and even I think discussion will be not completely, but very different. Uh, from starting with a kit like this and then fabrics is something I would like to investigate further for sure. For example, in last July, we run a workshop on data physicalization at the SUPSI, and we have the icebreaker done by this, uh, collective that work with the recycled, recycled and upcycled materials. Uh, and it was very interesting. I mean, even if a very like half hour exercise of create and express. Present themselves with the badges or something like that. You could do it to be done. It was very interesting because, of course, you have then also a way of cutting the materials, how you like,

I mean, a lot of variables that are can be used in that direction. And another one is the paper paper is something like very basic, but even in Because of weight, uh, roughness, uh, colors, uh, exactly. And folding techniques, uh, is something that I am investigating in that direction. Then you need probably more techniques or, I mean, skills. And it would be good to combine with someone that can provide at the very beginning some basic one. Then can, everyone can further explore and personalize later. But it's definitely something interesting, interesting. /Participant: Do you think that these shapes, the material and these textures, that you use in your workshop, was it already, like, was it done somewhere here? Like, you chose these shapes and these materials and these textures? Was there study done on this? Uh, like, how people react to these textures? /Researcher:Uh, like, how people react to these textures? Yeah, it's kind of, well, generally, it's made through, uh, interaction with materials, but it's not for this specific purpose and with this specific material. of material. Uh, what I've done, I've tried to consider, let's say, like the very basic vocabulary of, of shapes, and then investigate what might be, even considering what was available. I mean, this is like very clear from, from my statement. Uh, in terms of having very different dimensions and the basic shapes, so trying to, as you are noticing, for example, um, I mean, wood. There's someone also into like warmness and something actually cosy or like good somehow conditions. Uh, then the, the spongy thing, that's interesting how people relate to compression as well, so like the movement somehow. Uh, and then the polyester, which is something that, um, all kinds of sounds into the sound. And this is kind of very interesting for me because I work on sound before. Uh, and the way he sounds. The way data is not directly represented by sound, but the way the material works as a sort of, like, mediator between, you know, the meaning of what you convey and the sound that the thing does use, uh, is something, I mean, very interesting. The way also you, as, let's say, creator, designer, select the material. So you selected something physical, I mean, I don't know in your case, but you can confirm or not, Because of the sound. So just looking at the material you are linking more than the touch or whatever the sound that it does for you. So, which means that it's quite strong. It doesn't happen personally with the form or wood is something that happened with polyester because of... /Participant: So it was improved like after each of the workshop... / Researcher: Somehow, yes. So I started with very raw materials like. And then I added the holes and the wood pegsto make the combination easier. And then someone suggested a flexible connector should be longer. And then now we have like a longer, longer version to be integrated. But I'm trying to consider all the feedback to, I mean, this is an endless process, but to consider at least some of the most feasible one to integrate. /Participant: I found to write down the same clues and to share it I found it most, um, relieving because, um, to find out that we, like, all have, uh, made a thing that is somehow great to hear. Um, um, Well, I, I'm sorry for them (group mates), but it's like, uh, it gives me a bit more, like, Yeah, it's, it's, you have to carry less weight somehow.Um, Yeah. So, having that aspect, um, of the process, and with like, materializing it, um, for me, there, I did not have a benefit from that, so I was wondering in what ways does the materializing help people like me.

A.4 Transcript of the first workshop medical expert interview

The following transcript reports the semi structured interview conducted with the medical expert who took part in the pilot workshop at SUPSI on 23 October 2024, whose feedback informed subsequent iterations of the workshop protocol.

[00:00:03] Researcher: Penso che magari aspettare un pò di tempo serva un pò per contestualizzare tutto invece che magari dare subito dei feedback. Però, allo stesso tempo il rischio un po quello di perderseli, quindi che ci sta a riportarsi se tu ti sei segnata delle cose, allora ti lascerei tranquillamente parlare, nel senso che mi son preparata delle domande. Però se vuoi andare prima tu, poi nel caso magari ti chiedo di approfondire o di spiegarmi meglio qualcosa. Se Sei d'accordo? [00:00:33] P1: Sì, va bene, allora io e appunto, ho un attimo riflettuto prendendo, diciamo all'inizio la diciamo un po quello che volevo dirti, che effettivamente io non so se magari avevo capito male, però pensavo che ci fossero altri professionisti sanitari. E ed

effettivamente diciamo, quando poi ci ho riflettuto, non so se ecco questo, quando poi tu hai registrato tutte le attività diciamo fosse un po un bias, nel senso che alla fine io sono di fatto la professionista che non ho nessuna esperienza personale ma ho esperienza lavorativa, quindi ho una determinata conoscenza sulla materia. Rispetto. Ecco al gruppo, poi, che era soltanto di delle pazienti. Sostanzialmente, quindi, eh, effettivamente. Nel senso, poi ti ripeto, io ti dico quello che quello che ho pensato poi tu mi dici se... [00:01:35] Researcher Sì, sì, no. Certo, cioè vai super tranquilla, nel senso che anzi più emergono diciamo problemi o comunque cose che non sono diverse rispetto alle aspettative, più mi aiutano, magari anche a migliorare tutto. Quindi vai davvero tranquilla. [00:01:46] P1: Nel senso che io ho quasi pensato che fosse più interessante. Se in una seconda attività ci fossimo stati io e per esempio un'altra persona o anche un medico o anche, per esempio una fisioterapista, ergoterapia ista che secondo me sono molto utili per le infezioni del tratto urinario, che spesso anche cistiti eccetera per il pavimento pelvico, piuttosto come osservatori dell'attività, nel senso come facilitatori, in un certo senso, ma con una veste più di osservatore, perché effettivamente? È appunto, non avendo esperienza personale vero, che forse ecco alcune questioni, magari. Ecco, io ero un po un bias, in un certo senso, no, quindi questa è un po la prima cosa che mi son segnata. Poi effettivamente un po quello che era emerso durante la l'attività è che effettivamente c'erano delle ragazze che comunque di fatto hanno più del dei problemi di tipo alle mucose genitali. Quindi la candida che non è assolutamente un'infezione del tratto urinario proprio ci sono proprio due categorie proprio molto distinte, quindi effettivamente non so se vale la pena, perché non mi ricordo se nella tua presentazione l'avevi detto esattamente che cosa fossero le infezioni, cosa comprendessero? No, perché effettivamente, a meno che tu voglia includere anche tutto quello che è il discorso degli antifungini. Creme vaginali e compagnia bella che ci potrebbe anche stare, però effettivamente l'ho visto, un po come parlare di due cose molto diverse, ecco. [00:03:35] Researcher: No, se io allora un po per il focus della ricerca, questo lo terrei separato e forse anche come Suggerisci tu, oltre che nella presentazione, magari fare una specifica per differenziare queste cose anche nella prima fase precedente proprio di recruitment. Quindi focalizzarsi su quelli che sono malattie del tratto urinario e come cistite e magari non avere un colloquio, però specificare nella mail di un board in queste informazioni, così che come dici tu, possono escludersi dei fraintendimenti o comunque avere persone che magari hanno esperienze diverse, però non specifiche e non allargherei il focus dell'attività. [00:03:57] P1: Esatto. [00:04:04] Researcher: Perché secondo me poi è proprio un po diverso, anche io non ho conoscenza, però un po anche le cure, il trattamento, i sintomi stessi. Quindi vuol dire proprio andare un po a cambiare tutto, quindi no, questo assolutamente me l'ero segnato anch'io. [00:04:18] P1: Cioè volendo, nel senso. Io ho anche pensato, adesso forse io la vedo sul focus sanitario però Eh, perché magari ecco tu in un colloquio rischi di poi perderti in tutta la storia di malattia di una persona. No, semplicemente magari specificare, cioè dal dal rene fino all'uretra e la persona croce. Eh? Di di appunto specificare, Eh per secondo me anche lì nella tua, per specificare esattamente che cosa si intende per sintomo è cosa per segno, grazie nel senso, sintomo in in medicina obiettiva, nel c'è la dispnea c'è la la mancanza di fiato è una cosa soggettiva, la desaturazione che io vedo sul saturimetro che la situazione non va bene è un segno. Effettivamente quando poi dopo descrivevano soprattutto se poi tu vuoi facilitare un linguaggio, poi con i professionisti, è vero che vale proprio la pena, che poi si può anche distinguere, nel senso che cosa intendi di per segno e cosa intendi per sintomo, no? Cioè però, se proprio secondo me vale la pena differenziarli. È questa, poi il secondo lavoro che appunto avevamo dato una definizione comune, Eh? Cioè secondo me è stata molto interessante, però anche lì secondo me vale la pena. Piuttosto ecco dare una, diciamo una carrellata di sensazioni comuni e oppure una carrellata di segni comuni. Ecco, anche lì differenziarli, perché secondo me vale la pena anche per loro e differenziare proprio la cosa e poi magari non lo so. Mi è venuta così che sarebbe interessante dire, OK, voi avete avuto questo tipo di disturbi? Però, effettivamente la letteratura dice comunque che questo problema qua ha questi sintomi, no, la nostra definizione, noi abbiamo la la associamo questo tipo di sensazione, malessere eccetera. Però la letteratura dice che il

tratto urinario è contraddistinto da tot tot cose, no? Perché almeno loro hanno poi un riferimento di cosa veramente è il problema, perché magari poi loro hanno totalmente una perché, per esempio non so se tu lo sai, ma adesso per esempio c'è un esplosioni delle della cosiddetta di problemi neurologici della vagina, no? Dove ci sono appunto questi problemi di di natura dolorosa, eccetera, che però non sono assolutamente correlati alle cistiti eccetera, ma son proprio di natura, Eh neurologica no quindi, ma secondo me vale la pena non lo so. Poi questo, vedi tu. [00:07:27] Researcher: Ma questi scusa intendi, tipo cioè ci sono malattie specifiche cui ti stai a cui fai riferimento OE più in generale una tipologia di dolore, scusa? [00:07:39] P1: Ma per esempio, cioè, ci sono adesso tutti questi problemi? E adesso com'è che la chiamano la oddio? Adesso mi sfugge, non la vagina. Neurogena la aspetta, Eh? Eh, tipo la vulvodinia. [00:07:57] Researcher: Eh? Infatti infatti ti stavo perché questo coso ho sentito, so che è diverso, però infatti ti volevo chiedere se era riferimento, OK, ma la vulvodinia è proprio una patologia? [00:08:06] P1: Sì, e adesso? La vulvodinia è uno dei problemi, però ci sono proprio degli studi che vedono che appunto ci sono proprio queste malattie neuro neurologiche del della vagina, che sostanzialmente i tratti nervosi periferici sono comunque danneggiati, anche a seguito di una cestite, cioè come conseguenza, ma non solo. Dove comunque hanno spesso questi dolori fortissimi questi problemi, anche a livello sessuale eccetera, ed effettivamente sono anche simili a delle. Poi ci sono spesso delle anche dei dei, dei problemi anche nella diagnosi no, che comunque la diagnosi differenziale è trovare il battere sostanzialmente. Quindi anche quello lì. Ecco molto frequente e poi? [00:08:57] Researcher: Ok, scusami solo per vedere se ho capito bene riprendere un po, cioè far lavorare sulle sensazioni differenziandole dai segni di di quelli che sono i loro sintomi legati alle alle cistiti, malattie del tratto urinario e poi introdurre qualcosa da letteratura che possa darle ai partecipanti un riferimento più specifico rispetto a quello che si dice al momento, diciamo cioè nel senso quello che è riconosciuto formalmente. [00:09:18] P1: Esatto. Esatto. Esatto. E poi ecco, diciamo dalla terza attività in poi mi era mi ha ricordato tantissimo. Noi abbiamo fatto un casino di attività durante il batchelor di Storytelling, quindi che è una cosa che va tantissimo coi pazienti, anzi, ci sono un sacco di evidenze e l'ho trovato quello che tu hai fatto alla fine, molto che si sposi molto bene con lo storytelling della malattia, quindi. E praticamente allora io l'ho vista un po così, nel senso che la prima attività dovevamo unire le parole e poi dopo abbiamo visto i materiali e poi abbiamo unito il tutto. No? Cioe io ho fin pensato che fosse più utile fare prima l'attività dei materiali, nel senso che tu mostri questi materiali. No individualmente non a gruppi, perché poi ci si influenza così una persona dice Ah ma cavolo il sages mi ricorda di più il il mio problema piuttosto che le biglie eccetera no poi eh, si fanno un'idea, no dei materiali di individualmente. Poi, dopo sempre individualmente. E guardano anche le parole, no? E ognuna associa a una parola il il materiale no e si fa una specie di storytelling. Poi ci c'è una messa in comune, no, l'ho vista un po un po meglio così perché ho notato come si influenzassero molto tra di loro. No? Cioè, è quasi come se una dicesse, no, per me è così, è giusto così e tu non hai capito no? E ed effettivamente proprio nel contesto dello spiegare la malattia, così è una cosa super soggettiva, no? [00:11:07] Si, no questa cosa è emersa, un po anche dopo che te ne sei andata. Siamo rimasti un po parlare e infatti abbiamo pensato di, cioè ho pensato in seguito alla conversazione di scambiare le attività, quindi introdurre primi materiali, fare addirittura lavorare le persone sulla costruzione dei propri sintomi, così come dici tu la scelta dei materiali sia soggettiva e poi come attività conclusiva, anche per innestare una sorta di confronto, far combinare le etichette, quindi un po scambiarsi le idee su io ho usato questo perché possiamo scegliere questo eccetera, quindi avere più un confronto alla fine che però non determina. L'ha scelta dei materiali per la propria comunicazione e decostruzione dei sintomi. Si questa cosa. [00:11:51] P1: Esatto, addirittura ho film pensato che è anche proprio l'ultima parte che è stata poi la costruzione del modellino che secondo me è è una cosa geniale, nel senso che... far proprio delle etichette vuote che la persona scrive esattamente le le sue sensazioni rispetto al materiale, quindi dare tag soltanto vuoti oppure tag vuoti con le parole. Però così una persona ha proprio la libertà di esprimere anche più e poi farli proprio costruire. Il modellino e poi aiutare

il confronto tra modellini, no che ognuno racconta la sua storia ha scelto queste cose, eccetera, che secondo me è una cosa, anzi troverai tantissimo sullo storytelling dei dei malati. Ecco, e tanti lo fanno coi video, ecco coi materiali, con con un sacco di di tools, ecco che si possono fare. Quindi, lo cioè secondo me è geniale. Comunque quello che è impazzato quindi. E quindi ecco questo così l'ho pensato così. Poi ecco alla fine appunto, la la storia della malattia che che appunto tu col modellino lì ecco questa cosa qua di di farla. Ecco il confronto di farlo finale perché è vero che loro si confrontano, però sembrava quasi come. Appunto, devo devo sapere le cose. [00:13:45] Researcher: Mhm, sì, mi sono fatta anche di questa cosa che c'è stato un blocco in generale all'inizio della costruzione, proprio perché sembrava che ci fosse un delle regole che hanno definito loro, però prima specifiche da seguire, quindi forse un po più problematica. [00:14:12] P1: Sì, ma addirittura per esempio, che secondo me è un po eh. Poteva magari influenzare il fatto che tu comunque avessi già messo con un ordine di gradiente, diciamo i materiali no? Su questa tavola effettivamente ehm, cioè per dire sopra, magari tu pensi che la palla grossa e perché è una cosa grande problema grande no, però effettivamente per me potrebbe anche essere una cosa leggera, un piccolo problema, ma che comunque lo vedo esteso. No, perché è grande, quindi non lo so se vale la pena proprio mischiare i materiali che ognuno così dice, no. Questo materiale, senza influenzarli in quel modo? Perché secondo me un po era influenzante quella cosa. E ecco poi di cioè di per se, poi il resto, cioè secondo me funzionava molto bene. Ecco anche la disposizione del tavolo e il fatto che comunque tutti ci si possa vedere con un viso, questo sì, è una unica cosa che ti direi che cioè secondo me è un'attività del genere, le persone dovrebbero avere il telefono sul tavolo computer, nel senso dovrebbe essere una cosa proprio full immersion no? Quindi ecco. [00:15:31] Researcher: Perché hai percepito qualcuno che fosse tipo distratto, intendi o per. [00:15:37] P1: No, allora non non distratto, però comunque c'è. Lo sappiamo che alla fine se tu hai comunque il telefono o appunti eccetera, comunque in qualche modo non probabilmente non ti focalizzi totalmente su... Ecco sulla. Poi adesso io non non so se, ecco magari perché era era la il primo prototipo, però effettivamente il fatto che fossero comunque tutte diciamo della stessa branca diciamo della dell'arte, è vero che ecco per esempio, io all'inizio quando tu hai messi materiale ha detto ma adesso che cosa devo fare? Nel senso, perché ovviamente non è la mia materia, però effettivamente, ecco loro poi non so se se magari a un certo punto si rompe più focalizzate sul loro lavoro che sul focus del del lavoro stesso. No, quindi avere magari ecco di diverse. [00: 16:30] Researcher: No, si era un po un pilot, quindi l'idea anche di di avere qualcuno lato design che mi potesse aiutare, poi anche a capire effettivamente l'uso dei materiali eccetera più dal punto di vista dell'organizzazione effettiva. Che poi della raccolta dati, sicuramente quello che citi del fatto di concentrarsi poi sulla band riuscita del modellino invece che su quello che effettivamente vuoi comunicare. Un po un rischio infatti ti volevo chiedere, vabbè tu da questo punto di vista mi dici non hai esperienza della malattia? Quindi, Eh, hai avuto più difficoltà P4 lavorare nello specifico sulla sensazione dei sintomi e sulla costruzione. Se il materiale secondo te potevano avere senso, comunque erano materiali con cui hai avuto particolare difficoltà a lavorare, ad esempio, ad esempio ti solo per farti capire un po il contesto della domanda. Altre possibilita che sto vagliando sono lavorare con la creta, quindi, invece che avere dei pezzi da assemblare direttamente, costruire qualcosa oppure per materiali totalmente differenti quali poteva essere la Carta o che siano presenti sul tavolo ma non già in forma di moduli, quindi blocchi, sfere, eccetera costruiti che tu devi assemblare la non so se tu hai qualche sensazione più che vero. Feedback su questa cosa? [00:17:59] P1: Ma io pensavo che appunto tu avessi scelto questi materiali perché ci fosse dietro, diciamo un, cioè ci fosse dietro uno schermo, scusami, sta andando la voce. Uno schema preciso. Ecco però, secondo me ecco io, per esempio, se se dovessi ecco rappresentare qualcosa, per esempio, non so delle stoffe piuttosto che come dici te dei pezzi di carta e anche colorati perché effettivamente erano esatto piuttosto che ecco la pittura, che è vero che può essere molto creativa, però è vero che anche per te poi magari la gente si sporca in giro, eccetera. [00: 18:20] Researcher: Mhm. Manca il colore. [00:18:37] P1: Piuttosto, ecco dei materiali, oppure non lo so, cioè adesso anche non so se avete dei tablet è

una persona fa un disegno, non lo so. Però è chiaro che non non puoi metterli tutto il il centro di bricolage della della supsi piccolo. Chiaramente però, però sicuramente ecco dare più materiali. Sì, perché effettivamente quelli lì erano comunque pochi, anche se molto rappresentativi, eh, questo sì, Eh. Però ecco, non magari, ecco potresti anche provare a nei vari workshop a cambiare il tipo di materiale e fai a tema no, però poi alla fine secondo me le persone riescono comunque in qualche modo a dire la loro, anche perché comunque riuscito. Molto bene anche con quei materiali. Secondo me, comunque hanno rappresentato tutte molto bene il loro problema, ecco. [00:19:37] Researcher: Ehm, se posso ti chiederei un po meglio di approfondire. Magari la prima parte, nel senso che proprio come domande, mi ero segnata, Eh. È se avessi avuto l'esigenza di avere qualcuno altro esperto con te al tavolo, nel senso che da da. Da idea dell'attività, un po anche per tipologia di partecipanti, che io cerco, io cerco sempre più eh, persone e donne con esperienza della malattia, rispetto, rispetto esperti. Ora ho in questa sessione ho trovato te, magari nella prossima cerco di averne un paio. Questa cosa secondo te ha senso? E tu dici, io non ho l'esperienza della malattia, quindi in effetti mi sono accorta anch'io, essendo questa la prima volta, però magari quando anche nella mail di onboarding che Cavolata ti ho chiesto di condividere la tua esperienza, forse separare meglio i ruoli di quelli che sono gli esperti rispetto a quelli che sono i pazienti. La mia un po paura, diciamo di creare due strade troppo diversificate o lasciare gli esperti come osservatori diciamo, è quella di creare un po una specie di sentimento, di magari giudizio o comunque mhm come se fosse un consulto quando vai dal dottore eccetera. Per i pazienti che poi certo, tu non era il caso, non non sono sicura non l'avessi fatto, però proprio a livello di posizione, magari delle persone coinvolte e dei partecipanti, anche perché questa volta magari erano tutte della stessa età. Insomma, secondo me si è creato un bell'ambiente, no? E però magari poi averne già solo persone che non si conoscono di età differenti eccetera. Potrebbe non lo so, magari creare una sorta di boh, sentimento di giudizio esagerato, però un po questo tipo di dinamica secondo te? [00:21:30] P1: Ma c'è sicuramente un po come capitato, comunque indirettamente, alla fine a un certo punto. Poi io avevo risposto alle domande delle questioni, perché effettivamente succede sempre questo quando c'è comunque qualcuno che conosce il tuo problema da un punto di vista professionale, poi mi capita sempre per qualsiasi tipo di problema, quindi è normalissimo. Anzi, cioè non lo vedo più un senso di di giudizio, ma piuttosto ecco come un senso di chiedere aiuto, no? Quindi non so se allora a questo punto vale la pena rendere proprio anonimizzata la cosa, però è vero che è nel senso, nel mio caso, cioè e appunto conoscendo molto bene dal punto di vista professionale la cosa. E è vero che io ho proprio il il. L'attività di per sé non è che riuscivo benissimo a svolgerla, forse nel senso del della ricerca. Ecco, è un po. [00:22:31] Researcher: Sì si no, quindi sicuramente ripensare un attimo, magari i due ruoli come differenti e capire non per forza. Entrambi devono partecipare a tutte le attività come dici tu, magari l'esperto può semplicemente essere osservatore. In alcune fasi però, pensare un po a un percorso un po diverso, per per l'esperto, e quindi tu dici magari ti può averne due, sarebbe meglio rispetto il fatto che tu fossi da sola. [00:22:59] P1: Max, cioè nel senso, secondo me avere una persona due persone, quello indifferente proprio è il senso di di poi dare a questa figura qua, piuttosto di nel senso, secondo me già il fatto che comunque perché un conto è se fossimo stati io e te seduti ai due poli differenti e gli altri in mezzo, però io comunque ero mischiata tra di loro, quindi secondo me ci sta di dire guardate, visto che comunque parliamo di di sanità i problemi dedicati così non può invitato questa persona che si occupa di queste cose che anche se comunque nascono anche questioni eccetera assolutamente. E io partecipò attivamente alla discussione, però effettivamente fare l'attività lo l'ho visto un po come un byas. Ecco, in quel senso. [00:23:45] Researcher: Mhm, sì sì, sì, no. E mi ritrovo molto con con quello che dici, OK, non so se tu abbia qualsiasi altra cosa da aggiungere, ma è stato davvero utile in generale tutti questi feedback non so se tu abbia dei progetti specifici, magari che conosci di storytelling, di che mi, di cui mi parlavi prima da segnalarmi o anche se ti vengono in mente prossimamente nel senso adesso, visto che la Supsi organizza dei degli incontri P4 Manno, se non sbaglio. Esatto, infatti c'è, ne sono un paio, uno proprio sullo storytelling, la medicina narrativa che mi ero un po andata già a vedere, a

cui penso di partecipare, ecco EO in generale se ti viene in mente qualcosa, un manda pure senza, senza troppi filtri. [00:24:14] P1: Sì. Sì. Sì, ma appunto noi io vendo avendo fatto la ***, comunque avevamo fatto proprio tutte queste lezioni sullo storytelling e so che ha fatto queste tipo carte da gioco con per esempio le diciamo delle delle raffigurazioni, di malattie eccetera, ed era un modo per era sui familiari curanti, su per chiedere aiuto, diciamo ai professionisti perché sono sempre più familiari curanti, quindi hanno fatto queste carte da gioco, oppure per esempio avevamo fatto dei vabbè questo avevamo fatto il bachelor dei video no, quindi? Cioè montavano i video con le foto, con le animazioni, eccetera. Però questo è già più per un pubblico sicuramente più giovane, però. Ma sì, ma per esempio non so perché so che per esempio la sai che c'è nelle... ci sono tutti gli ambulatori di salute sessuale, eccetera, dove ci sono problemi di sesso, però spesso ci sono anche, ecco problemi di natura, di cistiti eccetera, e so che ogni tanto organizzano dei workshop per per le donne, soprattutto per come prevenzione delle malattie sessualmente trasmissibile che non c'entra niente, però più o meno eh si sposa bene con. [00:26:02] Researcher: Sì, dove questo, scusami. [00:26:04] P1: Nell'ente ospedaliero cantonale ci sono gli ambulatori di prevenzione delle malattie sessualmente trasmissibili sono gli ambulatori di. Adesso mi sfugge il nome, ma comunque se lo cerchi lo trovi. [00:26:18] Researcher: Sì, sì. [26:20]P1: Magari anche, ecco, secondo me non lo so. Se però, visto che il tuo è un dottorato secondo me potresti anche chiedere a loro per la partecipazione, non so se. [00:26:31] Researcher: Stavo segnando questo contatto anche per questo motivo si, grazie.

A.5 Transcripts of the medical experts' final interview on workshop results

[ME] stands for Medical Expert, and each interviewee is assigned a number for clarity and reference. These interviews play a central role in the assessment presented in Chapter 5, as they provide the clinical perspectives used to evaluate and contextualise the findings from the workshops.

ME1

[00:02:59] Researcher: Qual'è il tuo ruolo e qual'è anche l'expertise che dal tuo punto di vista puoi portare a questo tipo di analisi? [00:01:38] FME1: Io sono adesso sono Matre de research and de insegnament che in svizzera è una posizione che subentra alla fine del PostDoc. Quindi forse quello che in inghlterra chiamano Senior Lecturer or Senior Researcher, in Bioetica. Quindi mi occupo di porogetti di ricerca che hanno a che fare con l'etica clinica, l'etica della salute pubblica, l'etica della ricerca con una forte componente di scienze sociali perchè appunto il mio dottorato è in quell'ambito. Un PhD in comunicazione sanitaria, che ho fatto qua a Lugano dove appunto mi sono occupata di progetti di ricerca per i quali mi sono focalizzata sulla comunicazione medico-pazienti. In realtà il mio dottorato era focalizzato sulle vaccinazioni pediatriche, quindi mi sono confrontata soprattutto con genitori di bambini piccoli e adesso mi occupo di progetti di ricerca che abbiano forte componente qualitative diciamo. Questo è il mio punto forte diciamo e anche la cosa che mi piace di più. (Breve interruzione dovuta ad altre persone che entrano nella stanza dove è l'intervistata). Dicevo appunto che mi iinteresso di progetit qualitativi quindi interviste e focus group. Mi interessa molto anche la parte di Design, ho in mente un progetto su cui sto cercnado di coinvolgere un pò di persone, sullo studio degli spazi per facilitare l'intimità per persone con disabilità, quindi come agire sullo spazio per creare delle situazione che favolricano e inibiscano la tenerezza, l'intimità tra ler persone che abitano in questi istituti o tra loro e le persone esterne.Appunto poi lavorando nell'ambito medico, il tuo progetto era molto interessante perchè utuilizzi questa metodologia molte innovativa in cui ci vedo un potere trasformativo enorme: Unatecnica che non solo ti permette di raccogliere dei dati ma, come lo chiami tu, un vero e proprio intervento, anche se ovviamente non è controllato, non è randomizzato, etc etc. Quindi mi piace molto questo come approccio. Anche io devo dire, non mi spingo fin dove ti sei spinta tu con oggetti e materiali eccetera. Però devo dire che anch'io quando faccio dei Focus Group cerco sempre in qualche modo di sfruttare lo spazio e gli elementi all'interno dello spazio che può essere. Vabbè, la lavagna ovviamente, carta penna

disegnare e mi diverte tantissimo in realtà è una cosa che mi piace un sacco, perciò quando ho letto il tuo progetto ho visto le foto eccetera, ho detto, ma che bello ti volevo essere io a fare questi Focus Group con te, questi workshop quindi, come penso di esserti utile? Ma intanto vabbè, lo sguardo etico, quindi ho pensato, ovviamente mi sono venute in mente un paio di domande sulla rappresentazione delle minoranze, sul tuo reclutamento, chiaramente sulla sugli aspetti di genere, perché chiaramente sono sono tutte donne, ma anche all'interno del genere femminile ci possono essere magari delle delle sfumature che può essere interessante cogliere. [00:05:53] Researcher: Certo. [00:05:55] ME1: La io mi pongo sempre la domanda, chi è che stiamo lasciando fuori nella ricerca? E quindi è un po la domanda che volevo fare a te, senza sensi di colpa o giudizi per essere consapevoli? [00:06:05] Researcher: No, no, no, no. Beh, è una domanda che abbiamo affrontato varie volte, perché adesso mhm? Questo è proprio quello che sto indagando per il mio dottorato. Il tema di ricerca deriva da un'altro progetto che sto seguendo qui in **. Che riguarda la sensibilizzazione al corretto consumo degli antibiotici e quindi da quel progetto poi già proprio il progetto, che è un inno Suite, ha preso un po una deriva, focalizzandosi sulle malattie del tratto urinario, proprio anche per i tipi di esperti che sono coinvolti nel processo e da lì si è deciso di focalizzarsi sulle donne. [00:06:26] ME1: Sì. [00:06:43] Researcher: Ehm, quindi un po il taglio che è stato dato JA definito, diciamo il la tipologia di persone da da coinvolgere nel nel progetto è comunque un grande problema che noi abbiamo affrontato sia proprio quando iniziavamo le persone in generale, anche durante l'attività ai workshop. Nel mio caso ho cercato di utilizzare il corpo, cioè visto che le malattie del tratto urinario sono più frequenti nelle donne, per una costituzione proprio fisica e come elemento di, cioè recruitment delle delle partecipanti e quindi senza andare, diciamo a parlare più rispetto a sensazioni, orientamento, eccetera. Ma proprio a livello fisico e quello che poteva riguardare una parte della della popolazione. Certo, poi il tema del di chi rimane escluso è sempre, diciamo. Ricorrente e in questo tipo di ricerca, forse ancora di piu, proprio perche si è deciso a priori per una prima parte, diciamo fino ad ora di escludere poi già la ricerca. Un po si è allargata, nel senso che se è partito da il focus sulle malattie del tratto urinario già non so se se arrivato a quel punto, ma nell'ultimo dei tre workshop si è deciso poi di aprire, Eh, diciamo l'argomento. Quelli che sono più in generale, le malattie e le infezioni femminili. [00:08:19] ME1: Sì, ho visto. [00:08:19] Researcher: Diciamo che anche il fatto di avere un gruppo di donne che parla della malattia già ha le accomuna appunto dal punto di vista fisico e facilita anche un tipo di interazione su dati e argomenti che sono piuttosto sensibili. Sebbene devo dire che anche dipende dalla fetta di popolazione con cui si lavora, perché è una delle attività. Uno degli workshop l'ho fatto con un gruppo di ragazze sui trent'anni, più o -25 32 e loro come suggerimento, alla fine mi hanno dato quello di includere gli uomini, non tanto perché portassero il loro contributo o comunque condividessero le loro i loro dati, le loro posizioni, ma quanto più per renderli consapevoli. Più per renderli consapevoli, quindi, utilizzare il workshop come un momento per loro ad essere per essere presenti. E capire meglio, attraverso anche l'interazione stessa donna o donna, quello che questa malattia avesse come conseguenze quello che comportava eccetera eccetera. Perché i partner infatti, sono molto spesso coinvolti, è in realtà una cosa che vabbè, condivido più dal punto di vista della ricerca con cui mi sono interfacciata e ho fatto più fatica e fatto avere il permesso. [00:09:26] ME1: Certo. [00:09:36] Researcher: E dalla parte del Brunel University in Inghilterra, Londra, rispetto le lo svolgere questo tipo di attività in modo partecipativo, quindi loro hanno sempre cercato di suggerirmi o pormi il limite di un... di interviste, comunque attività che fossero uno a uno. Proprio per questo problema della raccolta dati eccetera. Quindi ho dovuto non non poco, cercare di dimostrare tramite letterature, altre ricerche, eccetera, il valore della partecipazione in questo tipo di contesto, sia a livello proprio di possibilità di costruire nuove idee e creare qualcosa di nuovo, sia a livello di scambio, che avviene anche in maniera naturale. Perché questo mi sono accorta a venire anche dove non fosse stato progettato proprio, cioè dove non ci fosse un'attività progettata affinché ci fosse uno scambio di interazione tra le partecipanti, rispetto, pratiche, tecniche, eccetera. Questo avveniva naturalmente, quindi proprio anche a livello di di scambio di di

pratiche, di di usi, di problemi, di definizioni eccetera, che che avviene tra in modo naturale tra le partecipanti. [00:10:47] ME1: Scusa, ma loro cosa avrebbero voluto che tu facessi? [00:10:47] Researcher: Loro mhm, hanno cioè che facessi praticamente che tenessi la tipologia di attività che avevo progettato, però svolgerla in sessioni uno a uno come se fossero state interviste con supporto di materiali eccetera. [00:11:00] ME1: Ah. Ma non è la stessa cosa. [00:11:04] Researcher: Però senza esatto è quello no. Poi sono riuscita, però diciamo che è stata una cosa che mi ha anche sorpreso da un punto di vista proprio di permessi di barriera, che poi non è stata una barriera. Però di Eh diciamo limite che loro vedevano che poi sono riusciti a sorpassare, però che non mi aspettavo. Ecco di di trovare che ho trovato in se vogliamo interessante, nel senso che anche quello che magari non so, magari mi puoi confermare o meno nel mondo dell'arte, ma nel design è abbastanza assodato a livello di partecipazione eccetera eccetera. [00:11:04] ME1: No? [00:11:41] Researcher: E visto che comunque il college a cui faccio riferimento include il design insieme a Physical Sciences, magari un pò il diciamo. Lo step è stato quello, però comunque è stato superato, quindi diciamo che è solo positivo. Poi aspetto anche a portare questo tipo di contributo nel nella metodologia. Penso che il campo del design EE il modo in cui si relaziona anche con altri campi, in maniera interdisciplinare, è molto più avanti rispetto a non so, alla comunicazione e alle scienze sociali in generale, senza l'influenzare il design, cioè io. Io percepisco una stagnazione nelle scienze sociali, onestamente, delle volte anch'io vorrei fare delle cose un pochino più all'avanguardia, però mi scontro sempre con una. Sì, non so. Una resistenza nei confronti delle tecniche un pochino più innovative, come se uscendo fuori sai da da quei da quel protocollo, da quella standardizzazione, allora diventa qualcosa di. Si di sì, non ortodosso, quindi... [00:12:48] Researcher: Sì non valido, cioè non ci fosse la metodologia per validarlo. Ecco no è è vero, invece ti chiedo se c'è magari qualcosa che hai letto su cui non Sei d'accordo o comunque di cui sei rimasta più stupita, meravigliata o sorpresa, ecco. [00:12:53] ME1: Sì. Allora direi che ci sono due cose fondamentali. E sono collegate sono le le domande principali che mi sono posta mentre leggevo. [00:13:14] Researcher: Sì. [00:13:19]: ME1: Allora devo dire che ho fatto un po fatica a capire quale fosse la domanda di ricerca proprio perché è uno strumento che ti permette sia di raccogliere dati ma anche di restituire un po del potere alle persone, ai tu infatti lo dici a una tecnica che fa un empowerment delle partecipanti e quindi di trasformarle. Io sono sicura che quando sono uscite loro non erano la persona, la stessa persona che erano quando sono entrate e qua, è chiaro che che diciamo la distinzione tra questi due aspetti da una parte e citare che è un po quello che fa la ricerca con IE, dall'altra intervenire in questo contesto questa distinzione rimane un pochino più, diciamo sfumata. Non è così netta e quindi ti volevo chiedere come l'hai gestita? Ehm, nel senso che ed è sempre stato chiaro per te in quale momento le partecipanti ti stavano comunicando qualcosa? Oppure in quale momento tu stavi? Questo questo laboratorio stava funzionando come un intervento e come come hai gestito questa? Non voglio neanche dire ambiguità, ma proprio dualità della metodologia, perché penso che potrebbe essere una critica nel momento in cui tu decidi di pubblicare i risultati a seconda dello sguardo che gli vuoi dare dell'angolo natura da cui vuoi guardare potrebbe essere una critica dei reviewer un pochino più, diciamo appunto coi paraocchi, ma per me anche interessante io che non sono così bigotta e interessante per me, più capire come l'hai gestita tu. [00:14:58] Researcher: Ah. Sì, allora ti ringrazio della domanda è un punto, diciamo anche che sto cercando di svolgere e rendere più chiaro. Mi rendo conto, non è così facile, anche per adesso avrò la revisione dei 30 mesi, quindi organizzare un report rispetto a quelli che sono i risultati. Allora, a livello pratico io penso che il metodo scelto, quindi il fatto di lavorare fisicamente con dei materiali, lavorare, come dicevamo prima, in un contesto partecipativo, fa sì che e molto spesso queste due fasi coincidano nel senso che quello che è il momento di eh raccolta dati o comunque quello che è un insight per me che mi posso portare a casa nel contesto, nel con con diciamo nel nel tentativo di definire meglio la malattia. Quali sono i sintomi, eccetera, che era un po il primo parametro che ho definito come come gol della ricerca e ne nella raccolta stessa di questo tipo di dati, credo sia avvenuta anche tramite presa coscienza delle partecipanti stesse, nel senso che il materiale ha molto aiutato a far emergere o comunque trovare

nuovi vocaboli, vocaboli non scientifici. Magari ci riferiamo alla texture del legno, al peso del polistirolo, al rumore che fa il polistirolo, quindi ehm, piuttosto diciamo un po speculativi sperimentali o comunque più eh della realtà quotidiana non classificati. Ecco come diciamo prompt o comunque stimoli e per richiamare nelle partecipanti determinate sensazioni e dolori, momenti, eccetera della malattia tramite un po la loro presa di coscienza che avveniva in questo. In questo modo, quindi anche col fatto sempre in un contesto partecipativo, di riportarla agli altri e doverla spiegare tramite questi materiali, anche solo per giustificare che stessero mettendo una palla sopra un triangolo di polistirolo. Ok e quindi qualcosa che aveva assolutamente bisogno di una spiegazione, altrimenti non poteva essere compreso e quindi tramite questa loro presa di coscienza e loro esprimere questa presa di coscienza che era possibile, è possibile, tramite il materiale appunto che richiede una spiegazione. Io potevo raccogliere i dati o comunque ho raccolto i dati che non avviene questa raccolta tramite l'oggetto in se alla fine, perché se non lo leggo a quella che è stata la registrazione dell'intervista non e non posso definire quello che è stato detto. Però vedo queste due fasi molto legate tra di loro, proprio perché il metodo cercava in qualche modo di migliorare o comunque ampliare il tipo di comunicazione di quelli che erano i dati che volevo raccogliere. [00:18:08] ME1: Mhm. [00:18:10] Researcher: Non so se ha senso rispondere alla tua domanda. [00:18:13] Researcher: Sì, sì, sì sì. Quindi, dove tu dove vedi il contributo più grande di questo metodo è per la tua raccolta dati, cioè tu pensi di avere dei dati ancora più affidabili avendo utilizzato questa metodologia è aver avuto un impatto ancora più grande rispetto a quello che avresti ottenuto senza utilizzare i materiali. [00:18:37] Researcher: Allora questo è un po quello che io sto cercando ora di chiedere agli esperti nel senso, visti i le definizioni dei sintomi proprio specifici. Molto spesso alla prima fase. Io ho lavorato con delle etichette, quelle di legno, in cui erano riportati tutti, tutti molti sintomi che io sono andata a recuperare dalla letteratura. [00:18:51] ME1: Sì, ho visto. [00:18:57] Researcher: Io, con cui mi sono confrontata con con altri medici, quindi li ho riportati su queste. Tutte queste etichette è la prima fase del una delle prime fasi del match. Per disporre tutte queste etichette sul tavolo, chiedere per selezionare quelli più comuni, quelli che con che hanno sperimentato ed eventualmente aggiungerne altri, quelli in quella fase era un po identificare quelli i sintomi più comuni o è avere delle descrizioni? Mi chiedo, chiedo a voi più dettagliate, c'è qualcosa rispetto e quello che esistente e in alcuni casi sono stati anche aggiunti dei sintomi? Ora magari mancavano solo nella letteratura, perché là in quel caso, la letteratura si focalizzava su un determinato tipo di malattie, del tratto urinario, eccetera. Quindi anche questo è è è da capire, quello un po che cerco di chiedere in altri casi ho visto anche attraverso sessioni differenti, un po emergere. Simili ai sintomi o talvolta anche quelle che sono sfumature diverse di parole che venivano suggerite dalla letteratura che suppongo io però senza nessun tipo di background medico, possono anche dare una percezione diversa rispetto proprio quello che è la sensazione del della paziente. [00:20:12] ME1: Sì. [00: 20:13] Researcher: Quindi un po rigiro, forse la domanda a te, in questo caso e ti chiedo se hai rilevato qualcosa di diverso rispetto a quello che sono i sintomi riconosciuti. La situazione attuale del della descrizione di questi sintomi come proprio sintomi e poi seconda domanda, diciamo se modi diversi di descrivere magari dei sintomi che già eh sono riconosciuti e comunemente descritti, nel caso di quelle malattie, ecco. [00:20:43] ME1: Allora io non sono un medico, quindi non ti posso dare 111 parere sui sintomi, però tu li hai cercati nella letteratura, hai dato la possibilità di aggiungerne altri, quindi io direi che hai fatto le cose come si devono fare. È chiaro che se ti fossi fermata ai sintomi non ci sarebbe stato bisogno né di stamparli sul legno, né di. Diciamo di fare altro. Avessi potuto elencarli o scriverli a una lava su una lavagna, io ho l'impressione è che il fatto di avere avuto le altre etichette con gli aspetti legati al colore brightness piuttosto che i suoni, questo striduli a un certo punto il rumore del polistirolo. Il fatto di aver avuto i materiali, quindi la ruvidità, la la superficie liscia, eccetera, secondo me è quello veramente che ha permesso un'elaborazione più sofisticata alle partecipanti di descrivere quei sintomi EE spesso è quello che manca. Secondo me se sei in grado di dire mi fa male lì, però magari il medico ha veramente bisogno di capire se un dolore tipo un bruciore piuttosto che una sensazione di

scossa elettrica però ecco, se non si è, cioè non si conosce il campo, è difficile verbalizzare secondo me il materiale limitato, per quanto limitato, ovviamente perché Leopoli, stirolo, corde eccetera. Comunque anche questo va riconosciuto, non dava la possibilità di esplorare tantissime consistenze, ma un numero sufficiente, secondo me per dare lo spazio alle partecipanti di descrivere in maniera più precisa i loro sintomi. Ehm. E cosa è successo poi alle opere che hanno creato se le son portate a casa le hai tenute tu? [00:22:39] Researcher: Allora, sono tutte in ufficio. Infatti tra un po sono fuori io, eh, però in questa. [00: 22:41 ME1: Ok, Beh, dovresti fare una mostra secondo me sul sull'onda di quello che ti hanno detto, che bisogna sensibilizzare gli uomini, dovresti fare un... [00:22:46] Researcher: Eh? No, si potrebbe essere un allora. Diciamo che a parte la prima sessione in cui i materiali erano proprio liberi, quindi ho fatto una specie di acquisto folle di varie cose che sono state disposte sul tavolo e poi ognuno le montava proprio come voleva. Quindi c'era sì, spago, colla eccetera.Dalla seconda sessione in poi ho lavorato ad avere un kit, quindi qualcosa che ogni volta propongo e poi si crea, faccio foto si disfa e riutilizzo un po per non avere spreco illimitato di materiali. [00: 23:22] ME1: Mhm. Sostenibilità. [00:23:27] Researcher: Esatto e un po anche per facilitare quelli, quello che è l'incastro delle parti, perché come hai detto Tu, è vero che il materiale proposto è limitato. Sarebbe comunque, in ogni caso limitato, nel senso che poi rispetto le proposte che emergono dalle partecipanti. Non c'è mai tutto quello che che chiederebbero però questa parte è stata un po diciamo, tamponata dal fatto di avere delle etichette tipo post it adesivi in ultima fase con quelle partecipanti scrivono quello che avrebbero voluto invece di qualcosa, quindi magari anche l'impossibilità di portare che ne so vetro o magari dei materiali più difficili, però questa possibilità permette poi di segnare quello che avrebbero voluto e quello che mi sembra emergere. [00:24:00] ME1: Mhm. [00:24:14] Researcher: Certo, più è ampio il kit più potrebbe proporre dei vocaboli differenti. Però anche il fatto per lavorare per similitudini o talvolta anche negazioni, e quindi contrasto, perché anche dalle lei è di trascrizioni. Io spesso emerge che utilizzano un materiale per dire quello che il sintomo non è o comunque si discostano rispetto quello che è il materiale è già, diciamo un punto di partenza, per poi ampliare e certo poi sta alle partecipanti, nel senso che dipende un po anche dalla fantasia e dalla e predisposizione, ma anche attitudini nei confronti dell'attività che si sta svolgendo perché potrebbe essere anche un po un non sempre lavorare con i materiali. Ecco, può essere visto positivamente, però è proprio utilizzata come occasione per poi portare dentro, nella parte di narrazione e di racconto di comunicazione, che è quello che alla fine a me interessa anche altri tipi di materiali che magari non sono fisicamente sul tavolo, ma che vengono citati eccetera eccetera. E questo è anche diciamo definito dal fatto che, per esempio si parla di suono quando stiamo parlando i materiali odore col fatto, quindi qualcuno cerca dei materiali che hanno un particolare odore eccetera eccetera, che non sono qualità, diciamo primarie rispetto ai materiali che che sono sul tavolo. [00:25:25] ME1: Mhm. Sì, no, no, bello vabbè. In quel caso potresti anche pensare di portare delle fotografie del del ghiaccio, un accendino. [00: 25:49] Researcher: Eh infatti no, scusa scusa, mi sono persa allora? Esatto. Per la parte invece di restituzione sto facendo delle foto quello che sto cercando di fare. Poi, a fine progetto sarebbe avere questi modelli tre D, che sono esplorabili da un sito, quindi un po riaccoglierli per legarli alle storie è andare un po anche a identificare quali aspetti sono ricorrenti, anche perché da un punto di vista più del design, invece è quello che mi interessa è mettere un po insieme e capire se c'è una direzionalità nel definire l'associazione tra sintomi e sensazioni è variabile e fisica, quindi anche il fatto che tipo la sfera venga utilizzata per i sintomi iniziali OI sintomi lievi, mentre tutta la parte di punte. [00:26:03] ME1: Mhm. [00: 26:33] Researcher: Eh c'ha eccetera, esatto e vi venga associato a un'altro tipo di dolore in legno, il caldo eccetera e un'altra parte più legata al design che diciamo l'aspetto medico che che che mi interessa indagare, ecco. [00: 26:34] ME1: E più spigolosa? Ma a me sembra che tu in questo lavoro hai fatto almeno tre cose così, esternamente, in primo luogo, hai studiato il metodo, cioè, al di là dei contenuti, hai cercato di capire come questa metodologia ti permetta di raccogliere dei dati nei studiato un po la fattibilità, la validità e la la l'affidabilità e quindi mi sembra che abbia funzionato da quel punto di vista e potresti descrivere bene il funzionamento di una metodologia di raccolta dati che seguo

appunto questi questi tuoi principi con l'introduzione del materiale, insieme alle domande classiche, Eh, poi mi sembra che in secondo luogo. Hai raccolto dei dati sui sintomi, quindi hai. Hai raccolto delle informazioni su come loro interpretano i sintomi, come li descrivono e quindi sicuramente questo dà un contributo anche per via del metodo che le ha permesso di descriverlo in maniera più specifica, da un contributo alla letteratura su come le pazienti fanno esperienza dei sintomi e come li rappresentano. Anche perché siamo su quel livello della rappresentazione, ma poi c'è anche un terzo aspetto che è quello che ti dicevo prima dell'intervento, cioè tu. Raccogliendo i dati, testando questa metodologia, hai anche portato un cambiamento e lì mi chiedo, perché tu dici nel nell'introduzione? Lo scopo è anche di diminuire la resistenza antimicrobica. E dico, caspita come l'ho letto, mi son detta però c'è. Ne passa dal dall'utilizzare del polistirolo per parlare dei propri sintomi, a diminuire l'uso degli antibiotici e quindi è lì. Mi sono chiesto, OK, ma ma cosa c'è in mezzo? Come pensi che questo progetto, effettivamente in qualche modo riesce? Poi diciamo soddisfare questo, quest'altro, questo terzo scopo, che è quello di creare un cambiamento, cioè non solo descrivere, ma anche intervenire e trasformare. [00: 29:01] Researcher: Ah, sono d'accordo. Rispetto questa osservazione è quello è il contesto in cui è nato il progetto principale da cui, da cui poi si è sviluppato questa tematica di ricerca più specifica. E allora l'intervento, come hai notato prima, mira a comunque intervenire su la conoscenza della malattia e di quelli che possono essere i trattamenti. L'utilizzo degli antibiotici nelle donne tramite queste attività di confronto prima viene fatta comunque una presentazione, si parla di di questo, delle malattie c'è sempre l'esperta che comunque accompagna tutta l'attività. Quindi c'e un'interazione in questo senso e quindi è più su 1 1 conoscenza personale rispetto a quelle che sono le pratiche. Questo nel contesto specifico di come era partita la ricerca delle malattie del tratto urinario. Quindi, considerando quello che hanno condiviso le esperte del progetto con me su questo tema. Quindi il fatto che molto spesso si interviene con un antibiotico senza essere sicuri che effettivamente serva un antibiotico o con un antibiotico che non è specifico rispetto all'infezione e per quantità e tipologia di antibiotici che si potrebbero evitare. Non sempre, quindi il messaggio non è quello però, che in alcune occasioni si potrebbero evitare il fatto di migliorare la uno prima di tutto la conoscenza di se stesse delle partecipanti. Secondo la il il vocabolario, il tipo di migliorare la comunicazione che loro hanno con il loro medico va un po in tutto il filone di cercare di identificare il prima possibile, meglio la la malattia, in modo da intervenire anche poi con quello che è il trattamento in maniera più mirata ed efficace. Sono d'accordo che rimane un po più in secondo piano ora rispetto il fatto di avere allargato il focus della ricerca sulle malattie, sulle infezioni femminili più in generale, è che sia una cosa anche più difficile di cui avere traccia o prova nell'immediato, in quanto va un po su tutta quella che è la (unclear word). Io mi vedo sicuramente ci saranno anche nel però Eh, quindi andrebbe a toccare tutta un'altra area in cui io non sono voluta entrare un po per in mancanza di tempo, un po perché non era il focus principale della mia ricerca. Però in quella direzione, a questo punto quello che bisognerebbe cercare e capire e inps, cioè che avere una sorta di assessment rispetto a quelle che erano le partecipanti e vedere non solo dal punto di vista. Immediatamente dopo il workshop, qual è la loro reazione? Come si sentono, eccetera. Ma effettivamente, se questo tipo di intervento ha prodotto il loro qualche tipo di Eh, percezione esatto, più a livello di attitudine e comportamento. [00: 31:47] ME1: Cambiamento, cioè? Sì. Sì, sì. E rispetto ai medici, tu cosa ti senti di consigliare? Cioè, alla luce di questi workshop che hai fatto? E chiaramente questo pone tutta la pressione sulle pazienti e sulla loro capacità di descrivere i sintomi al loro meglio. Ma il medico, secondo te che parte deve fare? Perché io penso comunque una relazione di reciprocità. Quindi il medico come può, alla luce dei tuoi risultati, come può andare incontro alle pazienti? [00: 32:26] Researcher: Allora è anche curioso il fatto che durante il workshop devo dire il medico non sia una delle figure o delle prime parole, che venga citato, nonostante l'attività inizia anche proprio la descrizione della propria esperienza della malattia, molto spesso purtroppo, con le cioè le persone che che ho coinvolto magari hanno avuto la possibilità di parlare con il medico solo dopo un tot di di tempo rispetto quando la malattia era emersa. Qualcun altro invece fa mea

culpa, nel senso che ammette di aver trascurato determinati sintomi prima di rivolgersi al medico e quindi poter intervenire magari prima di arrivare Eh, qualcuno all'ospedalizzazione qualcuna delle partecipanti che che ha seguito i miei workshop e Io credo che sia un po proprio una parte di comuni, cioè un rapporto di comunicazione EI ovviamente dipende tanto dai medici perché e dalla disponibilità stessa in tutta, in tutta la fase. Il motivo per cui non si è deciso di intervenire, diciamo bidirezionalmente. E sebbene sia un problema, diciamo doppio, anche considerando il contesto in cui avvengono, di solito i consulti qui in Svizzera, quindi sia a livello di mancanza di tempo e assicurazioni eccetera. L'idea era quella proprio di focalizzarsi, ma non per dare colpa, ma più per cercare di anche un po in tutto il il filone emergente di responsabilizzare il paziente che più che paziente vuole essere cittadino che si trova ad affrontare determinate situazioni. Per Eh poter essere in grado di gestire determinati mhm situazioni, problemi fin dove lo competono, perché in tutto questo ovviamente l'idea non è quella di tagliare il medico fuori dal processo, OEO minarne la credibilità, ma proprio cercare di supportare il medico e abilitare il paziente. Cittadino a supportare il medico e per un ritorno nel senso della della propria salute, ecco. Vedo più difficile anche scusami solo per finire il un intervento sul medico, nel senso che ora so che sta facendo anche tanto per la responsabilizzazione e per per della prescrizione antibiotici. E anche sul problema delle della resistenza abbiamo fatto qui in su option workshop non legato a questo format, ma più proprio al progetto e in cui lavoriamo nel boratorio di microbiologia con dei Petri eccetera. E l'abbiamo fatto, abbiamo fatto due sessioni con le. Le studentesse di cure infermieristiche. Eh è l'idea era un po anche quella di cercare di sensibilizzare dall'altra parte anche da altri partner che lavorano a Basilea. So che in questa direzione si sta facendo tanto, ovviamente sulle nuove generazioni di medici, mentre è più difficile intervenire su su quelle vecchie, ecco. [00:35:27] ME1: Certo. Sì, sì, mi chiedo però, sai per avere questo cambiamento le pazienti devono partecipare al workshop. È evidente che questo non è fattibile, a meno che tu non ti Apri 1 1 studio e passi alla rastrello. Tutta la popolazione femminile e fai workshop con tutte. E quindi mi chiedo dove spostare questo? Questo intervento può essere tipo che lo si possa spostare dentro lo studio del medico, dove il medico ha uno strumento in mano, che siano le tue etichette piuttosto che del un materiale può essere anche magari un disco che contiene. lati cioè lati, scusami spicchi con consistenze diverse EE il medico aiuta attraverso questo materiale. La paziente spiega le meglio i suoi sintomi, lo sente +1 sensazione ruvida, una sensazione liscia, oppure fa toccare cose più fredde piuttosto che piu calde e magari addirittura qualcosa che dà una leggera scossa per far sentire la sensazione, ecco senz'altro fulminare le pazienti. Evidentemente però, ecco, mi son chiesta come trasferire poi da qualche parte tutto quello che hai imparato rispetto all'uso dei materiali. [00:36:41] Researcher: Ehi, sì allora. Di sicuro, infatti, come dice l'intervento è limitato rispetto a quella che è tutta la parte di popolazione, quello a cui sto pensando è una sorta di mini kit, ma proprio tipo tre oggetti che di piccole dimensioni, comunque che derivino un po da tutta quella che è stata la ricerca, quindi qualcosa appuntito, trasparente, qualcosa con una forma informe eccetera eccetera, che cerchino un po di essere rappresentanti, come dicevamo prima, cioè il legno, il polistirolo, non possono essere tutti i materiali del mondo, ma in base a questa ricerca possono essere. Rappresentanti di quelli che sono tipologie di sintomi diversi o perlomeno fornire un'occasione per dire, non è questo, non sento questo che magari possa essere sia dei pazienti stessi o disponibile dal medico, in modo che possa fornire sempre dei degli stimoli, dei suggerimenti rispetto alla descrizione. Ti faccio solo un'ultimissima domanda poi ti lascio andare rispetto quello che hai detto, tanto grazie perché hai risposto praticamente da sola a tutte le a tutte le le mie domande no citavi prima come primo contributo la metodologia e sono completamente d'accordo con te e mi chiedevo se tu vedi questo tipo di approccio applicato in altri contesti, quindi magari anche altre malattie e... [00:37:37] ME1: Sì, Dimmi certo. [00:38:02] Researcher: Se si, che tipologia specifica? È perché magari una tipologia piuttosto che un'altra. [00:38:08] ME1: Ma allora... La prima cosa che mi viene in mente sono le malattie sintomatiche, malattie croniche e sintomatiche. Quindi, visto che lo visto che il materiale ti da la possibilità di descrivere delle sensazioni, devono essere malattie che ti danno delle sensazioni

forti, ecco. Per delle malattie invece più. Ecco, se penso alla salute mentale non so se il materiale. Si presta bene, ecco, forse per la salute mentale mi viene in mente più lo strumento del disegno della pittura, più l'arte. Ecco, forse di qualcosa ancora più libero, addirittura forse pittura a mano senza neanche strumenti, quindi qualcosa più libero possibile. Invece, vabbè, io conosco il Serious game, serious play. Non non so esattamente. Ecco, per quel che riguarda invece aspetti più relazionali della dell'ambito sanitario. Ecco, questo il materiale sicuramente per le malattie. E mentre se guardi altri aspetti più di etica, più sociali, più relazionali nell'ambiente sanitario, mi vengono in mente più costruzioni. Ecco forse dove puoi e dove identifichi chiaramente gli individui e poi li puoi mettere in relazione nello spazio più in alto o più in basso e poi rappresentare stereotipi molto facilmente. Se hai anche dei piccoli oggettini accessori, ecco, l'abbiamo fatto da poco per una. Che cos'era? Era una manifestazione sul sulle donne e c'erano sì, potevi rappresentare degli stereotipi sulle donne attraverso delle degli Omini Lego e quindi mi viene, sì sì. Tra l'altro c'è proprio un kit che la leggo, Vende per una fracassata di soldi e puoi fare anche il training e diventare moderatore ufficiale di Lego Series Game. [00:40:26] Researcher: Ok, questo non lo sapevo, OK. [00:40:28] ME1: Si, no, è molto carino per i laboratori, per per fare col design, è fantastico per progetti mettere insieme le persone. [00:40:35] Researcher: Sì, sì. Ok. Grazie.

ME2

[00:00:17] ME2: Yes, so I am a project manager and researcher at the children hospital at Basel I have a clinical background as a nurse and, so I work very closely to patients and in hospitals and with other with doctors and and all that and but then I also have like a research background. A MA on health, science and the PhD in clinical research and my main project at the moment is about antibiotic stewardship and the spearhead project. [00:01:02] Researcher: And then I have like. Some questions to guide the interview, but actually if you prefer to go through the document I see you left some comments on that and maybe there is something that you want to start with, please. [00:01:17] ME2: Yes. I can. I can maybe just tell you like my overall. [00:01:24] Researcher: Sure. [00:01:25] ME2: Impression of it. [00:01:27] Researcher: Was the activity clear? The explanation of the activity clear to you? [00:01:32] ME2: Yes it. [00:01:32] Researcher: The workshop, the material out that's been used, et cetera. [00:01:35] ME2: Yes, yes, it was very helpful with the pictures and to see the materials that you used and. I think overall, my main comments is about the participants. And who they are, what they have and what do they represent in the population of people with UTI or other gynaecological diseases, so this was my main reflection. Can I elaborate that if you want and then. I was thinking that for citizens communication, I think the output, at least in in forms of the material and the pictures of what the participant did. A very beautiful somehow and and that could be a very funny to like to, you know, use for a discussion or campaign for like if it was posters or postcards that you could actually use something that you would not consider related to your infection or other infections and so I think the output in terms of material is really strong. And so that said, not answering all your question chronologically, yeah. [00:03:28] Researcher: OK. OK. Now thanks for the feedback. As I said, thank you for reading the the document. About the participants, so the first pilot to the very first that was run last year in October 2023 was run mainly with like designers. So people with a background in design or working in design, field communication design more specifically. But all of them with experience of UTI. Some of those was just like one episode, some other were recurrent. One of those went into hospital in the end was hospitalised because. cystitis and then another, and another one was not hospitalised but still have like a very recurrent episode and she was very invalidated by by the disease. So the reason of running the first pilot with the design people with design background was to validate the methodology, at least like to see if from a design perspective the idea of working with variables material, this workshop schedule and even the strategy was OK. No? So of course the kind of results were, let's say was easier in the end to work on this kind of material because they somehow are familiar with like variables and even translating data from numbers or feelings to materials, stuff etcetera. But they were recruited this specifically with the UTI infection. Then the second run was at Brunel University, where I'm actually doing my PhD and

there I asked the help of my supervisor to recruit participants. The recruitment of participant in general has been a quite of a struggle. Generally speaking, during the entire work shop. I mean people at the end are very happy to have taken part but to look for and like find people available to come even if you try to organise it on afternoon or Friday et cetera is quite difficult. So the number of people participating at Brunel was like quite little but, and among those there was one person who never experienced UTI but was interested in the method. So she was like interested in the method and the following what happened. But never like properly experienced UTI. That's when my supervisors, who also took part in the in the workshop, suggested to open a little bit the. How you say the focus when recruiting participants and the entire automatic of the the workshop. So instead of focusing on UTI only, try to see if I can engage. If I were able to engage more people and even see how people would interact when speaking about intimate infection, I still kept the focus of intimate infection of woman because I think. [00:06:21] ME2: Yeah. [00:06:43] Researcher: The fact that all the participants are female help a lot in terms of sharing the experience and have some common let's call it background or like a common like feelings and understanding about each other based on body condition and other stuff that happened because they their bodies. And so at that point I opened to intimate infection. That's also why during the last session that happened here in at the SUPSI back again, we had some people mentioning like Candida or other diseases. But what I found relevant is that even when the focus were on UTI or intimate infection, some people attended the worship like in the first case, thinking that what they were affected by was UTI or intimate infection and then kind of discovering during the activity and like speaking with the expert because there was always an expert with us. Or even among participants themselves that they what they were suffering was not UTI or cystitis, but maybe something different. [00:07:54] ME2: Yeah, yeah. [00:07:57] Researcher: And and. [00:07:58] ME2: This is also what I understood from what I read that you elaborate you you you the inclusion criteria you you opened up for them to recruit and recruitment is of course always a challenge is also also key that you have the right people because that the affects the outcome. I think my worries would be with what you did. If is this what you want me to do to to share, OK. [00:08:29] Researcher: Yeah, yeah, yeah, yeah. Please [00:08:32] ME2: OK, so my worries would be as a clinician and someone working directly with these patients that, I don't recognise those I know from the clinic or from the literature necessarily in your participants. What I when you look at at, you know, epidemiological studies where you see who is it, who have Uti's? It's typically so it's, of course mostly women, but it's also typically women around around pregnancy. [00:09:08] Researcher: Mm hmm. [00:09:09] ME2: And then you have a peak and you also have a peak with all that [elder] women. And then and then, at least for recruiting and and of course, then there's a lot in the middle. They often have other chronic diseases. [00:09:14] Researcher: Mm hmm. [00:09:27] ME2: And it's rarely there is, but it's when you see the picture, it's not a young, healthy woman and you have a young population. So for that I would consider the outcome when you have that. How would that reflect the order in this AMR population specifically to UTI? And then of course, you mentioned it yourself. You have people who are familiar with this kind of design. [00:10:00] Researcher: Mm hmm. [00:10:01] ME2: And that is for this. It's it's good for you to to test your your tools and all that. But I would also think about if you had to present this for someone who are not not in that [design] universe and how would that be? And then my one thing I have paid attention to is both what you write and what you say. [00:10:38] Researcher: OK. [00:10:38] ME2: "Intimate infections". I don't know this term, I never heard intimate infection. So maybe to to take be more sure that this is actually correct because the way I would phrase it, it would be more infection in the lower genitals and a sexual transmitted infection. [00:10:46] Researcher: Mm hmm. [00:10:58] ME2: Intimate you would also believe it had maybe something to do with the rap, the breast or, you know, intimate. It's it's it's, it's not precise and. And I think scientifically you would have to be precise. [00:11:13] Researcher: Sure. [00:11:14] ME2: And then I see a little conflict, not conflict, but I I worked also with sexual transmitted patients. And often when you have that it's a different way of you received it from a something that you can be shy about. A shame about you know and in reality, often these people, they want to be

anonimised when they go to the doctor because they don't want it to be in the record or anything and and when you have a UTI, it can be. So many other reason that something transmitted right? Because you drink too little water because of something. Your flora you use tampon, blah blah blah, which is more eligible to have this disease. So when you mix these two groups, I think there is some there is something about perception about the disease and symptoms would would be very different. And and that's also why I at some point asked, did you see any? There was only one with a sexual transmitted, but if she had something? [00:12:22] Researcher: You refer to a candidate infection. OK, yes. [00:12:24] ME2: Yeah, yeah. If if there was in your analyse, did you notice something particular about her capacity? Others because you could assume that there would be? [00:12:35] Researcher: Mm hmm. [00:12:36] ME2: And and that in and it's in that sense, I pay attention to the group, the population who they are, what do they represent and how can you bridge it to another setting? And I I understand it's not a hospital setting because the goal is citizens engagement. But yet the citizens who have that [UTIs] do have different faces than your group. [00:13:03] Researcher: I see, I see what you mean. [00:13:03] ME2: Yeah. [00:13:06] Researcher: I see what you mean by saying that the most people affected by UTI are pregnancy, woman and elderly. But could you also recognise in like young people, a different kind of target, but still people who can suffer from from UTI, or you do not consider them at all? Because ideally, while I suppose but This is why I'm engaging you. [00:13:26] ME2: Yes. Yeah, so. [00:13:35] Researcher: Is that like for elderly and pregnant woman the situation is very specific because other factors such as the fact that they are pregnant or the fact that they are elderly. So usually I suppose there are other disease or like things going on let's say. [00:13:52] ME2: Yeah. [00:13:54] Researcher: While the idea of even like bringing materials is to kind of enrich the vocabulary of of people suffering from it. So they can be more accurate, and because they might be affected by UTI. But even other kind of infection or diseases which should help them in best describing their symptoms. So to best then as a very second step I do recognise that improve the improve the treatment through the communication with the doctor or you see that I completely like group that is not affected by UTI or not be worth to be target somehow. [00:14:33] ME2: Yeah. No. So we can of we you can split the population and you can focus on one group and focus on your target and approach with them. And if we look at in that win in that perspective and then I think what you you find out is if I I didn't read all in in details but my impression was that it was about contact with the doctor. [00:14:57] Researcher: Mm hmm. [00:15:03] ME2: And it was something about finding information. And also to describe what you were feeling, how do you precede your symptoms? A lot of that and that you are not really you didn't have there was something I very interesting someone said. That you you don't have. You don't even think about it as a symptom because. You don't see it and that's why you need help, right? That's why you need to have to find valid information from and. Yeah. So I think in that context it's very fine. Very, very fine and also very learned I I mean it, it's. I think just like of of interest, I think what what effect what I learned from your result was. This about not really knowing your body well enough or. Or maybe not well enough, but not in that way. What could that actually be? This itching, this pain that you don't? You don't necessarily put it on something medical or disease or it's. Yeah. Symptom, so. [00:16:00] Researcher: Mm hmm. [00:16:13] ME2: So in that regard, in that context, if you isolate, move everyone else and that then I can I can. I think there is a lot to learn, yeah. [00:16:24] Researcher: Would you see like this sort of activity run for, let's say, for pregnancy people, for example as well? and might be more dedicated to their condition. Or you think because of their condition they need something completely different to to approach the disease. For example, I mean, I see elderly. [00:16:44] ME2: Yeah. [00:16:47] Researcher: Approaching elderly within this kind of activity quite difficult because all this stuff going on and materials. And even thinking about physical variables might be something like that. Need some. [00:17:00] ME2: Mm hmm. [00:17:02] Researcher: Exercise, but maybe for pregnancy people, would you adapt to the format or is it? [00:17:09] ME2: I think for I think what the group of you and pregnant people might have in common is that being pregnant can also, especially if you're first time pregnant, there is so much you don't understand about your body. So you have no clue like everything is growing and and everything.

So so this about being having something as in symptoms of infection is new. Right, so this about the novel being in that position of not have explored your body in that direction like the people you interview, I would see there is some similarities. Yeah, definitely, yeah. [00:17:49] Researcher: OK. OK. And from a medical perspective, considering of course the target as you just mentioned, have you spotted, let's say, any kind of different symptoms from the one you are inhabited to, to to hear from patients or recognised, because what I did is taken from the literature all the symptoms that I found related to initially UTI. But then, because people were working with these labels and there were also empty labels. So I asked them to if they have in mind any different symptoms to describe and add those, would you recognise anything like new or different from the usual ones? [00:18:28] ME2: Yeah. Can you remind me about the new ones? [00:18:37] Researcher: Yes, let's give you one second because I need to take the the table. Which is not this one. OK, for example, during the first session. Someone was differentiating, bloated from swollen stomach. [00:19:25] ME2: Mm hmm. [00:19:25] Researcher: Someone mentioned fever, which I didn't found and listed from the literature. But maybe is of course also about the literature I considered because it might be that the case as well, but. And then there was someone in the last session talking about this swollen kidney bladder. So this is how they composed the the symptom and panic attack that they wanted to figuring out in the in in the list of symptoms, not just as a consequence, but as a as one of the symptoms. [00:20:06] ME2: So fever, I would expect. [00:20:08] Researcher: OK. But is that is that correct that is OK, so it might not be appearing in the literature, but you say that it might be probably was someone that was in hospitalised or maybe not hospitalised but very like feeling very bad. [00:20:11] ME2: No, it's not always. Yes, yes. Yeah. It's more the severe. And most of UTI are not severe. Most of them are private general practitioner. For hospitals, for example, UTIs for SP2 we consider fever. [00:20:29] Researcher: Mm hmm. OK. OK. [00:20:46] ME2: Yeah. Swollen. I think it's. I think it's sometimes also because where is the pain coming from around your around your stomach and then people can describe it different, but it's to the same area of your abdominal. [00:20:57] Researcher: Mm hmm. OK. [00:21:06] ME2: I've never heard this about particular organ, a kidney or a bladder. Maybe the bladder, because it can be hard. [00:21:14] Researcher: Mm hmm. Mm hmm mm hmm. [00:21:16] ME2: Kidney. Yeah, you can feel the side. [00:21:22] Researcher: What about panic attack? Would you have any? [00:21:24] ME2: Yeah, panic attack. [00:21:28] Researcher: I think that was related to the fact that they are. They become anxious when they have to leave home, for example, because the feeling and the need of going to pee or that kind of feeling to have the bathroom close by or they cannot socially like integrate to others and always have this kind of. [00:21:40] ME2: Yeah, yeah. Yeah, yeah, yeah. Yeah. [00:21:50] Researcher: Inappropriate, yeah. [00:21:52] ME2: Yeah. Yeah. So for for example, there are some people they suffer of incontinence. [00:21:58] Researcher: Mm hmm, you continue and same yes. [00:21:59] ME2: Why they cannot control right, and they they worry a lot. Like it's really, really a burden. So if you have that feeling coming from a UT I I can imagine that is very true. Have I met anyone with such a fear? [00:22:20] Researcher: Would you consider it? That should be kind of added to the the literature, even if it's not like, of course a symptoms as like burning when you pee or this sort of stuff because it actually emerged several times from participants who wanted, as like, oh, who are talking about panic attack or if not, panic attack, but a sort of like anxiety. [00:22:38] ME2: Yeah. Yes. Yeah. [00:22:48] Researcher: As a sort of symptoms and trying to say, but this is a very like physical stuff is not just something as a consequence and would be would be cited as like other more recognised or like visible conditions. [00:23:04] ME2: Yeah, I mean, if it's something that appears as a team when you have these three different workshop, it's something that is addressed. Then I would put it, I I would mention it definitely as like a psychological reaction to that. [00:23:20] Researcher: Mm hmm. Mm hmm mm hmm. [00:23:22] ME2: And because you are right, when you read about risk factors and symptoms, there is not that. There is not that and and then and then if if that is a team, then this would be something to maybe explore more in a in another study that could be a nice suggestion. [00:23:44] Researcher: OK. Thank you. And may I ask you if from like the physical variables, so the way they associate symptoms or feeling with that like material stuff,

have you have you been impressed by any association or use of material or even word that they metaphor metaphorically used to describe their symptoms? Is there anything that you remember or you were impressed by? [00:23:45] ME2: Yeah. I like there was something that I, yeah, took my attention was someone who said she needed to use different materials to express herself because it was different. Feelings and different. Her symptoms were very different and they could not be presented by one material. They they had to be and I think that's also like what is mentally what is physically, what is emotionally, emotionally. That was a nice way, at least that caught my attention this. [00:24:30] Researcher: Mm hmm. Mm hmm. Mm hmm. Mm hmm mm hmm. [00:24:46] ME2: And she made for that. And then I also noticed that there are a lot who built, like with these, like, this foam paper. But someone ended up with a necklace and someone ended up with a something pointing upwards and a lot had this kind of, I don't know, things together objects, but those who had different. [00:25:00] Researcher: Mm hmm. Objects. Yes. Mm hmm. [00:25:14] ME2: This one that goes up and and the necklace they got my attention. [00:25:20] Researcher: Yeah. What I notice actually is that when. Participants got recurrent diseases. [00:25:28] ME2: Yeah. [00:25:29] Researcher: That it was easier that they were building something like, as you said, like or a sort of structure that. [00:25:36] ME2: Yeah. [00:25:37] Researcher: Help in going through the disease step by step. So even the necklace, but also the long thing... So what they did, they kind of generalise what's happened during all the diseases they experience. So they say for example, at the beginning it happened, this happened this and then always happened this which drive to this and blah blah blah while... [00:25:45] ME2: Yeah, yeah. Yeah, yeah. Yeah, yeah, yeah, yeah. [00:26:02] Researcher: People who experience like one episode or a episode that were most more severe. They tended to build a sort of unique, let's say, artefact, pulling all together, or the symptoms and and feeling they they got. I think it was about they, sorry, they kind of need or attempt to rebuild the disease so to avoid. [00:26:18] ME2: And yes. [00:26:28] Researcher: Or recognise what happened last time or what they usually drive them to the severe getting worse. So to avoid it. So they kind of build a sort of timeline, let's say, to identify the step and try to intervene somehow naive naively in the step that drove the the disease worst. [00:26:49] ME2: That's very interesting how that it's very fascinating that one occurrence is very detailed and the others where there's more. It's a more process. [00:26:59] Researcher: Yeah, it does the process that's the right word I I think. [00:27:01] ME2: Yeah, of of the event that happens, yeah. [00:27:05] Researcher: Why the expert that were attending most of the time. We'd like the most beautiful, let's say artefact and they were like completely generalising the disease. So first of all you need to be mentioned that they were saying I never experienced UTI. So I support people and blah blah blah. But I never like suffer from it. So of course make the the artefact completely different. But what they were doing is like. Focusing on material and stuff and generalise symptoms to so to kind of, probably because they were kind of reporting the feelings from patient or people they were working with instead of like trying to express what they suffered from. [00:27:48] ME2: Yeah, there were. It's their interpretation of their practise. Yeah, yeah, yeah. And that's very that's I like, actually also that you caught these aspects of someone who works very close with the people with UTI, those who have one episode and how that reflected and those who have more. [00:27:51] Researcher: Exactly. That's where the mouth and interpretation, yeah. [00:28:11] ME2: Maybe also because also some some part you said someone didn't even know they had that or that. But actually maybe working with materials without knowing, you can actually. Your your memory will know your actions of that, so it can really. Yeah, yeah, yeah. [00:28:29] Researcher: Yeah, yeah, you work on yourself no? Somehow through the material. Because you do you focus on that particular moment, time and even like sharing the experience with other help to kind of rebuild the what has been the the experience? OK, I don't know if you have anything to add for me, it's been super useful. So I really thank you for your feedback.

ME3

[00:00:30] ME3: OK, so I'm infectious disease specialist. I'm working here in CHUV in Losanna. Originally I'm from Belgium, but I arrived here five years ago and I finished my specialty here

and now I'm really like working here and I will continue here in Switzerland. I've been working in research I've been working with ** for transplant infectious disease, so not in urinary retract infection actually, but of course it's one of the main topic even in transplantation so. We have done some research also you in in pill nephritis and urinary tract infection in transplant patients. So yeah that's that was mainly my research area even if I have done a bit of different things. So yeah, and for now I'm working in septic surgery, so really infectious disease with infection with osteoarticular infection. Yeah. So that's my topic now. [00:01:49] Researcher: OK. [00:01:51] ME3: For now, yeah. [00:01:51] Researcher: Thank you. Thanks. I've seen you highlight some things within the document and left some comment, I don't know if you want to start from there or you prefer to me to ask you some questions, but if you want to start even like providing an over all feedback, I would ask you first if the activity was clear to you. So the explanation of the worship the strcture and the material that have been used, do you have question on that? It's more or less clear what I asked participants to do. [00:02:24] ME3: And that was clear. That was clear. Yeah. [00:02:26] Researcher: OK. [00:02:28] ME3: Yeah, well, the only thing maybe I'm not really the I I I think I can add an insight and an input on the really medical part and like the infectious disease part on UTI, but maybe my input in really qualitative study as you are doing, I'm not sure I'm really. I'm not really familiar with that actually. I'm not sure I'm gonna be the right person to really add something and help you, but I'm really. OK, to help you if you have like. Proper medical question or if I I can add something on that matter, but yeah. It's true that for me, I'm not really familiar with that kind of with that kind of study. Yeah. [00:03:20] Researcher: OK, let's not. [00:03:22] ME3: But but I'm I'm I'm happy to help if I can in any way. [00:03:27] Researcher: And that's not a problem in term of like the activity. As you saying, as you bringing like your medical expertise. I'm more than happy to hear from you in terms of maybe the symptoms that were discussed. If you like found or read like some uncommon symptoms or like uncommon way even to describe or to relate the symptoms within the disease, is there anything you read in in in that direction? [00:04:04] ME3: Actually, not really. Everything was. Quite. I mean thing that we hear in our daily practise with with patients and I think as I'm a also I'm a woman and I knew what it can be. No, it sounds quite familiar with the symptoms they were explaining and I didn't see anything completely illogical. The thing that you see when you read that kind of thing is that actually that when you're not from the medical, medical job or and I don't know if you don't know a lot about infections, you you see that there are some like way of thinking or way of thought that are really incorrect or really like yeah, not right. And that you can hear in the in the population when they are not working in the medical medical job. So that's why it is funny, not funny but to see that actually something quite common as urine urinary tract infection is not so well known. So that was interesting to see I think and I think that was a good thing that you add a medical doctor on really part of the in the meeting to actually clarify and add inside the medical insights in the discussion, because I think it's important to correct some way of thinking that are really wrong and I think that's that's add a lot. And what I've thought too, and I think maybe it's because it's a quite common and really (unclear) disease. We usually forget that part, that it's it has a real impact on the daily basis on the life when you have recurrent UTI. Actually it's it's really pain in the ass and it's, it's something that, as a medical doctor, you will not really. You're like, oh, yeah, it's OK. It's not. It's not a big deal because it's so common and so not severe and whatever. It's not. It's not that a big thing, but actually for the for the patient, it is a real big thing. And I I guess that kind of work can express and and highlight that parts, that is maybe a bit overlook in the in the medical like point of view, I don't know. So yeah, but that was quite interesting. [00:06:53] Researcher: Do you have feedback on the anxiety and the how they were called it? Like panic attack at some point that is related to the disease because both not actually all the three groups I work with, they were trying to kind of add and make panic attack if not panic attack, let's say an anxiety related to those symptoms and they need to go to the bathroom as one of the symptoms while... You can provide more feedback on that, but as I got those symptoms to start the conversation with from literature, those kind of feedback, those kind of like feelings were not considered as symptoms, while participants... [00:07:40] ME3:

But because it's not a symptoms as your like when you're describing a urinary tract infection will describe the the pain and the like, really the local symptoms. [00:07:43] Researcher: OK. [00:07:55] ME3: And but you don't describe the impact it has on your life, which is completely different. [00:08:00] Researcher: OK. [00:08:02] ME3: And never in a in a book you will find that psychological part and point of view in urinary tract infection. Never. You will not find out because it's it. It's not relevant for us because it doesn't help to treat it. But of course, it's gonna have a huge impact because if you have to go every 5 minutes to the bathroom, you cannot live a normal life. It's not possible. And if you have to wake up, I don't know, 10 or 15 times during the night because you have to go to the toilet. It has a huge impact. And of course that brings anxiety and that brings, yeah, might bring like. [00:08:41] Researcher: Yep, yeah. [00:08:41] ME3: Panic. And so that's the that's the secondary impact of being sick. And yeah, and even if it's something not not (unclear) at all, it has obviously an impact. And and secondary effects that are not mentioned by and not tackle or even by the the medical doctor. [00:09:07] Researcher: Yeah. No, I see what you mean. I see what you mean. And you mentioned the presence of the experts within every group I work with, I don't. If you have the chance to read the point where some of the participants it happened that they they attended the workshop because they were sure to got or have experienced UTI and cystitis more precisely, but then find out during the worship that was something different. Because they got the engage with others, but also have the chance to speak and confront with the with the expert. Is that something like I wouldn't say common, but that might happen. Or do you think there is still like even if some people suffer from if not recurrent, but some episodes of UTI not being completely aware of of of the disease? It might be possible or is is something... [00:10:02] ME3: Yeah, I was. I was a bit surprised by that. I think. But I don't know but. But that's a point that maybe patient don't understand well, actually the the the infection because when you read that kind of thing, you're like, OK. For for me, it's it. It's really clear and it's. Yeah, it's crystal clear that you have a difference between UTI and other infection like as you call it, intimate infection. Whereas apparently it's not that clear for them. So or not for all of them so. [00:10:47] Researcher: OK No, no is there. You said like you were surprised. Is there anything else in term of like answers or findings that emerge within the the analysis that you are surprised by, I mean? [00:10:59] ME3: Yeah, I think I I I read and it's exactly the same that, they were not really aware that when you have a UTI, it's a bacteria infection, as other like vaginitis and stuff like that are not always bacterial infection. That's. Yeah, that's something that is really important, actually in UTI, because Candida is not, never will never be with really few exceptions, will never be a pathogen UTI. So yeah, it's that kind of thing showed adding value of a medical doctor and that kind of a workshop actually, because you can really answer some question and some thinking. The other thing the the thinking I have heard that already, but I feel so weird. I don't know really why that when you you are sitting on the cold place, that is this factor for developing UTI. Just. [00:12:09] Researcher: You don't think I mean, that's not OK. [00:12:11] ME3: No, that's that's not scientific at all. And I don't know. I well, I've never learned that in any medical courses. So I don't know where that come from, but I've heard it from also non medical. [00:12:19] Researcher: OK. Because it's curious actually just the other day, no, any workshop going on, we were just sitting outside for lunch and a colleague of mine because we have some chairs that are made in concrete and some others that are metal chairs. And because it was quite cold but still sunny, one of our colleagues will say if we sit there, we wonder percent like getting cystitis. [00:12:29] ME3: Persons. Mm hmm. Yeah, I think it's really a like common thing, common photo, but I don't know where that come from. I have no idea and I don't think that there is any scientific basis on this. [00:12:54] Researcher: OK, not probably OK. OK, so there is no medical? OK, OK. I'm thank you. [00:13:07] ME3: I may be wrong, but I've never heard of it. [00:13:10] Researcher: OK. And regarding the description of symptoms, I know you're probably work in a different setup because you probably do not work with the out of hospital patients. Is that correct? OK, so OK. So maybe you don't have the chance to speak about symptoms with your patients or with people in general. Is there any way of describing? [00:13:23] ME3: Rarely, rarely. [00:13:36] Researcher: Or you face like you recognising in people the difficulties in describing and expressing their symptoms or

not really. And if you found in any of these description anything interesting that may clear the idea of the symptoms and something that you might find useful in having those symptoms described by your possible patient. [00:14:06] ME3: No, I think it was quite well described and I didn't. Yeah, I think I've never really. But maybe the patient had some difficulties and they didn't fool me, which is possible always. But I think again, as UTI is quite common and quite. It's always more or less the same. Maybe you have a bit more of this or a bit more of that, but at the end, the way to treat it is exactly the same to diagnosis exactly the same and to treat it it's exactly the same. So even if the symptoms are not perfectly described, I don't think it changed anything in the way you will treat it. And that was also one of my remark and maybe one of my general comment for the work you say in the first part that you research is about like describing symptoms and help patient to visualise and describe that better. [00:15:11] Researcher: Mm hmm mm hmm. [00:15:12] ME3: With the final goal to help decrease the antibiotic prescription. And the only thing I I have as a question at the end of this is how how do you manage to decrease antibiotic prescription with that? And I think it might be a really good idea and clearly we need that. We need to try to decrease the user. Antibiotic prescription. I'm not sure that I don't know actually, but it's clear that we prescribe a lot for UTIs. [00:15:47] Researcher: OK. [00:15:48] ME3: And maybe the duration of the treatment is not correct. Or maybe we give too much, too, too too many antibiotics for too many people, I don't know, but. Yeah, maybe it could be. There will be adding value of your work to add a bit in the conclusion how you think it gonna improve antibiotic prescription with that kind of work. [00:16:21] Researcher: Yeah, let's. No, that's a good feedback. Actually. The research has started addressing AMR and we focused because of the project on UTI and women affected by UTI. [00:16:22] ME3: I think that that's like a bit. [00:16:37] Researcher: So ideally at the beginning of the project was about empowering women in best describing their symptoms and together while working on materials also get more awareness on the disease and their bodies as well. So to have this chance to recognise some like pre-symptoms or some of the patient, the participants already call them pre symptoms so like mild symptoms that appear in the beginning so they can get an are aware of maybe not to go to the point that they need antibiotic but they might do something that can like stop the disease that coming out and this is useful in term of like exchange in term of like having your occasion for people to exchange possible. [00:17:27] ME3: Mm hmm. [00:17:29] Researcher: Findings, alternatives or behaviour that they found useful. [00:17:32] ME3: But I think you should add that because it will bring a bit. [00:17:45] Researcher: OK. OK. OK. And then through their building of awareness, also building of and like improving their communication so to help, ideally doctors as well in best understanding wha est. I mean, what antibiotic may be prescribed to be more precise on antibiotic prescription as well and see if sometimes that antibiotic can be avoided. Again, back on those findings that emerge within within people then because no, sorry. Just to conclude then I will leave you. Then the focus has been opened a little. So starting from UTI and cystitis, I tried to engage more people and talk about what I called. [00:18:13] ME3: Uh huh. [00:18:26] Researcher: Intimate infection. But I just got another call yesterday with another expert who was saying there is no definition of intimate infection. So it's something that probably I created myself and now I have feedback from you. So it's it's useful as well. So I tried to open it and of course the discussion changed a little because those people then are not mainly focus on those symptoms but. [00:18:36] ME3: Yeah. Of course, yeah. [00:18:51] Researcher: A more general symptoms. [00:18:53] ME3: I think it would be important to one focus a bit more about one specific topic, and I think it's gonna be more constructive and and you will bring, I think a better feedback from the patient with if you include only a patient with recurrence UTI and not any type of intimate infection because. That doesn't mean anything, and and you're going to have a lot of different. Background and different. [00:19:23] Researcher: Yeah. [00:19:24] ME3: Infection and topic, and I think it's gonna be better if you really focus on one problem and probably the big problem is recurrent UTI because a person who have done one UTI is something really, really not, she will not describe the same symptoms as you can have if you have urinary tract infection as every time you have an intercourse or every time you

you go, I don't know. [00:19:32] Researcher: Yeah. [00:19:52] ME3: Anything that will bring you a UTI and impact your life in a way that for a couple of days you're going to be like, well, not well. So I think that's probably one of I think important and another thing and oh yeah, and I wanted to add also that I saw that some describe like vomiting as a symptoms of UTI. So again, I think it's important to focus, but because probably vomiting is a symptom when you have a pyelonephritis, which is absolutely not the same as cystitis, like really low urinary retract infection, uncomplicated urinary tract infection which is something completely different of pyelonephritis, where you can have fever, and feeling not well and like vomiting. And then so I think that's completely to things completely different, and I think it would be better to focus really on low UTI and complicated and maybe recurrent in in women, because you're gonna have a more standardised group of women with. And probably the one we have the the, the, the. the bigger impact on the life, yeah. [00:21:16] Researcher: OK. OK. Thank you very much for your feedback. If you do not have anything to to add, I think we can we can conclude on this.

ME4

[00:00:22] ME4: I'm a pharmacist. I did my PhD at the Swiss Centre for Antibiotic Resistance. I worked there with data and performed epidemiological analysis in the area of antibiotic use, antibiotic resistance and antibiotic stewardship and since 1 1/2 year more or less I work in the University Hospital in Basel and the geriatric hospital in Basel for education as clinical pharmacist. There I try to support physicians and nurses in optimising treatment or just to answer to their questions or whatever and I'm also part of the Spearhead project and there we focus on how to use real time alert system to support physicians in optimising antibiotic treatment. [00:01:31] Researcher: OK. Thank you. Have you had the chance to read the document and understand the the description of the activity? I don't know if you have a question about the material and the activity participant have been engaged with was is that clear to you? [00:01:48] ME4: Yes, more or less. [00:01:51] Researcher: And if you have a question in that direction or you was there was something not clear to you, I'm more than happy to explain in detail. [00:01:52] ME4: Yeah. [00:02:02] Researcher: Then I don't know if you want to start with general feedback or a general like any kind of feedback. Don't feel like anything that I need or should be useful for me, but in general if you have any feedback regarding the activity or more in general about what you read. [00:02:23] ME4: I read the descriptions and for me it was difficult because I'm used to analyse and interprete data and not descriptions of an activity. I realised that there is discrepancy between medical terms and terms I don't know how we say it in English, yeah... [00:02:48] Researcher: Yeah, used by participants. [00:02:53] ME4: That they understand and that's that's important for this reason to have not only this medical terms and to talk about it and that the participants in general really understand what a symptom means. And I could imagine that's good to have a room to discuss such questions and feelings for the participants, or that was for me, seemed a result of the workshop. But I'm not sure if yeah, if it's needed that's work with material. [00:03:40] Researcher: Mm hmm. [00:03:41] ME4: You described a procedure about or a few procedures where you built it some artefacts and the participants need to described based on artefacts and material, how they feel it. That's for me, a really new method, I thought about that. It also depends how the participants or persons in general, how open they are for such methods, and I could imagine that would be a good method for also for children to learn about to talk what they feel or to describe symptoms. I could also imagine that's a cultural thing that we're not used to such a methods and I thought as well that I don't have contact with patients directly and that's it, for example, would be more that someone who works in the general pharmacy store, or is a General practitioner could probably give you more feedback than me, and that's also why I'm not sure if Andrea or Christoph can support your project this way and I thought, yeah, that were my general impressions and thoughts. [00:05:30] Researcher: Yeah. Have you ever took part or know about any, I mean different method, but to to work, let's say with the similar goal like you said that the method it quite new to you, but have you ever worked with the people to or engage people in, or took part, or know someone who have done something similar to engage people in talking about the disease to better

understand the disease and symptoms, for example, or not really? [00:06:01] ME4: Not really, no. [00:06:03] Researcher: OK. And and sorry, no, I was just trying to remember what you said the beginning. About participants and if if there is any like from a medical perspective, maybe something that you have spotted in terms of symptoms description or if you found any, like uncommon symptoms or any symptoms that is not usually described or present when talking about urinary tract infection. [00:06:49] ME4: Not really, but I'm not used to talk about symptoms with patients or clients, so. [00:06:52] Researcher: Mm hmm. [00:06:57] ME4: Doesn't say so much. That's why I thought it would be for this question. [00:06:58] Researcher: OK. [00:07:03] ME4: Be better to ask someone who was in daily life confronted with these questions [00:07:11] Researcher: Yeah, yeah, yeah, yeah. [00:07:12] ME4: Such a General practitioner, or yeah, in their official pharmacy store, because that is our frequent questions there. [00:07:18] Researcher: And yeah, I mean, I have other people involved, so I will address those questions specifically to them and from more, let's say, a personal point of view. Have you found any? [00:07:25] ME4: OK. Yeah. [00:07:33] Researcher: Unusual like, word or like definition that particularly impressed you in describing some feelings or or symptoms? [00:07:47] ME4: Not really. [00:07:49] Researcher: OK. And have you the other side identify any maybe problem within the method of like adopting physical materials to talk about the disease and involve people describing their symptoms? I mean, you said that you're not familiar with the method, but even from a non-expert point of view in in in this direction. [00:08:14] ME4: Mm hmm. [00:08:20] Researcher: But based on your medical expertise, do you find any like possible problem or? Even bias that might emerge in using material in this direction? [00:08:39] ME4: I think you have a bias in the group of participants because a lot of people would not participate or share. [00:08:50] Researcher: Mm hmm. [00:08:50] ME4: Share the experience this way. Or I could imagine that. And that. [00:08:56] Researcher: You mean because of the topic or because of the method? [00:08:59] ME4: No, not only because of the topic because of the methods, yeah. [00:09:08] Researcher: Because of the method. OK, OK, so you like thinking that is more something like for children, or even something not serious that I have to use to speak about something serious as their diseases. [00:09:15] ME4: I would not say not serious. I would just say that children are more used to play and discover material and that I think there are adults which like. [00:09:23] Researcher: Mm hmm. [00:09:29] ME4: And are open for kind of methods like this, but I could also imagine that there were would be. [00:09:29] Researcher: Mm hmm. [00:09:36] ME4: Up there a lot of, lot of persons would hesitate, hesitate in participating. [00:09:54] Researcher: Because maybe the fact of building something and the idea of having an artefact in the end. [00:09:57] ME4: Yeah. Yeah. [00:10:01] Researcher: So have some, let's say aesthetic composition or anything like that. Sorry, I'm I'm going through through the questions. And on the other hand, would you like see any other problem in sharing this kind of information from participant? I mean like talking about this kind of topic and diseases. It might be a problem in your premium for participants to do that also like in front of others or would it be something that they can discuss without any problem? [00:10:49] ME4: I don't understand your question. [00:10:50] Researcher: Or did you spot? Sorry if you spotted within the analysis some like let's say problem in participants to share their experiences of this kind of diseases, UTI and other intimate infections. Or not really? [00:10:55] ME4: Yeah. No, I thought that it provided space to share. [00:11:16] Researcher: Mm hmm. [00:11:16] ME4: Their feelings and that this work with this method, but I could also imagine that there would be other methods which would create this space to talk about insecurities and feelings and symptoms, and I read also that the participant like that there's an expert, so they could clarify some doubts. [00:11:34] Researcher: Mm hmm. Yeah, yeah, there was some cases where participants started the workshop considering to have a specific disease while discovering during the workshop itself that they what they were affected by was actually something different. So having experts, it's also something. [00:11:59] ME4: Hmm. [00:12:03] Researcher: Useful in in in that direction. Do you think expert might be interested in taking part in this sort of activity or not really? [00:12:18] ME4: Depends. [00:12:19] Researcher: Time of life. Time consuming of course. And what kind of feedback they might be

provided with, or information that might be useful for them. [00:12:22] ME4: Yeah. So your question was if I think that experts would like to participate in. [00:12:33] Researcher: Would be interested, yes. [00:12:36] ME4: In being participants or in being, yeah... [00:12:37] Researcher: In win, yes, I mean every group I organise they worship with was about participants and so women with experience of UTIs, different kinds, and then in every group there was one expert like a different kind of expert, but a medical expert that somehow support or answer some question from participant. And I was asking if in your opinion experts or physician, pharmacists. [00:12:47] ME4: Huh. Mm hmm. Mm hmm. Hmm. Mm hmm. Mm hmm mm hmm. Mm hmm. Mm hmm mm hmm. [00:13:04] Researcher: Gynaecologist, I mean different kind of expert might be interested in taking part in this activity to like engage with the part with participants, patients and see maybe what kind of information they might find within this conversation, or not really? [00:13:28] ME4: I think that that that our education is really focused on, I would say school medicine and you're not used to approaches like that. And I could imagine that a lot of expert would be open to give room for discussions [00:13:40] Researcher: Mm hmm. Mm hmm mm hmm. [00:13:54] ME4: To support participants in talking and clarifying their doubts. But I'm a little bit. I doubt I doubt that they that. [00:14:11] Researcher: Do you see any? [00:14:17] ME4: I doubt that this method would be an approach a lot of persons would be interested in being experts. [00:14:24] Researcher: Mm hmm. And do you see in this kind of activity or like group of people any useful information for experts, for physicians, pharmacists, gynaecologists, that might they might let's say extract or gain from taking part or would you like engage participants somehow to get some information in one Direction or in another? Or like nothing completely... [00:14:57] ME4: You mean, what them... [00:15:00] Researcher: Yeah. What kind of information would you like to ask or, not to ask maybe, know from from patients. Let's say that they might be engaged in a group to provide you with. [00:15:01] ME4: What? What, what? [00:15:17] Researcher: Is is the question clear? OK, not OK. So from a medical perspective, you were saying maybe they're not interest in engaging or taking part in this sort of activity, what might make the activity interesting for them would be like? [00:15:17] ME4: Don't unders no. I'm. Yeah. [00:15:36] Researcher: Them accessing some information from patients that might be relevant to them. Or maybe not. I mean, this is my. [00:15:44] ME4: Maybe not other. I think I have two 2 thoughs. One is to, I don't know, to organise a small event, for example in the in the pharmacy store that you have a small presentation about urinary tract infection and then what 1/2 an hour time for that's the clients or participants can ask the expert the questions and I could imagine that. [00:16:16] Researcher: Mm hmm. [00:16:21] ME4: The the medical expert would profit if they understand which medical terms are complicated. [00:16:34] Researcher: Mm hmm. [00:16:34] ME4: For for general patients to learn kind of more less medical vocabulary. [00:16:46] Researcher: OK, so how people... [00:16:46] ME4: Yeah, yeah. As, I don't know that it was just the impression when I read the document for me that that could be an issue, but I don't know because I'm not working in a pharmacy store. Yeah. [00:16:53] Researcher: OK, mm hmm. Yes. So you mean like the how patients or like general people describe their symptoms because that's different from medical vocabulary. So to better understand patients and general people more in general, how they do express and describe their symptoms, OK. And the last point last question is about empowerment. Do you do you see like possible and it may be useful to empower this sort of patients to? [00:17:15] ME4: Yep, Yep. [00:17:29] Researcher: Better understand and consume, I mean better understand the disease. And so this might lead to better consumption or not consuming antibiotics? [00:17:39] ME4: Huh. [00:17:39] Researcher: Do you see this sort of like empowerment might be useful in that direction, or is more about if they follow or not follow the the the the medical prescription? [00:17:52] ME4: I Think that I'm improving and understanding about the disease and what works sure has an effect on antibiotic use. Also because then the patient don't think, oh, I need an antibiotic and go are. I know that's a frequent issue that the patients ask the doctor for an antibiotic [00:17:57] Researcher: Mm hmm. [00:18:19] ME4: Doctors to refuse and say no, you don't need one or wait three days and I could imagine that. This problematic is improved. But for me the point would be also there that. It's a better

understanding and not it not needs to be the kind of activity such as exploring material and creating artefacts to better describe the symptoms. So it's more about a better understanding. [00:18:51] Researcher: Yeah, you mean. Which camps, for example, with the presentation in pharmacies that you mentioned before, something like like more direct to communication? [00:19:01] ME4: For for example, but yeah, more direct communication and not only presentation. I think it's really important what you created a room or space where you can ask your questions and that you're not too shy not to ask. [00:19:17] Researcher: Mm hmm. OK. [00:19:19] ME4: And a space where you have time. I think it's also an issue that when you go to the physician then you know how you only have 10 minutes and yeah. [00:19:30] Researcher: OK, thank you very much. I don't know if you have anything to to add. Otherwise, I really thank for your your time and reading the analysis and that's it.

ME5

[00:00:17] Researcher: I don't know if you had time to read more or less the document. I don't know if you have question regarding the workshop structure. The way I presented the activity, if there is anything that's clear. [00:00:27] ME5: No, I remembered you had explained it to me before, so it it was. And then you explained it very well in your document. So I don't I didn't have any other questions. [00:00:37] Researcher: OK, so if you want maybe starting introducing yourself with your background role and. Yeah, from study to what you're doing now. [00:00:52] ME5: OK, well, I'm **. I graduated from Geneva Medical School in 2022. So two years ago and then worked for a year as a intern in clinical research, medicine in infectious diseases at the hospital in Geneva. Working with **, Professor Huttner, who is specialised in urinary tract infections, so I helped her on different projects, but notably. A cohort study to. Be able to get data and try to understand incidents of urinary tract infections in the general population. It's a study that will be on a couple of sites, notably meant like 3 hospitals in Switzerland, some in the Netherlands, one in Germany. Yeah. And I also helped her with her, with her urinary tract infection clinic, which was a clinic that was just. Devoted to people who had urinary tract infections that were complicated and couldn't be and were not treated by general doctors, mostly people who had immunosuppression because of transplants, but also just patients that had multi resistant bacteria. From taking a lot of antibiotics and or from different reasons, but mostly was this. So I did that for a year and then this past year I've been studying epidemiology at the Shahite University Hospital in Berlin. [00:02:23] Researcher: OK. OK. Thank you very much. I don't know if you want to start with like general feedback. I actually seen that you kind of already start answering the question in the document, but if you want to like provide a general impression or something that you have been impressed the most. If anything within the within the analysis. [00:02:59] ME5: Well, I found that the the. It was interesting to see. And it's also what I wrote in the comments, how confused patients are about their own symptoms and also how unsure they are just in general about their diagnosis. The kind of confusion that like as a group, they can, they can influence each other and that it'll be like, Oh yeah, that reminds me of the pain. Right. So me too. And just the kind of general lack of knowledge when it comes to just the how it happens like. Just even if they have urinary tract infections or not. And. How it's a kind of collective. Thinking that helps them identify what the symptoms are exactly. And to put words on them better, you know. I was trying to understand. I don't know what the aim of the the thesis is this I didn't understand very well from like what is. What is the end point like? If it's something that is for the patients or is it for them to be better understood by the and get better treatment? This I'm not very clear about, but I found it very interesting. At least just for to create spaces for for patients to be able to better understand their symptoms and to therefore maybe better identify them. [00:04:31] Researcher: Sorry, can you hear me? [00:04:33] ME5: Mm hmm. [00:04:34] Researcher: OK, I don't know what happened to my computer because it looks stacks if you just wait a second because I can actually hear you. OK, it's back. I'm so sorry. I'm so sorry. I was trying to see if I can get my my phone to record you, but actually is back. Sorry. So sorry. [00:04:48] ME5: No room. [00:04:49] Researcher: Yeah. So about this study. The study started within the Spirit project, so the focus was to involve female woman with

urinary tract infection. To better understand their symptoms and kind of help them in developing as you're saying, the understanding of the diseases, so to act more properly in terms of consumed antibiotic consumption when possible or to start the cure before when it gets like the disease is it's getting worse. And then. As I say during the document. The focus open a little bit in terms of diseases considered and this is also what I see from your comments and this is something that someone else before you during this round of interview pointed out is the definition of intimate infection, which is something probably that I took from Italian and I never like had the the occasion to confront or see from within the English. But I will definitely like. [00:05:56] ME5: Mm hmm. [00:06:02] Researcher: Try to reframe the. The focus because I started with urinary trim tract infection that I've been suggested to open a little bit, so to allow more people to take part in the workshop and also because well as you were, as you are saying, some people attended the workshop because they were thinking of having UTI, but then discovered during the workshop that what they were affected by was not actually. Scientist or any other urinary tract infection, so was just to open a little bit the discussion and see if the material can help in. Working defining symptoms so enabling self-awareness of the disease and then communicate those symptoms to to the the specialist exactly. [00:06:42] ME5: Mm hmm. Professionals. [00:06:54] Researcher: Doctors or even pharmacists, as a first, like point to, to interact with them. So I do recognise the the fact of like most of participants actually do not properly know the disease and this is also why I found quite useful to have an expert within the the worship activity, even if the focus was not to like, teach them about the disease, but at least providing some some useful useful information. [00:07:14] ME5: Mm hmm. Mm hmm. Mm hmm mm hmm. [00:07:29] Researcher: OK. And then on the other hand, if there is anything maybe that you read and you do not agree with in terms of like? What have been said, or if there is anything from the method that maybe doesn't match the the the definition or the the needs of people in in terms of describing their symptoms based based on your expertise. [00:07:58] ME5: Yeah. No, I think this is a bit of a tricky one as well because these symptoms it's, I mean it's very personal and obviously like I don't really feel like I have anything to say that is wrong about how people feel and how they how they live their symptoms. I think that when it came to this description and the teaching of like you're only tract infections and and what brings them on, how to differentiate them from that vulvov, vaginal infections, which may be a useful term for you for the instead of intimate. [00:08:26] Researcher: Yeah. What did you say? Sorry. Did I? Yes. OK, yeah. [00:08:27] ME5: *****. No, it's usually what we call these infections and then like a better, a better teaching, as you said, it's not a teaching workshop, but just there were a couple of things with that that I didn't completely agree with or that maybe weren't as precise as I would have taught them, I guess. [00:08:46] Researcher: Mm hmm. [00:08:48] ME5: But apart from that, like no, I think that it's it's it's just difficult because. Obviously like it these these infections, they're very similar. In that they are the same. Sphere like it's just not the same sphere, but it's the same. Environment that they function and it's also very intimate, but they're very they're treated very differently and they're very different in terms of like how they're seen like most of the vulvov vaginal infections, not a lot of them would get would be treated by antibiotics. So it's just it's it's kinda hard to link them together. In this way, I think it it, it becomes a little bit more scattered and again I understand why it's done because obviously if you don't know the difference and if you think that a a vaginal infection is a urinary tract infection, but it isn't quite so it's it's a, it's a bit of a big bag you know. [00:09:56] Researcher: Mm hmm. Mm hmm mm hmm. [00:09:58] ME5: Because obviously then it will be. Will be a different set of symptoms, and that's also how how medical professionals are going to try to to go from one to the other, like to differentiate if it's a urinary tract infection or vaginal infection, it will be definitely because of the symptoms. So linking them together and trying to find. Some kind of homogenicity in the symptoms is going to make it difficult for. Like it, it kind of takes away from like the point of like diagnostics. But then if the if the aim is to try to like better understand symptoms in general, whatever they may be. [00:10:42] Researcher: Mm hmm. [00:10:42] ME5: Then that I think is is helpful. Yeah. [00:10:45] Researcher: OK, I see what you mean. So in terms of like understanding the

disease, you should keep, you would keep the diseases separated. So have a workshop session run on UTI, another one on different diseases. [00:10:58] ME5: Mm hmm. [00:11:01] Researcher: Would be the comparison or like at least like people speaking about maybe what's appear as a similar same symptoms but. Caused by different diseases. Be useful to understand the differentiation between these diseases. We're not really. [00:11:20] ME5: Sorry, could you repeat that? [00:11:21] Researcher: Yes, sorry if the the conversation that might happen between participants that experienced the kind of similar symptoms but caused by different diseases may be useful to better understanding how those different diseases actually. [00:11:34] ME5: Hmm. [00:11:44] Researcher: Like the effects of those different diseases on on on the way people perceive those or it's better as you were saying actually to to keep them separated. [00:11:50] ME5: Mm hmm mm hmm. Well, it's just I think it's difficult because in our kind of like teachings of these two diseases, they're not the same symptoms you know? So that's the thing. They are different. And so I would be worried in this case that it's influencing each other. So two people are talking about pain, but it's not pain in the same place and it's not the same type of pain. [00:12:02] Researcher: OK. So they're completely different. Hmm. OK, OK. [00:12:19] ME5: In general, like vaginal infections will be more of different like different like it. Obviously it depends which ones. There are some that are sexually transmitted, some that are not. And then it would be more of kind of difference in odour or or smell. Discharge, whereas in urinary tract infection in that case will be more of an incontinence, more of pain and a different type of pain and slightly localised, differently localised so. It's difficult to yeah, because if they're together, I would. I would be afraid that they were influencing each other in the in the. In exactly what the symptom is, you know. [00:13:00] Researcher: OK. Yeah, no, I see what you're saying. Actually, you mentioned the fact of influencing each other. Is that something that you have seen as well when you say about like it's interesting how they are not aware of the disease and they maybe say I have that kind of pain. Any other participants say, oh, me too, that was blah blah blah. Do you think they can somehow influence in the way they perceive and speak about the symptoms when together? [00:13:13] ME5: Mm hmm. Mm hmm. Well, I think it's very helpful to have somebody say something and then you can say if yes or no, that is the same. I don't think it influences in the sense that I don't think people are lying about like that happened to me or not, but just I think it's easier to like when it comes to pain. It's very difficult to to describe it yourself, especially like to describe it in a way that people will understand it. This is why in, in, in medicine we talk like to give options like how do you see your pain? Is it like a stabbing? Is it like a burning is it like? [00:13:37] Researcher: OK. OK, OK. OK, OK. Mm hmm. [00:13:55] ME5: In the case of of urinary tract infections, it will often be. Urinating needles like you're feeling. And so these are things that you you give them examples just because it is hard to to describe it. It also in a way that will make medical professionals understand a path that is linked to it. So I think that it's useful to have these words to be able to be like, do you feel it as a heaviness, do you feel that as a this and that like typically with prostate infections in men? [00:14:01] Researcher: Mm hmm. [00:14:26] ME5: This is a it is a pain that they have a very, very hard time describing. Men don't often have pain in general, so they have trouble when they have to describe it and. Typically with this it's also a part of their body that they're very not. They're not very in linked towards, right, so we'll say does it feel like a hot potato in the in your pelvis? And this is always a bit surprising. But then if they're like, Oh yeah, kind of, I don't think they're lying about it, but it's just, it just helps them. [00:14:51] Researcher: No, no, no. OK. Yeah, just a sort of, like collective brainstorming, let's say, where everyone can help each other in. [00:14:58] ME5: Exactly, exactly. Just just because it is hard to figure it all out on your own, I think. [00:15:02] Researcher: Yeah. And in terms of symptoms? That you have the chance to read the through the document. Is there any like let's say uncommon or anything like that you are not inhabited to? To listen from people experience those kind of infections and diseases. [00:15:23] ME5: I think people don't talk about the anxiety and the fear behind having infections enough. It's it's. It's also then it's like a bit of a circle. Like are they afraid? And then they have the infection. Does it feed into it? But it was also the swollen, the swelling. This is not something that we hear often with urinary tract infections, but at the same time it was not. It was not used As for from

what I saw from the document, they didn't keep it as a as a main symptom. [00:15:49] Researcher: OK, OK. [00:15:50] ME5: I think I was a bit of. I was surprised about, yeah. [00:15:52] Researcher: OK. And on the other hand, if you identify any unusual word to describe the symptoms, the disease that maybe you never linked those symptoms or never hear about linking those symptoms to in terms of for example even. I provided them with the physical variables so someone was even mentioning like the temperature or like smell or this kind of stuff. And is anything that like. [00:16:19] ME5: Mm hmm. [00:16:24] Researcher: Call your attention. Let's say your were you surprised by the association? [00:16:26] ME5: No. Not particularly like I think that, especially with temperature, it's definitely something that we see with with your new tract infection patients that they like this link to cold is very, very common that it's this peached person who was saying like, oh, if I sit down on a rock, then I can be sure that the next day, this is all something that it's. It comes quite often. So this I wasn't, there was nothing that I was very shocked about now. [00:16:51] Researcher: OK. OK. And would you see any like specific or like general problem in providing material to help people in describing their symptoms. So associating symptoms and feeling with like physical material if there is any, I don't know maybe limit or? Anything that in my in your opinion might not work or might be problematic. [00:17:24] ME5: Well, I depend. I think it depends on which goal, like when. If it comes, if it was to make doctors better understand what the person is feeling, I think it's difficult because then if a patient's like oh, it feels it reminds me very much of this and they take out a wooden sphere then like the doctors may not know what that means. Do you know what I mean? Like, I think it would have to be. [00:17:47] Researcher: Contextualise somehow or within a conversation when you use that that object to describe a more. [00:17:48] ME5: Mm hmm. [00:17:54] Researcher: Like. [00:17:54] ME5: I think a link to a symptom that doctors would know more because what what or anything of or a like any healthcare professionals they'll focus on on like the burning or not. So it's it's just these abstract. [00:18:00] Researcher: Mm hmm. [00:18:12] ME5: If it is true abstract, I think even the the medical professionals won't won't really understand about it like it it has to be finding a way to find words that are in understood by both parties I guess. But I think that maybe. Maybe if patients, I think it's good to have them think about it more as well to be able to to say no, it's this or not this. But the problem is then time wise I don't know how that would work. You know the problem is that these consultations usually last maximum 15 minutes and in general if there's a, if there's a suspicion of urinary tract infection, it's going to go very, very fast. [00:18:53] Researcher: Mm hmm. [00:18:55] ME5: So I don't know to what extent this is. The problem is that often times patient and this is problematic, patients are not asked to describe it. They'll they'll be asked to answer questions. [00:19:05] Researcher: OK, OK. [00:19:06] ME5: Just like that, like. [00:19:08] Researcher: So even like for example, as multit made out of free object that the patients can handle during the conversation to like describe the pain without specifically like build or do stuff maybe not like decades because you say you see you consider that it takes too much time. [00:19:29] ME5: Might, yeah, because it would just be easier to be like is the pain more of a burning or is it more of a, you know, like, just to answer this way and to answer questions directly. [00:19:42] Researcher: No, I see. OK. And the last question, if you see like this kind of describing symptoms, I mean. You are expert in this direction, but would you consider for any other sort of diseases or would you apply this sort of activity to any other kind of body conditions? [00:20:06] ME5: I think it's very interesting for chronic pain. [00:20:09] Researcher: OK. [00:20:10] ME5: Chronic pain is difficult because it's very, very personal and a lot of times it's it's very hard for patients to describe it and then very hard for for medical professionals to understand it. It and it can pain takes on a kind of like different meaning. People get used to it. People don't. It's it's people live with it a bit different, more differently. And I think it might be helpful there. And there we have more time to try to understand what's going on and it's and it's there's more of a need to try to characterise what the pain is and to try to understand it. I think with other symptoms it's maybe not so necessary but pain. In itself, when it is like chronic and in places that. Are not very common for a certain for a specific disease and not like linked to a specific disease. Then that could be more practical. [00:21:01] Researcher: OK, so you're not speaking about

urine tract infection like a chronic diseases, but more general about like chronic disease that are not already somehow linked to specific diseases or causes. OK, OK. And the last thing, sorry, because you were mentioning say, what is similar and what is different, do patients like also? [00:21:14] ME5: Exactly. Chronic pain, yeah. [00:21:27] Researcher: When describing the pain or their condition, they seem to be in general. Use negative sentences or just positive sentences. I I mean maybe this isn't something that you never like pay attention to because I seen and they didn't. I mean expected because never thought about that. But they quite often use also. I mean they were using materials also to say what they were not feeling or what the material does not represent so. In terms of like designing the workshop, I was preparing material to enable people to take the object they were. Feeling close to and then associate those symptoms. But very often they were thinking the other way around. So maybe choosing something because that's far away from something else. Is there something that? [00:22:19] ME5: I think they describe what's normal to them and then they'll be like, it's not like normal. [00:22:22] Researcher: OK, OK. [00:22:24] ME5: You know, especially with your. [00:22:25] Researcher: So comparison between what they do consider normal and not. [00:22:28] ME5: Because especially with your only tract infections, a lot of the times very early patients who have them and have them often they know even though there isn't a pain or there isn't there, like something's wrong, something's not normal. I know I have something is coming. But otherwise it's very much like if a symptom's there they'll they'll talk about it, yeah. [00:22:48] Researcher: OK, OK. I don't know if you have anything else to to add there. I more or less ask you everything I was. I was interesting in and has been very useful. Thank you very much for your availability.

ME6

[00:00:03] Researcher: Was the description of the activity, the workshop in the document clear to you? Do you have any question regarding the method or any other point within the analysis? [00:00:20] ME6: No, but I didn't... yes so. Yeah. So the purpose is to empower women in data collection of the symptoms of UTI, is it? [00:00:33] Researcher: Yes, yes, I mean. Then research started within this period project and so I started facing UTI. [00:00:41] ME6: Mm hmm. [00:00:46] Researcher: To trying our. To best describe it, empower woman. So best describe the disease they symptoms. So better communicate the disease to doctors and try to get the. Treatment as accurate as possible, so to avoid. Any misuse or overuse antibiotic when, when possible, and to get like precise antibiotic for for the specific disease. Then within the course of of the research. Because they were participants, sometimes they were attending being like. Having or having experienced the UTI then discovered during the workshop that what they were suffering from was not sometimes. Yeah, I open up a little bit the focus of the workshop, including other what I actually called within the document, intimate infection. But as I run already some interview colleagues of you actually suggest me to go them Volvo vaginal infection. [00:01:55] ME6: Hmm. [00:01:57] Researcher: So I opened up a little bit the focus, but the purpose is still is to is the have a sort of like three goals that match. And support each other. So empower woman and through the material promote the self-awareness of the disease again through the material. Try to improve the communication of of symptoms of the diseases. So this woman can not only better understand what happened to their body but also communicate it better to to doctors and then as. They ideally better communicate the disease to the doctor, improve the collection of data and information within the. Description of symptoms and disease more generally. This is like. I the ideal situation there, the purpose, the purpose of the study. The goal of reducing antibiotic consumption is quite far in the mean that for a design purpose I should have. Go deeper into behavioural change which which I didn't because of time and because was not like. The main interest of of my research. But of course, if we mention the fact of reducing antibiotic, I should add then find a way to assess if people engaged in the workshop change day consumption habit or more generally, the attitude in consuming antibiotics. [00:03:37] ME6: OK. Yeah. I mean it's it's interesting. Like from an artistic point of view, maybe like to raise awareness on vgi. But I am like, did you to to start this because like in our clinical practise? [00:03:53] Researcher: Mm hmm. [00:03:54] ME6:

That usually the woman really know their symptoms. You know? So. So there's there's there's very rarely problems. [00:03:57] Researcher: OK. [00:04:03] ME6: In the communication between the doctor and the patient and our practise at least. Sometimes maybe there are some people who have. Urines that have a false smell and they think it's a UTI, so we tell them it's it's studies have shown that if you don't give any antibiotic, you're not going to have other symptoms and you're you're going to get better. So it it's not a sign of your child. But other than that usually when they say like I feel I have the UTI and we do an analysis, it's a UTI you know. And it's rare that they. But I mean sometimes, yes, it's it's it's like the the the symptoms can overlap with with mycosis. But then you you need like lab work to distinguish the two you know like I mean I I don't think that's by really like developing all the symptoms exhaustively. We're going to be able to differentiate the two you know. We'll never be able to replace the. What's labs ad in this case? You know, because sometimes they overlap, but it's it's not so frequent. But sometimes they do. So. So did you feel that the the patients were? Had this request to you. Like we're saying, we feel that doctors don't understand us and we tell them we have symptoms and they tell us no, it's not an UTI. See what I mean? Like, is there really a needs to develop these symptoms so much like? [00:05:41] Researcher: Yes. To be honest with you, when I was running the worship, the doctor was mentioned just sometimes and not so often. So at usually at the very end of the. Of the process and of the activity. So what happened is that they usually try to. Do or act as they've been told. For example, maybe because they went once to the doctor or because someone else say them what to do. So they try to manage by themself and during the worship I have a three participants in the three during two actually different session that were saying that. They were. They have been hospitalised in the end but they were saying that's sort of like. One of those was saying that's fault of mine because I'm very busy. I'm working a lot and I kind of like. [00:06:49] ME6: Hmm. [00:06:49] Researcher: Not considered the initial symptoms, and because the doctor were not like responding and I didn't have time to go to the doctor, then symptoms to get to the point that there was like they were severe and these two people actually have very like a bad experiences of of UTI. Then in terms of the other, I felt that there were different occasion where. [00:06:53] ME6: Mm hmm. [00:07:16] Researcher: These participants were not. Aware of the disease itself. So. They took part in the worship, but during the worship got understanding. What the disease is and what's the consequences of the disease. So they knew something. They knew usually more like the effect more than the symptoms and the causes of the disease. And there was interesting conversation between participants themselves because they were kind of like this happened to me. Oh, that's happened to me as well. Is that related to that or maybe not, etcetera. And because during the session there was always. An expert present there was the chance for the experts not being like professional in terms of like. Terminology and and the way she was speaking, but more about trying to understand and maybe find an explanation for what participants were making emerge from their experience of the disease. So it's maybe I see what you mean about not the need of describing symptoms, but that. Helped for what I observed in making them understand the disease. [00:08:31] ME6: Yeah. Yeah, yeah. That that's for sure. That's. I mean, it's two different topics, you know, like if if the patient comes to the doctor usually they will be able to identify that there's a UGI or there's a migosus, you know, with the symptoms and the additional work up. But then you're right that sometimes people have symptoms and they think that, oh, it's because I went swimming or exactly I'm too busy. We we have had. Yeah. The these patients who waited way too long before coming to the doctor. And ended up with Upper Utis and arthritis and things like that. So yeah, it it might help to. Yeah. And usually it's people who don't have regular infections, because women who have recurrent tuge they know, you know, like in the end, but but those maybe who experience their their first Utis and maybe they will say oh it will pass. And I I don't know as you say I'm busy I'll I'll yeah and and and elderly also have have but you didn't have elderly eyes so you had like from 25 to 40. [00:09:35] Researcher: No, I work more young people, but please go ahead because you I've been, I mean, elderly. No, go ahead. Sorry. [00:09:38] ME6: Yeah. Yeah, yeah. Yeah, yeah, yeah. But it's true that. Yeah. [00:10:05] Researcher: Mm hmm. [00:10:06] ME6: We will

treat them for UTI. But now there is a new entity that's emerged. It's I think it's called, like Lucas, Victoria without with unknown significance or something like that. Yeah, to to put an emphasis on the the the need of you know like creating a new category especially for for elderly people and sometimes in the suppressed people also who have less, less like lower UTI symptoms but. [00:10:32] Researcher: Mm hmm. [00:10:37] ME6: Do have sometimes you say? [00:10:39] Researcher: Yeah. Do you see the need of thus describing symptoms useful to understand any other sort of disease that might be correlated or even confused with the UTI for women? [00:10:59] ME6: Maybe the the foul are smelling. Urine is often something we hear, and but there have been studies on that that showed that if it's if it's it's an isolated symptom, it's really not specific to UTI. So that we do have sometimes women who take antibiotics for this and think that. It's a UTI, but it's not, so I mean from what we know, it's not from the studies, but then we yeah, we. [00:11:32] Researcher: K and did you find anything like? [00:11:33] ME6: Yeah. [00:11:38] Researcher: That impressed you from the analysis in term of like. People behaviour or anything that emerge within the analysis that positively or negative or just you've been surprised by what you were reading. [00:11:56] ME6: It was interesting, I don't think. Have you described like the the demographics of the people, I mean like were they like university students or I was a bit surprised by the the people who didn't recognise that their symptoms could be linked to, you know, urine infections and like had symptoms for days and thought that it could be linked to something else. Were were these people, who was it like their first TTI or you know like were you able to to identify some factors explaining that like I don't know, did they speak about this were with their family members, for example their friends like? How come that some people are able to to like are so much more informed than Utis and some other not you know? [00:12:45] Researcher: Mm hmm. I mean there was no. So when I recruit the people I was looking for, people who experienced UTI in general. So there were people who had like severe. Occasion, like severe diseases that maybe not happened so frequently but very like severe episodes. There were people who had like, recurrent Uti's, and people who experience size dis because I'm speaking about sizes in most of the cases. Only once. It is interesting from my point of view, what I found is that people who experience youth sizes only once when building the artifacting, use the material, just build one block, let's say. So try to kind of recreate what the feeling they had when. Experiencing those symptoms while people who experience UTI more than once or chronically. They kind of. Build the steps of the diseases. So in term of a timeline that may be a threat or maybe like little blocks that are different and that are associated and when they were narrating they story the the experience was saying OK this is the first step, this is what happened. Then I stepped to the the second session and then blah blah blah even like four or six steps they were included. [00:13:53] ME6: Mm hmm mm hmm. [00:14:17] Researcher: And I found their description trying to kind of generalise the experience, because probably was chronically or it happened more than once so. They were trying to look for correlation or causes of specific symptoms and and that's why they build this sort of timelines that usually they were highlighting that they were repeating itself. So starting from the beginning when the disease were not completely treated or after maybe some months or week when the disease was started starting again. And and in term of symptoms. Did you find any relevant information regarding? UTI or more in general vaginal infection described by participants, or everything is more or less what usually your patients say you're the little to say about the the disease. [00:15:27] ME6: Yes, it's it's really what facing, but it's interesting that. This this idea that cystitis can come after sitting on a a cold chair or like the the cold and link with the status. I don't think there are many publications on that in the literature, but we we often hear, I mean not so often, but sometimes we hear that from patients as well are they whether. Yeah, maybe. Yeah, yeah. [00:15:54] Researcher: OK, that's. No, I was saying that's curious because as I was saying and other interview days past days, and there was another. Medical expert who's who's saying that? Never hear about that and was saying that that's not proof from the literature. Why? Yes, they have another interview with an. [00:16:13] ME6: Yeah. [00:16:18] Researcher: PhD student assistant of a person who is working on with with patient in the studio. Who was saying that? Frequent to hear from patients that that sort of behaviour or like thing lead to. Cystitis.

So that's curious to hear from you that you spotted that that symptom as well and about anxiety because participants were trying to, let's say, make that recognised as a sort of symptoms. [00:16:39] ME6: Yeah. Uh huh. [00:16:53] Researcher: It's different, of course from from others, but what? What? What's your opinion on on the comments you read? [00:17:01] ME6: Yeah. Were you able to identify where whether it was a symptom or like a consequence because it's clearly a consequence and you know, with what's his name, you know, he's in Basel? [00:17:08] Researcher: Yeah. OK. [00:17:16] ME6: March lampiris. You know, I think that and spearheads. Yeah. So he asked that he asked us to to add the the E Col like a European quality of Life questionnaire to our. [00:17:19] Researcher: Yeah, mm hmm. [00:17:30] ME6: Charcoal. So we're we're doing that in the patients. And clearly when when there is a question like have you experienced anxiety or depression and we have to ask this question during the infection and outside of the infection and many people do experience that just sadness, anxiety, etcetera. When they have an infection. But it's like really secondary to the infection, it's not the infection that is causing. [00:17:49] Researcher: OK. Mm hmm yeah. [00:17:56] ME6: See what I mean? It's not that E coli goes to the head or something. It's not like. [00:17:58] Researcher: Yeah, yeah, yeah, yeah. And back back what you were saying at the beginning? You were saying that usually doctors spot and they didn't defy symptom very well from patients. So don't need a really deeper description or find a description of of the symptoms would be. They need any other kind of information from you when you read or you think that there is no need at all to identify any information that patients can report to the doctor to improve their their diagnosis. In the end, the discrete the prescription of treatment. [00:18:42] ME6: Yeah, that, I mean, this would need really a study, you know like from for example **. She tells me that. [00:18:46] Researcher: Mm hmm. [00:18:49] ME6: Sometimes when you see and and I think she saw that in her study of, you know, she did a study of postal mycin versus neutrophils to treat the status. And she saw that the the rate of response was lower and patients who had hematuria for example you know. So she told me that most probably if there is blood in the urine, it means that it's quite an invasive infection. [00:19:06] Researcher: OK. [00:19:14] ME6: But yeah, this would really need to be further investigated, you know, I mean we we can decide that based on like. And I go to reports, you know, we have to check like if there's a link between a specific symptoms and then the the rate of relapse, you know, and also I think the duration of symptoms has been LinkedIn, some studies with the the rate of progression to upper UTI. So, so yeah, I mean, it could be important for for doctors, I mean for us when we see hematuria or like infections lasting for a week, we tell patients, OK, we prefer to treat you than with antibiotics then give you like non steroidal anti-inflammatory agents and just like yeah, tell you to drink lots of water because in the study it was shown that you have a higher. Rate of complication. [00:20:09] Researcher: OK and. Do you see useful from a patient point of view being I mean not from a doctor point of view. Sorry. Have a patient who are more informed and more aware of their symptoms and the disease or is something that they it doesn't provide any benefit to the doctor. [00:20:36] ME6: Yeah. Clearly it's it's very important. [00:20:40] Researcher: How do you think that can affect? [00:20:41] ME6: Yeah, because. No, but because sometimes, for example, we have a patient who he's paraplegic, you know he's like, paralysed. Yeah. And when he has a UTI, he has some sort of fever. But then we we. So we think it's, you know, an opportunity I postpartitis or chemo right is. And then we do the CRP which in in the blood should increase if there's really like. An upper UTI, but it's negative, you know, so the the. The symptom doesn't match the the biological response, so it means we can. We can only give him like nature parenting, which is a very targeted antibiotic that only penetrates the bladder and will not do anything if there's an upper reach yet. So. So yeah, it's super important that this patient remembers and see he for example, is very well informed. And so now when he tells us I've had some fever, but to me it's normal. It's just like the usual. So we tell him, OK. Gonna do a blood test because you know yourself. We're gonna treat this as a cystitis and then you tell us if you notice anything, you know. [00:21:47] Researcher: Mm hmm. [00:21:54] ME6: Different than the usual usual that could lead us to suspect prostatitis or gene arthritis and lead to more tests. Yeah. [00:21:57] Researcher: Yeah. Yeah. That's I suppose it's

possible because if he has a sort of like experience of the disease or able is able to recognise. [00:22:08] ME6: Mm hmm. [00:22:12] Researcher: And communicate with you and about negative description, I mean I noticed during the worship that sometimes people try to describe something and when they have some difficulties they just go on the opposite saying like it is not this one. It is not that one when they cannot find words or like the feeling to to describe what they are experiencing. Have you ever identify some similar behaviour or not really? Or comparing maybe with the sort of normal situation when they are not affected by any disease. [00:22:45] ME6: Yeah, I mean. [00:22:56] Researcher: I mean. [00:22:56] ME6: I mean, yeah, that there are patients like that. But usually when you when you give them more tools like you, you tell them like, what do you mean? But by it's abnormal do you mean that you go to the toilets more often et cetera. They will be able to to give a more precise answer. [00:23:14] Researcher: OK. So you kind of like. [00:23:14] ME6: Yeah, but it's true. There are patients who have like, who get very detailed descriptions, like without you asking them, you know, like. Expontaneously and others who will be very vague and you have to. To help them to describe better their symptoms. [00:23:30] Researcher: And to help them, do you have like sort of question that you ask them or ask them to do any, I don't know metaphor or any other information that might be useful to for you to understand. [00:23:48] ME6: Yeah. No, we don't use metaphor, but we would ask them like, do you have burning pain? Do you feel it burns? Do you do you need it? For example to take paracetamol or like ibuprofen or? Do you have to wake up at night to go urinate or ask them very precise questions? [00:24:09] Researcher: OK, OK, I. [00:24:11] ME6: Yeah. And then usually if they don't know how to answer, we will do a, you know, a urine exam to to check if there are white blood cells because in the end it will give us the answer. [00:24:24] Researcher: K Yeah, thank you. I don't know if you have anything to add, otherwise I will ask you to. Sorry, because I forget the beginning. Introduce yourself and if you can just say about your background and study. So I I I know. I can contextualise the the interview. [00:24:44] ME6: So I'm married. She did. I'm 32 and I was trained in internal medicine 1st and then infectious diseases. It's my maybe 7th year and infectious diseases and I've been working on Uti's for a year with the professor. Igna. Yeah, who is like the? Yeah, who started the UTI clinic. And actually 10 years ago. [00:25:05] Researcher: OK. OK. OK. Thank you very much, Marie. I don't if you have anything to add. Otherwise I just remind you again the consent form please and wish you a good afternoon and weekend. I know that you always like working, but. [00:25:21] ME6: Right. Yeah. [00:25:31] Researcher: Thank you. [00:25:33] ME6: OK, thanks to you and I just had a question for a patient that was interested in in maybe like future workshops. Is there any workshop planned?

ME7

[00:00:29] Researcher: OK, thank you. I don't know if you have the time to go to a a part of the document if the activity are run. So the workshop with all the labels and materials is more or less clear to you or do you need any further explanation of what participants were involved in? [00:00:50] ME7: Do you want to just walk me a little bit through whatever you consider the most important pieces? That would be quite helpful. [00:00:56] Researcher: Are you sure? Absolutely. So maybe I just share the screen so you can also see a picture from the documentation with you. Do you see my screen? OK, so ideally the group is composed about like 6–7 woman who experience a UTI. Then I started with UTI. Then I opened up a little bit of focus to more women. [00:01:05] ME7: Yeah. Yes, I did. [00:01:21] Researcher: Infection so not only UTI. And together with people with the experience of UT I, I always combine one expert who might be a pharmacist, a gynaecologist, still woman that can like be part of the group and then the worship is about 3 hours. First of all, we define what is symptoms for participants. I help them with the labels. So who takes symptoms of UTI from the literature? And I ask them to select the most important for them. Add if there is any missing and order them from the most severe the most like common they usually experience to the last one. [00:02:01] ME7: Mm hmm. [00:02:02] Researcher: Then I introduce some materials on the tables which are units of cubes, spheres and triangular shapes in wood, polyester and form in different sizes, small and big, with some joined and the connectors that

helps through holes in the units to connect the the units of materials. And then I bring another set of label that the shape match the first one. In this case, I asked participants to go through the materials so touch materials, let's say, play a little with materials. And focus on physical variables, so physical properties of materials such as colour, brightness, orientation, texture, weight. This kind of stuff and then associate the symptoms labels with the one of the physical materials. So ideally to identify some physical property that can help in describe the symptoms in participant. They face interesting not only for the results which. Provide me with some combination, but also because of the conversation that these labels enable in participants who started to describe in the symptoms describing the feeling they got to during the. The disease. And then finally, I asked them to shape their symptoms. So recreate they disease through these materials and like pieces that connect these materials. So now this is not loading but we have other picture down there. OK OK OK. [00:03:30] ME7: I can see it. I have it open as well. [00:03:35] Researcher: Then I mean I run three session, I will have another session in Bern next week. I can stop and share my screen maybe? And the results I provided you. Relates to what is being said during the workshop. If participants were able to identify or describe differently the symptoms. They got. [00:04:05] ME7: Uh huh. [00:04:06] Researcher: And. Let's say yes, ideally I mean the focus for me and the goal. Is to provide participant with some materials to not only enable their self reflection on the disease, which is supported by the exploration of material, but also conversation that those materials enable within the table, but also try to enrich their vocabulary in describing the symptoms so to provide them with. A different of course not like technical, but a different way of trying to understand their body. And express what they feeling during the disease. [00:04:49] ME7: Mm hmm. [00:04:49] Researcher: So I don't know if you like identify maybe some. Different symptoms or different ways of describing symptoms. If this sort of material in your opinion, might be useful to describe the symptoms related to infection, diseases or. People or those symptoms are not like. Let's say. Appropriate for to be explored with a with my materials. [00:05:23] ME7: So I mean, I think when I was when I was reading through what you had sent, I think it's quite interesting to think about particularly using that type of communication. Kind of building on that and almost using that as a diagnostic tool. Because obviously there are and this is coming from my perspective. [00:05:46] Researcher: Mm hmm. [00:05:52] ME7: As a paediatrician, there are nonverbal people, but it's not just me. It can could also be, you know, geriatric patients, for example, who may actually be able to express what they're feeling through those kinds of materials. Better than they would be to express it verbally and so. [00:06:14] Researcher: So you mean expert that express those feelings to no patients? To experts. OK. OK, OK. OK. Sorry. [00:06:17] ME7: No. Yeah, because and I think it's this thing of. Act so in a way I would like to ask you some questions back so we can see whether that but you know if if you basically. [00:06:32] Researcher: Sure. [00:06:38] ME7: You know, is there some consistency in how people, you know, do you find that certain? Groups of of signs or signs or symptoms, symptoms or feelings that they have about their body. Ever tend to result in them? Using similar images I guess or textures or whatever then that would be really something very interesting as an observation because I think that. That's often something that's quite difficult for patients to express or for people to express, but I think they're often quite often quite expert in it. So. You know, they're quite so, especially people who have recurrent. Disease, whatever it is that comes back again and again, and in this case it can be infections. But that's true, I think of any person who has similar symptoms over and over again. They're usually pretty good at telling whether something that they're feeling or they're observing about their body or themselves, their psychological state means that this is another episode of whatever that disease is. In fact, something else. [00:08:02] Researcher: Mm hmm. Mm hmm. [00:08:04] ME7: And that I find quite fascinating, because they're not always able to. Verbalise that. Especially not in medical terms. So certainly that is something that's quite difficult, but they would often be able to say I can feel that this is the same thing that I had last time or I'm not quite feeling myself. But this is something different. And I find that to be quite. Interesting. And I think it'd be quite. One thing that would be interesting to me in a way. Would be to have this kind of

interaction with these types of materials. So this way basically of telling and I'm always taking the medical position here, you know telling sharing your. Signs and symptoms with the expert. [00:09:01] Researcher: Mm hmm mm hmm. [00:09:04] ME7: For people who have who are experiencing an episode for the first time or have had only one of them, because I I think you might find that, for example, things like stinging as a there might be tonnes of different ways of saying this. [00:09:10] Researcher: Mm hmm. Mm hmm. Mm hmm. [00:09:26] ME7: Burning, stinging, whatever. Pain here, there or everywhere, anywhere. But I think in terms of materials, I can imagine that it's always going to be pointy, sharp, hard, whatever. And so is that something that can be replicated, it actually means that you have the potential for someone to show you what is going on with them. Even at the time they're experiencing that symptom, when they cannot actually tell you in any other way, and that to me, is absolutely fascinating. [00:09:55] Researcher: Mm hmm. So you mean like from the expert point of view, try to recall for some shapes or like feelings related to shapes that can help a patients to like bring the the verbal communication of that. Yes. So I have some. Try to answer to your your questions. So first of all I noticed the saying that while people trying to explain the disease, even with materials, sometimes they what they do they. Compare to normal conditions. So they say, like I build this or maybe when I build this which is normal condition, but what I feel is completely different or speaking negatively so. The I select this material because it does not. Communicate, in my opinion. What is that? So like going, let's say opposite to what they actually feel. And so material sometimes I mean what emerge in my opinion is that is useful. Because even people do not have the vocabulary or the idea of expressing what they found, and maybe they do not find the the the material that can express what they feeling, because of course my selection is limited, but they are able to identify within material some qualities that still enable their communication and try to communicate what they felt. Secondly, there are some recurrent. Combination and that's like interesting. That's not the primary goal of my research. It is my interest as a. Diner and then wanted to go deeper in that direction as well, because in physicalisation there is not, let's say vocabulary while in visualising data for example there are some already established rule that you can follow or not, but there are some sort of vocabulary insignification. So translating data to sound they're working in this direction. So trying to understand above culture etcetera, if there are some way to represent. Sound data with sound that can be like general worldwide valid. In Physicalization there is not this sort of vocabulary yet and what it might really help in my opinion, is to focus in on one specific domain and topic, because people try to address this like generally. But of course if we go to like symptoms representation, we are within healthcare and intimate data and that might be more appropriate. I mean more focus and precise. And there are some like recurrences. So for example, as you were saying about edges. That people mention differently, so then they related to for example. Glass as materials and they mentioned the spheres. Especially when the disease is like at the initial stages, so spheres combine to mild symptoms. In general, which is like, let's say, the opposite of a. Shape with the multiple edges or angles. With that and then there are for example like even the cone is different from the pyramid which is associated with the froic which is not with intimate infection but still is something that emerged I didn't share with you that part of the research because this was already long in my opinion and that is more related to design. But I will be happy to to share that part as well if you're interested in. And related to that part. I have a question for you. So do you think that having for doctors or like in the studio a little very little kid with not all those material, but that just three shapes that come out from my research that maybe? An. How you say sorry unshaped thingy. Then a sphere of wood. Because wood then is also associated to. Warm feelings still related to mild symptoms or when the disease is like getting better. Not sorry the the it's. Yeah, it's kind of ending and there are some improvement and then shape full of edges like transparent shape this might in your opinion help in the communication without making the conversation too long and losing time because I know that's very important to like. [00:14:20] ME7: Mm hmm. Yeah, but I think what So what I would do your questions, I I think that actually this is something for if we're talking about UTI specifically or infection specifically and then we

think about you know the types of symptoms associated with that. Then I think that in in a way to me, that kind of kit would be very useful and it would be a replacement of a visual analogue scale, which I think we now use. But of course the the. [00:15:06] Researcher: Hmm. [00:15:07] ME7: Visual analogue scale has the limitation that it doesn't actually tell you about quality. It only tells you about quantity. It goes from 1:00 to 10:00 or from Smiley to to crying, which is something to do with intensity. But I think with the objects. Essentially, you can have quantity and quality, so actually I'm not sure I would make it maybe 3 shapes, but if you had your 3 shapes and you have them in. Three different sizes, so that would make it 9 objects, which is something that is still quite manageable. I think you could capture intensity, but you could also capture quality and I think that is something that is really that that is something that I could kind of sense from what the the people were saying that it's not just about how bad is it, but it's it's it's also. It's also about, you know, the the quality. And so you know, I was looking. Just before we connected at this paragraph, let me just see, I think page 15 or something where someone is saying first I got the small polyester ball, which is the representing the lighter symptom and then the big yeah, exactly. I can see you then the worst symptoms are big wooden, so you can see that people do do that. So it's it's it's it's it's the they are more intense but also the quality is changing and I think think so this suddenly they're they're using some they're using a different. [00:16:27] Researcher: Mm hmm. [00:16:41] ME7: Real, but they're also using size to say something about, you know, how bad is it? And I think that that's really fascinating. And we often ask about, you know, intensity, but we don't usually we're not usually able to combine it with quality in that way. And I think that's something like, it's like a dimension that is currently not even. [00:16:47] Researcher: Yeah. [00:17:07] ME7: Included in conversations. But I think. [00:17:10] Researcher: Yeah, what you say now? It's super interesting to me because what I've been questioned, let's say, is about data I'm working with and the reason why I'm mentioning data physicalization is because I'm trying to bring not only quantitative information, so quantitative data, which is always like easier to recognise, let's say, but also qualitative information within this material and what you're saying it it it's really. Interesting to to me so. And I see the point of all society then. The quantity of that. What you mentioning as the the scale, the scale you mentioned, how you say that? Is that something that you can share with me or is just like smiling that go to bed to happy? [00:17:56] ME7: Yeah, I I can send you an example. Yeah. Yeah, yeah, yeah, it's it's. [00:17:59] Researcher: Thank you. Because I know for example you do as I mean in during consultation, ask questions to understand which kind of like pain or disease etcetera. Is there a table or like a guide for this question that? My refer to or if there are any like a question that you always find interesting and useful to us because that might help me guiding in defining those. Objects in the end to prepare the kit. [00:18:32] ME7: Yeah. Yeah. So I mean, this is something that is. So I'm just putting some very typical things that people would use, you know, in, in, in, in. In in as these visual analogue scales, but you could see that it's it's it's very. It's very much. Just focused on intense on intensity. So it's very quantitative and it it, it doesn't really have that quality element at all. And you, I mean you can do this for every single symptom that you ask, but that's assuming that when I say. [00:19:08] Researcher: Mm hmm. [00:19:17] ME7: You know, do you have a singing? A stinging sensation during passing water that, that, that what I mean by that in terms of quality is the same as the patient. And I just don't know that that's always the case, you know, so especially around, especially around pain. [00:19:32] Researcher: Mm hmm mm hmm. [00:19:41] ME7: We're very bad at finding a shared language, I think. [00:19:47] Researcher: Yeah. Mm hmm. [00:20:05] ME7: Things that actually objects in a way may be much more universal as a communicate to communication tool. [00:20:13] Researcher: Julia, I lost your voice. [00:20:15] ME7: Oh, hello. Can you hear me still? [00:20:17] Researcher: Yeah. Yes, yes, yes. Now, yes. [00:20:18] ME7: Yeah. So I think I think objects might be much more universal as a communication tool. [00:20:25] Researcher: Yeah, no. And would you see on the other hand, like any problem using objects, maybe that recall to your mind or like? [00:20:35] ME7: Well, I think that there that a lot of these things have a cultural dimension. So I think that that is obviously something one would need to. [00:20:41] Researcher: Mm hmm. [00:20:45] ME7:

Well, would need to be aware of language. Does too of course, but you know, I think that things that are. You know that that evoke a certain emotion or a certain response in one culture aren't necessarily always the same as. What evokes that in another culture? So I think that is one thing that be very interesting. To explore, I think when think when you're talking about. Pain then I think that's more universal because that's like a very basic. Emotion, but I think things that are more interpretive. Than you know they they, they're sort of they're sometimes things that have a different kind of meaning. [00:21:36] Researcher: Yeah. No, I definitely see what you mean. Of course, objects and selection of objects from patient must be contextualised within explained. So that might be the first step of like something that goes farther and explaining and contextualises my reduce. But I completely see what you say and do you think like last questions? Might be useful in terms of the urine tract infection diseases, or you see that more useful for maybe other diseases or other sort of pains. [00:22:08] ME7: Oh, I think that it would be super helpful for that one. In fact. I mean, I because I'm an epidemiologist and so I'm a bit boring like that. But I think it'd be super interesting to actually do some sort of observational study where you offer objects to kids who come in with potential urinary tract infection or adolescents or whatever. And you actually get them to select and then. Before anything has been done, and then you actually look at the. Sense of what objects are selected as most indicative of their disease state in relation to whether they have a diagnosis of UTI or not. Because I think that is like the thing that you know, for a clinician this is like if I know that I can basically give them these, I don't know six objects, 9 objects and I know if someone picks out this one. [00:22:43] Researcher: I select. OK. [00:23:05] ME7: That has a strong predictive kind of capacity for them actually them actually having UTI. That be mind blowing, but I think it might quite be quite possible, because I think that. [00:23:16] Researcher: Mm hmm. [00:23:17] ME7: As I say. You probably based on the work that you've done. You will find that there are some things that really express a sort of intensity and quality of disease. That means that it's pretty certain that something is actually wrong. And and so that I mean, that'd be super interesting to do. [00:23:35] Researcher: Mm hmm. Yeah. You cited the kids. Would you see this possible even with adults or not? Really. Yeah. OK. OK. I don't know if you have anything to add. Otherwise, I really thank you for this super interesting conversation. And maybe I'll keep you updated and let you know about the next phase. Thank you very much for your contribution and time. I know how precious it is.

ME8

[00:00:20] ME8: Mm hmm. My name is **. I have a PhD in social anthropology and did my research on. Liver transplantation, liver transplant medicine, temporalities and materialities in. This field looking at waiting at various from various angles and. Perspectives and my. My recent the postdoc project was part of a bigger snsf project on. Palliative care, it was called settings of dying, and it was the project where I there was also like a design part, a communication design, part, a product design part. So we had like a multi interdisciplinary project where I for the first time more intensely collaborated and worked side by side with. Also designers and yeah, we're kind of the ethnographic data was influencing also design products, but also just the exchange of methods topics was. Regularly. Initiated through project meetings etc. Also publishing in the end and also did another project with design on pandemic objects on the role of the like everyday and. The change of everyday objects over the course of the pandemic in a University Hospital, so this is where I connect with design and I'm currently located at the Bern University of Applied Sciences and Nursing Research. So I'm yeah have a a different lens now on the healthcare professionals. And particularly the nurses in these settings. Then I had like for example, during my PhD. [00:02:30] Researcher: OK. That's that's very interesting. So thank you. Have you had this chance? I know we said the call in the end this morning, but to go through the analysis of results or to read about the protocol, if you have any question or do you want me to like idea within the protocol? [00:02:50] ME8: Read through the like the not the obligatory, not the detailed. [00:02:55] Researcher: Yes, yes. [00:02:56] ME8: Stuff, not the objects that were built, but I. [00:02:59] Researcher: Mm hmm. [00:03:03] ME8: Read through the document I

was able to and. [00:03:06] Researcher: OK, OK. OK. Thank you. [00:03:10] ME8: Also left some comments, not too many, but a few. [00:03:12] Researcher: That's great, yeah. [00:03:16] ME8: Yes. Yes. [00:03:19] Researcher: Yeah. So maybe do you want to start from the comment you left in the document or if you have an like a general comment on what you read, if you have any question of course, just ask me if anything was not clear to you. [00:03:33] ME8: Yeah. I mean the first comment I left was more like. A very general that from the description and the images of the materials, I thought when I read through the. Comment the. Yeah, your analysis I was missing it from a material perspective like metal, more metal parts, bigger metal parts like cold round balls for example. I don't know something that represents the coldness more than the heat. I really enjoyed and I left that also as a comment. I really enjoyed the studio Rapport in the the Polly Stereen. I looked it up in the the plastic stuff because. It has this very some people, really. Get like a big feeling when you touch it or when you even like connect it and I thought this was really good thinking about how I. Recall the sensation of a UTI like this. It's just like this is discomfort, so I really like to play with that. And the also the yeah, the temperature and texture aspect of. [00:04:36] Researcher: Mm hmm. [00:04:52] ME8: Oh yeah, of the of the workshops for me, it was still like, what do we gain through that and how would this be used for, like educative purposes? It's not, this is not. Clear to me yet, and it's also hasn't been convincingly described why it seems like a nice thing to do, but not like, yeah, this makes sense to educate. [00:05:15] Researcher: Mm hmm. [00:05:18] ME8: I thought at a later stage I. There's certain things I I felt really interesting and that I kind of connected with, and one was as a medical anthropologist, where you also like always questioning like definitions and. Trying to, yeah, broaden the the. You want certain phenomena and one was the. Right at the beginning, the notion that a symptom has not necessarily a negative connotation, and I was like ha. That made me think that made me really think like in a sense, because for me the the 1st. That feeling and impression is like no, a symptom is for me overall, a negative description of. Sensation that is out of the ordinary or out of the normal range of how your body feel. But then, yeah, what if you, for example, want to become pregnant and you have certain? [00:06:17] Researcher: Mm hmm. [00:06:31] ME8: Symptoms, but they are also most of the time. Associated with discomfort like swollen breasts or, I don't know, like this is not like. Yeah, for me it is an overall negative description of a sensation, but I was wondering also how the language issue comes in here. Like with Italian, English and my mother tongue, German. How certain words have different? Connotations depending on the language you. You think with? Certain words are not not translatable. So how do you then yeah, I'd be also curious to to. Like in your PhD to reflect on that. How does that influence because you did the workshops in different languages. How does that play into your analysis? [00:07:29] Researcher: I mean, to be honest, I can, let's say control English and the Italian, but what was curious that I wrote somewhere is that I thought at the very beginning that the language might constitute a barrier because participants were not maybe understanding what others were meaning or like. In trying to communicate, but in the in the end I think actually was something that. Facilitate my scope within the workshop so as I was looking for description of symptoms and identification of. Feelings, body or mental conditions. The fact that there were some participants at some point asking, I don't know what that word means or I'm trying to express something and so others came in to help this participant to express the feeling. Sometimes it's not about the right word, but more about the description of the word of the feeling. So the fact that not all everyone was even in the same session. Align on the like same language. Of course everyone was able to communicate, but maybe there are some specific terms that still, I don't know the fact that they were helping each other in this through the description allow me to collect even more material because otherwise if everyone was aligned on the word, there was no point of describing some basic. Maybe for them words or feeling. [00:08:51] ME8: Mm hmm. Or they think they're aligned on the word and don't have to explicate. More or less what they. Yeah, yeah. Yeah. Mm hmm. Mm hmm. [00:09:01] Researcher: Yes, yes. Exactly. Exactly. Even like for, for example, blood stomach. There was someone not knowing what blobs means. And so they started the conversation between different version of bloated stomach and the one that for menstruation the one is because you ate

something or different kind of bloated stomach. And this allowed to distinguish the bloated stomach caused by UTI. In that case was because of probiotics and the treatments that follow. The fact of having UTI like. Precise description of the bloated stomachs that otherwise people would just mention like bloated stomach and everyone know what that means. So there is no point and we can move forward. And this is something. Then of course it's different from what you were saying about the word or the concept of symptoms, but the fact that different participants makes made emerging. The positive conception of symptoms. It actually was recurrent in different workshop, so maybe I don't know if that's, I mean the experts. Present during those session were not, let's say. I mean didn't complain about the positive interpretation of symptoms, but there was different one different participants that made emerge the the positive affection of of the word symptoms and as a signs they define symptoms vary with different words, bells, signs, ringtones and and very different words. But there was different version because of pregnancy but also symptoms of getting better. So after the disease, something that is actually a sign that you are recovering. [00:10:48] ME8: Mm hmm. [00:10:54] Researcher: But yeah, I mean. [00:10:57] ME8: Yeah, yeah, yeah. [00:10:58] Researcher: There was some other medical expert who are pointing to the the the difference between symptoms of the disease and other. Let's say effect of. Not the disease, but what might be medical treatments or? [00:11:15] ME8: Mm hmm. [00:11:17] Researcher: Other diseases that were affecting the disease we were talking about or maybe not diseases, but condition for example menstruation that can cause Uti's. So cystitis. So at that point the symptoms you are feeling might be because of the sizes or you if you don't know the disease or you don't have like a lot of experience in that direction can confuse the symptoms of menstruation, menstruation to the one of cystitis or even the. Effect of taking probiotics, for example. So there is like a way of trying to understand where those symptoms are from. [00:11:46] ME8: Yeah. Yeah. No, I think it's like an interesting, like from a semiotic perspective, like, what kind of words are used for what and what are the connotations. And then also what are the connotations in the different languages? It's not to say that anything like this doesn't work, but just to to something that can't be, yeah, be conscious and reflect also as part of the phdi would say then if I would be. [00:12:17] Researcher: Yeah. [00:12:19] ME8: A supervision person here like this is. This can't be. Just like, yeah, just need some attention analytically. [00:12:27] Researcher: Yep. [00:12:29] ME8: Also, it's interesting like to really like use it as a as a as a insight into how people. [00:12:32] Researcher: Mm hmm. [00:12:39] ME8: Think about their sensation, symptoms, signs, et cetera. In the different contexts and language, yeah, what role language plays there? [00:12:53] Researcher: Yeah. [00:12:55] ME8: One another thing that I had in mind was. The what I connected with was the. How kind of initial knowledge by an expert helped to recognise and identify a disease? Like distinguishing between. Person, what was that also with? Yeah, experiencing menstruation for the first time and. [00:13:23] Researcher: You mean they're all? [00:13:29] ME8: Yeah, maybe this is the like, how? Ah, this is me. No clue is this. So yeah, kind of how? And you mentioned that there's like about the identifying the disease and I thought it's not only about identifying the disease, but also the symptom itself. Like when you feel something. Is this, how can I is this sensation a symptom or a sign for something? Or is it just like a a sensation that you have for whatever like. And so how? Yeah. For example, like when you experience menstruation for the first time, that the cramps can be connected to that. And how I think in various. Experiences with our bodies that we undergo need either like experts like formal experts like doctors, nurses, whatever, or also experts by experience like friends. [00:14:39] Researcher: Mm hmm. [00:14:45] ME8: Family members who are like, ah, yeah, this could be this. So. So how I didn't say this here, but how? Diagnosing. Knowledge I added is always relational. [00:15:02] Researcher: Yeah, I mean then the reason of trying to have a medical expert within participants who are bringing experience of the disease was I was especially to try to mix those kind of different knowledge. And combine different background of experiences of the DDD itself from medical perspective, from personal perspective to see if that might help in providing most accurate definition of symptoms or even find the new symptoms that are not part of of the literature. To identify size TC Utis, especially at the beginning when something can be done to avoid

taking antibiotics, as emerged from some participants who are pointing to. Taking care of their body food habits. Even clothes and other stuff that might help preventing the disease. So the idea was especially to mix those kind of knowledge. I don't know if you means even considering something outside from the Group of the workshop in terms of friends. [00:16:00] ME8: Mm hmm. [00:16:11] Researcher: Family members, et cetera. [00:16:14] ME8: Yeah, yeah, yeah. I would say like the the the issue that they were discussing was how you need like an expert that helps recognising and identifying. Symptoms and then acting on it. And for me it was like it's not only it's like really this is really crucial thing that happens. I think in a lot of not very also not consciously in. Various stages that we undergo. That we need other people to kind of help us identify what we're like, what we're like, the sensations, what we're feeling, what this is what we're feeling. [00:16:51] Researcher: Mm hmm. [00:16:59] ME8: So yeah. [00:17:01] Researcher: OK. [00:17:02] ME8: There was more like about that and. And yeah, like you mentioned it before, how the cure or like certain probiotics also cause symptoms. I think this is also a really important point because mostly the women talk about the symptoms of the UTI and not really the symptoms of the treatment. And also like with particularly if you have like a recurrent UTI. [00:17:16] Researcher: Mm hmm. Yeah. [00:17:34] ME8: It's also so important to, I mean, I don't have expert knowledge on Uti's but my. The insights would or like. Yeah, very superficial insights would be OK you maybe you take antibiotics, but then you have to do probiotics otherwise because you're getting rid of all the good bacteria as well. So you have to do good. Probiotics for your stomach and your vagina to not. Suffer from the same thing again, and so this is hasn't been discussed in the group. So. So I think which or or. [00:18:05] Researcher: Yeah. It's actually something, yes, that emerged within the group. So first of all, it emerged from participants that. You need a sort of like basic knowledge to recognise symptoms because there are some symptoms that naturally ask or require your attention. So even if you don't know you then go to investigate them or ask someone that might be mother, friends or doctor to know what's going on. Some others are maybe just a normal and not normal condition, but something that you do not. Ask head for because you do not recognise as those as symptoms, so there is the medical. Support required for you to firstly identify the symptoms or even friends, but someone external that's point to something anomalous. And so you go and investigate that more. So then a basic knowledge, let's say if for sure recognised by by participant themselves, someone was saying about you. [00:19:07] ME8: Mm hmm. [00:19:20] Researcher: As someone that needed to recognise symptoms, someone was saying about tools and devices such as the thermometer or tag devices that help you to identify some some something going on. And but yes, the the basic knowledge is something that that emerged for sure. [00:19:44] ME8: Yeah. And then the other thing. And then also I left those comments in the in the document. In the end there was I think another. [00:19:54] Researcher: OK. [00:20:08] ME8: But yeah, this is more like methodology wise I I think I missed a bit the role of like because the use of materials. And the. Like how you connect with certain materials and forms. Is very subjective and how what you how you connect and associate with how or no how you sense the sensations of your symptoms, what you suffer from and how you suffer from or how you kind of talk about it is also very subjective. So how to tackle with the subjective subjectivity in the in the data. And also then the Intersect subjectivity in between, like what happens in the workshop where people then discuss these very subjective. Interpretations of their sensations, but also how they kind of connect to the objects and the materials I was like I this would be something that I thought would be needed also a bit more space to reflect on that and more also. [00:21:08] Researcher: Yeah. [00:21:24] ME8: Also bit more self critical. Take on your change of who are whom you are recruiting so that the broadening of. From just women who suffered from a UTI to women who suffer from also unidentified like intimate conditions or symptoms or symptoms to yeah to to, to broaden that category. And I thought maybe that also. [00:21:56] Researcher: Yeah. [00:21:59] ME8: Is it sign of certain diagnostic bias that you reproduced? You know, like this idea from? That the diagnosis is more important than the symptom, and so the reason why you suffer from like a weak bladder or pain while peeing is. [00:22:16] Researcher: Mm hmm. [00:22:24] ME8: More, yeah, more important, because of your focus on antibiotics. And the IT

makes I and I get why you looked at UTI and not on like fungal conditions which are not treated by. Antibiotics. But women suffer. Maybe the same symptoms or very similar symptoms. And how? Yeah. What is more depressing? What is more important? And. [00:22:43] Researcher: Mm hmm mm hmm. [00:22:54] ME8: What do you gain? Also by broadening this category? It would be, I thought it was really also interesting and to like if if. [00:23:01] Researcher: Yeah, yeah, yeah, yeah. [00:23:09] ME8: I mean, those are things that I would require for my students in the sense of why did you broaden it and what have you missed also before with the categories that you were using? [00:23:13] Researcher: Mm hmm. Nice to your point, I think the topic is something quite difficult to set because I started with UTI, which means most of the cases. [00:23:27] ME8: Mm hmm. [00:23:32] Researcher: I try to make it bigger because what you're saying, and also because people have different. Experiences and because some people attending the workshop, sure of being affected by UTI discovered during the worship that was not to UTI and having a conversation of similar symptoms but faced from different perspective because caused by different diseases was very useful. But on the other side. I recognise that opening the topic. Does not allow to make so much highlights related to the disease itself. So if one of the primary goal is to identify and better describe symptoms related to UTI, if I open the topic then I have a similar condition described from different point of view. But that's not really helpful for UTI. Definition, you know. [00:24:24] ME8: Mm hmm mm hmm. [00:24:25] Researcher: So there's something like in between that might be applied to other condition, but for now I would keep the topics and the disease separated or find a way to identify them within the same group. How to manage the the group of people affected by the different diseases. But that's something like that emerged continually and and actually thank you. Thank you for your figure maybe. Just last question and then I leave you if there was any association between symptoms. [00:24:52] ME8: Mm hmm. [00:24:55] Researcher: Material that you have been impressed by or any use of material that coats your your attention. Or any even like unusual description of symptoms, diseases or medical condition from what you are inhabit to hear or to go through. [00:25:16] ME8: I mean, for me, I looked at the not all the images but some and like I from the big wooden puzzles, I didn't really get those. I really I didn't understand the the emphasis on the word. I think for me the word like this is what I think that the Stew report the the the plastic was really. [00:25:21] Researcher: Mm hmm. Mm hmm. [00:25:40] ME8: I could relate to that and also what I missed the like the metal. Like the coldness. [00:25:44] Researcher: Mm hmm. Mm hmm. Mm hmm mm hmm. [00:25:45] ME8: The wooden materiality I I was surprised by the frequent use of that and the heaviness people, the wood, yeah. [00:25:52] Researcher: The food do you mean? Yeah, OK. [00:25:59] ME8: Yes. And I I mean there was one. One I that stuck with me on page 30. Maybe this is I can leave a comment there. [00:26:08] Researcher: Mm hmm. [00:26:35] ME8: No, all the no. Not really like symptoms that were like, huh? No, I did not. Came across anything that. [00:26:41] Researcher: OK, OK. [00:26:46] ME8: Was irritating to me or like confusing to me. No, no, no. [00:26:50] Researcher: OK.

ME9

[00:00:14] ME9: Yes, sure. I'm a originally pharmacist by training and I'm I've worked for many, many years in a community pharmacy, but also did a lot of research and I'm specialised in pharmacopedemiology for drug safety research and in hospital pharmacy and I'm currently the the head of the hospital pharmacy here at University Hospital in Basel and running a research group in Pharmacopithmiology. And so I have a bit of. Experience in patient related pharmacy. Pharmacy, but also research pharmacy. So that's briefly my background. [00:00:51] Researcher: Thank you. Thank you. I don't know if you had the chance to, like go through the document and the initial analysis I've written is the workshop and the activity around clear to you. Do you want any further explanation? Do you have any questions regarding the activity itself? [00:01:10] ME9: No, I don't think so. I think I I'm not really of course a specialist. This is a very special methodology that you're using here. So that women try to conceptualise and to be sort of picture and to symbolise their their symptoms which is I think quite a creative way to do it. And so I wasn't familiar with this technique. I mean what I what

I was used to to get in the in the pharmacy is women. You know complaining about the symptom, asking me what could this be? This particular symptom that I'm having most of the time? It was a burning sensation. When going to the toilet and stuff like that and then they were a bit insecure and said could this be a infection but sort of to conceptualise this in a more in depth discussion was quite a new concept for me. Even you know with constructing whatever. All these things that that sort of came to their mind, so I can't, you know, contrary to tell whether this, you know, the validity of this whole thing, this is sort of your research topic, but I think it's it was quite quite interesting to see that. [00:02:08] Researcher: Mm hmm. [00:02:16] ME9: And a lot of things that I've read which you know we're trying to be, I don't know. Were explained were were described in these in these interviews were things that were quite common that you sort of know that this is what's going on, but sometimes it, you know, there were very special comments that were kind of original and and new and apparently, you know, very individual. Very individual feelings that that woman can have. [00:02:46] Researcher: Yeah, Yep. Definitely. So I don't know if you want to share anything. We have been impressed by both positive positively and negatively that you read or go through the analysis. If there was. [00:03:03] ME9: No, I think the the for me really special, even though you said you know, I'm sort of being interviewed as an expert, I certainly know quite a bit about urinary tract infections and have patient contact. I have that a lot in in recent years, but I'm not really an expert in these methodologies. So in that sense, you know, I was just intrigued by reading it and say it interesting approach. And then I think what what is a bit the. [00:03:21] Researcher: Mm hmm. [00:03:29] ME9: What I liked about it is that you have. In these workshops, even though of course, it's not 10,000 patients, but nevertheless it's quite a substantial number, you have sort of the classical symptoms that were described by women. And then you have some outliers, some various, you know, special things like which was relatively new to me. Was this feeling of what was it called? A bloated stomach or something like that, or a full stomach or so. Apparently some pressure. And as you wrote and as I commented, hard to tell whether this is really a symptom of the infection could well be, or it's a symptom of the treatment could well be as well, particularly with antibiotics. Maybe after the second or third dose. You can of course have GI symptoms. [00:03:54] Researcher: Mm hmm. Mm hmm. [00:04:13] ME9: And that was was quite interesting, I think. And other than that it also shows that the manifestation can be quite quite individual. Probably some women may experience it completely differently than others. And even though there may be a sort of a joint, the common overlap between certain things, but nevertheless some interpreted it rather, you know, they said this is felt like this. Autos said it felt like that. So I think this is very. Special and particularly difficult for the first time, if a woman has experienced the first time UTI, she doesn't really know what to expect. If somebody had a second or third, she probably will react much, much quicker and know exactly what this was was about the last time. [00:04:58] Researcher: Yeah. No, that's for sure. You mentioned the subjectivity. So like personal interpretation, I suppose. And then communication, do you see that? As a problem in term of describing symptoms, do you think that might be an advantage in trying to relate to the disease? [00:05:23] ME9: I think it's an advantage that you know this special methodology, having workshops and discussing symptoms in depth with patients, with women, it's a different approach than if you just interview very superficially 1000 women or have a clinical trial with 10,000 women. And this is of course, much more superficial and everybody takes a box and says yes, no or so. And here you have a qualitatively completely different level and quantitatively, of course, it's not huge, but this doesn't have to be, I think it. It probably shows that. You we have to be aware in clinical practise that they are very, let's say unspecific, very subjective manifestations of a disease that is that that women can feel it. Probably this is true with many, many other diseases as well. For some people it's painful, for other it's different sensation and others don't feel anything. So this is this is this is special and I think it illustrates very nicely that this is again something we have to be very aware. In clinical practise, be it in pharmacies, be it in the GP office, to know that you know certain certain descriptions of symptoms can can be quite different. I think from that point of view it's it's interesting to have this in depth discussion and and not just a

very superficial protocol to to follow. [00:06:44] Researcher: Yeah, what you mentioned actually is what also I'm kind of trying to assess in terms of type of data. So I've been running other interviews and what emerges that very often, I mean you can correct if I'm wrong, but I've been said that there are tools or yes like support that can help patiently express them in expressive quantitative information related to pain such as case or smiling. [00:07:12] ME9: Yeah. [00:07:12] Researcher: Coloured faces something like that. But nothing specific on qualitative of of pain in term of like not all the yes not quantitative but the the type of pain I've been linked to some literature and someone was saying that might be useful because doctors sometimes have like questions that ask patients or like some kind of keywords to describe the pain. But is this is not. Assessed or there is nothing like. To refer from in terms of a list of typology of pain or this sort of information. I don't know if you know anything in that direction. Maybe you do in case I would ask you to to suggest. If you know, for example, I was speaking with someone from the Spirit Consortium who pointed me to the Socrates pain assessment. [00:08:11] ME9: I don't know that. No, no. [00:08:11] Researcher: Socrates. Socrates. No. OK, so just to ask, like, some some questions related to quantitative, but also qualitative information such as what is the pain like if that's more innate or stabbing or? Where does it radiates and this kind of questions that try not only to understand how much is the pain, but also try to understand exactly. I don't know if you have any reference in that direction. [00:08:30] ME9: No. More quality of the pain I think. Yes, I think this can be particularly interesting if there is enough data to say, you know, for example, if this combination of, I don't know the symptom in combination with, as you say radiation or with something else is predictive of higher likelihood of having a for example like a coli infection or a. Fungal infection. I think that that is then actually the relevance of it that that you know, you can try if if if there is enough information and if this is really substantiated and and reliable enough with enough data to say, well if this goes goes along with this and that then it's more likely this and it's been shown that it's statistically highly significant more likely this than something else. Then I think this is is very important. The rest is of course, as long as it stays sort of anecdotal, anecdotal that we just know that. Can experience different feeling than others then that's that's interesting and and raises the awareness that I think practise you have to listen carefully to symptoms that may not exactly be what you learn in the textbook, but it could be something slightly different, but it should. It should trigger you to ask them the right questions like oh, interesting. But how does it feel? And and did you have that before and maybe we should do a urine test. Even though it's a very unspecific occurrence, but really interesting would also be that you have. You can say you know if it's 80% likelihood of this and that if the following combination of, I don't know, burning pain combined with radiation into the kidneys or whatever, then you're pretty sure that this is this or that even maybe with the differentiation of certain subtypes sometimes there can be. [00:10:16] Researcher: Mm hmm. [00:10:30] ME9: An inflammation of the urinary tract, which is even sterile. Sometimes it feels like it's a urinary tract, but there are no bacteria, no bacteria or fungi. Sometimes it is really. And if you could maybe direct the diagnostic procedure, let's say the diagnostic questions and the conclusions, you know based on two or three symptoms to say this combination is highly specific for this outcome that would of course be very interesting. And I think this is a great start to just go qualitatively as you did it in your workshops. [00:10:54] Researcher: Mm hmm. So yes, you point the, let's say, attention to the combination of things. So from symptoms to any other kind of information that might be both qualitative and qualitative, but like how does those information relate to others around? [00:11:15] ME9: Yeah. Exactly. And maybe just for example, what all the textbooks say if within your tract infection, you can have a burning sensation while you have to go to the toilet and maybe there is frequent. Frequent urge to go to the toilet, but the quantity of of urine, urine that comes is just very little and maybe you some women also complain about, you know, almost *** pain, cramps in the urinary tract and you know. [00:11:49] Researcher: Mm hmm. [00:11:50] ME9: If maybe just all these qualities of symptoms, which all sort of are in the same location, could in combination point toward towards. A. You know, a better guess what the outcome could be or what the reason could be for that. So for example, the combination, let's

just you know, make it up after many, many interviews. Maybe the combination of burning sensation together with a sort of spasm of the urinary tract which are very painful, this 90% of the cases, it's a bacterial infection and it's never, it's for example never candidate, it's always bacterial. Or it could be a 5050 viral or bacterial or something like that. You know, having this quality of combinations that then the doctor or pharmacist could specifically ask for additional symptoms. And they do. You also experience this? No, not at all. There's never occurred. No. Then you know? Well, most likely this is not the case or it's a weak form. And, you know, just just going on to on the symptom of the of the urinary tract could already mean a lot, but. For example, radiation into the kidneys, back pain, or something like that. Most of the time, according to textbooks. Speaks, you know, for a for a sort of ascending infection, going maybe to the kidneys, which which is much more difficult, of course, to treat and more, more dangerous than just sort of, let's say, a basic urinary tract infection. And those are usually things that we standard standard care routinely asking the pharmacy to see, you know, is there any systemic effect? Is this radiating pain into the kidneys? Is there is there fever? Because then you have to act differently than if it's just. Sort of a minor urinary tract infection or a suspected urinary tract infection, but no, no, really, feelings of of sickness or illness. And so I could imagine that having a combination of certain things that pop up all the time in these, in these interviews that combining the right questions or combining the right symptoms could lead with high specificity to A to a certain. [00:13:48] Researcher: Mm hmm. [00:13:55] ME9: You know the likelihood of having a bacterial infection, for example, is 80% with this combination. Like that can be very helpful. [00:14:03] Researcher: Yeah, yeah. And about. Participation. Let's say because what emerged is that? Different participants were not actually aware of their disease itself, so some of those actually took part in the workshop thinking of being affected by UTI. Why discovered that was actually candidate or other kind of infection, and I pushed the, let's say to have this situation with the different participants working together. [00:14:25] ME9: Yeah. [00:14:33] Researcher: Also to allow like exchange of information and also what emerges that people sometimes feel or recognise in what others are saying similar condition or something that they couldn't explain themselves before. It that kind of like might help in your opinion to improve the awareness of people and if the awareness of people might be helpful, then in both describing symptoms, but also like understanding the the best treatment so. The the the disease 1st and then the treatment. [00:15:11] ME9: Yeah, I think that this could help, particularly also to realise that the spectrum of symptoms can be very, very different. And that's something that looks like you're urinary tract infection doesn't necessarily have to be one or it could be caused by something that is not bacterial, which may ultimately. Probably reduce the demand for antibiotics, but we have a lot of pressure in the pharmacies. You know, we are sort of protected by law that we can, you know, exception. There are exceptions, but most of the time we can just say sorry. They're not allowed, you know, to give an antibiotic, you need to have a a clinician looking at it. It's then a bit embarrassing if the clinician makes a diagnosis on the phone and the patient says he I just called him, I can have an antibiotic. And they say, well, that was not the whole purpose. I could do that as well. The point is, we should actually have a look at your urine. But sometimes this is the same for for throat infections, for chest infections. The pressure of patients kind of get an antibiotic and be healthy quickly. Is very high and sometimes you can have a hard time explaining patients. You know what, 90% in in your situation is viral. So there's no point in oh, why this doesn't antibiotic. Why shouldn't they work? Because they only work against bacteria. And then you also have to be very specific about the right bacteria and for the right disease. So it's not as easy as you think. What you just read in the Internet is maybe not the right thing and. [00:16:23] Researcher: Mm hmm mm hmm. Mm hmm. [00:16:40] ME9: By by knowing by by realising that. Maybe the the spectrum of of symptoms is very broad and is very individual. This may increase the awareness of of women to say I shouldn't just ask for an antibiotic. I should maybe, you know, be aware that it could be something completely different. And if I take this for three or five days, it doesn't help at all. I I really didn't do anything intelligent. It didn't help. I'm I'm still sick and I. You know, I got in contact or my my bacteria got in contact with a lot with antibiotic that we're not supposed to be

the right one. So it doesn't. It probably could help raise the awareness. Don't ask for an antibiotic in each situation and also for clinicians and pharmacists. Pharmacists are not, at least not here. In other countries you know you can basically buy antibiotics OTC and and you know to raise also the awareness that this is the completely wrong way to go and that there needs to be more diagnostic. I think this sort of qualitative discussions and descriptions of symptoms can. Can help understanding. Oh yes, this could be something completely different than I thought it would. [00:17:52] Researcher: In terms of. Recurrency, I mean, I see what you say. Does in case of recurrency, the situation might be different. As patients people know or can recognise symptoms happening, for example, I know about this UK project which actually I replicate. I mean here in Lugano the UC University is studying the same kind of like. Approach that I know they experiment in in the UK so people have recurrently affected by UTI, are provided with antibiotic in advance and then is like. Up to them know and recognise when to take those antibiotic or when not to take them. [00:18:35] ME9: Right. [00:18:42] Researcher: So do you recognise the same kind of behaviour or importance in term of behaviour even in case of recurrence diseases or that might be different? [00:18:54] ME9: I think this is this is it would be important if if some woman are, you know, heavily affected or just never. But those who are affected by Uti's learning more about themselves is probably absolutely crucial. Because if you, if you're not at a point where you know your symptoms well, you probably shouldn't be in a position to have the antibiotic at home because then if you just feel like something's going on, I don't know what it is. And then you just try for whatever. [00:19:17] Researcher: Mm hmm. [00:19:23] ME9: With the first symptom, you take it that will be wrong, so I think it. Is we have that a lot that that physicians prescribed antibiotics in reserve to take at home and then then of course this was only really good for for women who had maybe the 15th or seven or so and they know exactly it starts on a Friday or Saturday. My doctor is away. I have to explain everything in the pharmacy. They tell me they're not supposed to hand out antibiotics. So then you go to the hospital and wait for two hours. So to prevent this then. [00:19:46] Researcher: Mm hmm. [00:19:55] ME9: This is very very good. [00:19:56] Researcher: A very specific case of patients knowing the there are no doctors knowing the patients mm hmm. [00:19:57] ME9: Very specific, but yes, yes. But really knowing knowing there yeah and some have just anatomical problems or elderly woman sometimes they have also an atomic changes or have a dry vagina. So and then they just know they are they are very vulnerable and when they know this is exactly the way it was the last five times and then it I know exactly what to do now then it makes a lot of sense I wouldn't recommend that for a younger person. And maybe I don't know who has that the first or second time just to self diagnose it doesn't make sense. But for women with sort of a career or history in this disease, yes, absolutely. And the more they they learn, the more they understand their own symptoms and and and you know that the more specific probably their self diagnosis will be in the end. [00:20:30] Researcher: Mm hmm mm hmm. Yes. And how do they know their symptoms? I mean, it's just about having the disease. Is there any kind of support or action that they can take or that can help in building their awareness related to symptoms of the disease, in your opinion? [00:21:05] ME9: It's really trying there. If they know I have a symptoms, they see a doctor and the doctor makes a proper diagnosis, not only a phone diagnosis, but actually a proper diagnosis, maybe with a urine test or something like that, and says this is clearly a coli infection and we need to treat this and it will take 3 days and it's it, it it goes away. You just have to take these tablets or so. And this happens two or three times, then it will most likely just be, you know, the the right thing in the future as well. This will work. [00:21:15] Researcher: Mm hmm. [00:21:36] ME9: Probably you know, you can't really. You can explain that in theory and say it must feel like this and that this is what we read. But the proper feeling, as you've seen in your in your interviews, you know, the ranges were a little bit broad. So it it, it's maybe something that that somebody says it's very unspecific, but I'm sure it is a UTI again. So it's really learning, learning, diagnosing, treating, learning. [00:22:01] Researcher: Mm hmm process mm hmm. [00:22:03] ME9: Having it again having the same diagnosis again and after the second, third or fourth time, you're probably. Specific top. In theory, it's probably hard to explain that to

somebody, and if they haven't experienced it themselves. [00:22:15] Researcher: Yeah, yeah. And back from the analysis, have you identified any? I would say unusual or like curious word to describe any feeling, any symptoms, any words or even like physical variables that have been mentioned by patients to this kind, their own condition that you you were surprised by or that impressed you? [00:22:42] ME9: Well, I think the only one that I was really not aware of was this. I don't remember. You may know the warning. One person I think was particularly or or more than one with this this stomach symptoms and how was it called? There was a special expression of a full stomach blown. [00:23:00] Researcher: Swollen with my be. [00:23:01] ME9: Swollen stomach. I think it was not bloating, swollen stomach or so. Yes, that was was sort of new new to me. I've never heard that from somebody in the pharmacy. [00:23:05] Researcher: Mm hmm. [00:23:12] ME9: And maybe maybe this. You know, your explanation that you also stated in your text I think is to me the most likely that it's not the a priori symptom, but after treatment that will be interesting to actually distinguish. If they say yes, the doctor prescribed this antibiotic, I've taken it for three days and and you know, I have some indigestion and I have a swollen stomach. Then it could very well be a side effect of the drugs which heavily affect the GI tract if you're. But, but I've never heard about that thought, but I don't want to rule it out that it this is true. Maybe you know, clinicians who've treated themselves many, many, many patients and more recently than I did will say, yes, this is something that is that that occurs even even before the treatment. But this distinction, the distinction is difficult. But that was sort of the only unusual. [00:24:04] Researcher: Mm hmm. [00:24:08] ME9: Expression or explanation or symptom description that I read that I thought interesting, interesting wording. [00:24:12] Researcher: OK. OK, OK. And on the other hand, do you see identify any problem with this this method, so using materials to try to identify and express communicate symptoms so body and mental conditions? [00:24:15] ME9: Yep. No, I don't. I think there's is not problematic. It's it's very of course very qualitative individual. So it's something that you can't probably extrapolate to $10,000 woman, but just say it's a individual experience based on whatever that somebody builds a huge tower and somebody else constructs something with with peaks and needles or whatever, which sort of makes more sense to me because this is this, this, this. Stinging sensation that that is there while other things were sort of, you know. Probably a lot to do with the creativity of people, and if somebody's an artist then tries to express everything, whatever in a three-dimensional model, then this is much easier and somebody else sits there and says I have no clue what to do with this because you know I can express it the words, but not not in the in the form or so. So I think it's it's just interesting to see the spectrum of reactions somebody immediately can do something with it or does not. I wouldn't say this is something that you can really apply maybe. [00:25:23] Researcher: Mm hmm. [00:25:30] ME9: Doctor's office or in a pharmacy and say, you know, here we have a big set of toys. And now please construct something and I'll tell you what you have. It's it's more like again reflecting the individual sensation that that that will have, you know. [00:25:35] Researcher: Yeah, sure, yeah. Yep. No, definitely in this case was more to engage in a conversation. So the the focus was more on what people were saying by doing that. So having material just to sort of activate the the, the, the feeling and then the the conversation. [00:25:54] ME9: Yep, Yep. Yes. Yes, exactly. That's clever. Yeah. [00:26:01] Researcher: What about like instead of like building stuff? But would you consider like 3 little objects of those shapes are out of the study, so let's consider like a wooden little sphere and unshaped form. And there's something with the glass and some, like sprunes on that in, in a sort of like moment of consultation to to try to, I'll put and support passions in describing their feeling. They symptoms might be useful. Might be just time consuming. Would you not have more information than the one you usually have while asking specific question, you know. [00:26:40] ME9: I frankly would doubt that I could, unless there is really some very I don't know structure structure that well validated that you say, well, you have three materials, you know, a cold, whatever metal, a glass and a wood. And whenever people explain these symptoms and say it feels like that, then it is very specific. I'm not sure whether there's probably no validated test. It's probably very, very. [00:26:50] Researcher: Mm hmm. [00:27:10] ME9:

Unspecific and in this case when it's very unspecific and some women can't, I wouldn't expect too much from it because. My experience is I I I've never tried it of course, but in the pharmacy, if somebody they, you know, they express themselves verbally and say please can I explain you something? I have a problem here. It's a bit embarrassing, but I think this is something that could, you know, what is what are your thoughts about it? And then I'm not sure. Frankly, where the most women would be as creative as being able to actually really try to construct something or to talk about the material and to it, probably the women that you attracted by this workshop. [00:27:44] Researcher: Mm hmm. [00:27:51] ME9: To sort of a selection of women who were interested in expressing themselves, who were interested in learning from others, who were maybe more creative than others, who knows, and probably the average stressed young woman or elderly woman that had that for three times and comes to the pharmacy wouldn't probably really know what to do with this sort of diagnostic steps. Do you? Do you think this feels rather like wood or glass? You will probably stare at me and say, what are you talking about? [00:28:12] Researcher: Mm hmm. Mm hmm mm hmm. [00:28:20] ME9: I've I've had pain down here though. What can I do? But then it could be it could be interesting. Maybe you know. Again it's it's all like in in research if. [00:28:24] Researcher: Yes. [00:28:30] ME9: If if you can really validate that by and and say you know this is 80% correct whenever people combine this and this and this, then you know this is specific then that would of course be interesting. Then you could really have a sort of a set for these situations. Go to the to the consulting room with the patient and say by the way, if you have to choose a material that best describes your pain, what would you choose? And you know, whenever they pick this then it's it's most likely cola infection that would would be quite. It's sort of a magic approach. [00:29:02] Researcher: Yeah, this is will be very magic. Very last question. If you have time regarding the way you. Not understand, but consider I would say symptoms. I mean UTI are women are most affected by UTI compared to to men, but men as well can suffer from UTI when. Patients report those symptoms to you as men. Do you think like, considering the perception of woman differently, can you like? Based the the feelings on on the literature, or do you consider the any gap in in this direction? [00:29:45] ME9: I think it's sort of, even though I'm a man, it's sort of easier to try to, you know, to diagnose just based on before having a urinary test or whatever. I think there is much more literature and description on urinary tract infections in women because it's also much more common probably. So it's much better described I think in men the spectrum of symptoms is is even broader most of the time most likely it is also just. [00:30:02] Researcher: Mm hmm. [00:30:14] ME9: Burning sensation when you have to pee that then something you know sort of doesn't feel right. But other than that, it could of course sometimes also being as an ascending infection going to the to the prostate or so on. Then it's of course more difficult to treat, but I think other than a burning sensation, it is very rare and we have I can hardly remember any patient, you know, showing up with these symptoms. Maybe it's a lot of catheter associated infections, infections in hospitals, yes. Yes, that that is. They are often completely sort of mute. You don't they don't. Patients don't feel much, but nevertheless they have a lot of bacteria in the urine and need to be treated sometimes. But in the pharmacy that the patient, the male patient came in and said, you know what, I have this problem then it was most of the time it was the the suspicion of maybe. Sexually transmitted disease that you have to say, you know, you need to see a dermatologist and have a proper diagnostic because it could really be something that is not just sort of the classic. [00:31:13] Researcher: OK. [00:31:23] ME9: UTI but actually some some wild or bacterial sexual transmitted disease. This is I think more much more of a of a reflex that you would have and most of the later trend what we were actually dealing with in clinical practise was always women. So I think men would be a completely different game and I think it's great that you just focused on women because otherwise it gets way too confusing and you wouldn't have a hard time finding probably men who. [00:31:45] Researcher: It's different, OK. [00:31:50] ME9: Maybe have that two or three times who would be willing to, I don't know, participate in a workshop. And to talk about that, you know, this is probably would be relatively hard quantitatively and qualitatively to find men who would be able to do that and willing to do that. So most likely you'll probably

do it do well by focusing really on on, on females. [00:32:10] Researcher: Mm hmm. OK. That's all. Thank you very much again for for your time and your your answer.

ME10

[00:00:49] ME10: I am ** and student of Medical School [00:01:44] ME10: So I have some feedback, so globally I've I found it very interesting. What went out of this. [00:01:48] Researcher: Mm hmm mm hmm. [00:01:57] ME10: This workshop I have a few a few feedbacks that I I noted. The first one being that. What we can see is that with such a workshop, the patient tend to make a lot of introspection. Which is very good in a sense that when you do introspection, you focus on what you feel. What are your symptoms and you begin to understand better what happens to you, which is a good step when, for example, you have recurrent infections or something like this. A good step also to explain it to the doctor. And at the same time. Symptoms can be very subjective. So this is one of the challenges you have, like standardised symptoms, we could say or very specific symptoms or so less specific very unspecific symptoms on the other side. But you also have very subjective symptoms which do not really correspond to the disease you are diagnosing, for example, and this is also something that came out a lot during the workshop and was very interesting. So. I don't know if you want to react about that or. [00:03:20] Researcher: Mean I completely agree. What about what you're saying? I think what was also important in this context was the conversation that happened among people. So I was first suggested to ** the activity kind of 1 to one, but I pushed to have a participatory environment because I think that first people can always like learn or at least. [00:03:42] ME10: OK. Yeah. [00:03:51] Researcher: Hear about others experiences that might be useful for them as well. And secondly, from the conversation itself sometimes. You are kind of like reminded or. There is something that push in your mind about experiences or way to understanding your own experiences through others. So I think that's, I mean that was important and I recognise that in what you're saying. Of course there is always this like subjective component that is on one hand, I think what allow us to bring in more information. [00:04:15] ME10: Yeah. [00:04:29] Researcher: Not only to. [00:04:29] ME10: Mm hmm. Mm hmm mm hmm. [00:04:31] Researcher: Allow people to know better themself, but on the other it always something that must be considered contextualised, so not the only source of information, but something that must be related to other. Information and and data and that's that's for sure. [00:04:52] ME10: And the subjective part is also very important, because if we speak particularly about recurrent infections. The burden of the disease can be quite different from a person to another, meaning, for example, someone that has recurrent ones and maybe mild symptomatics or something that she qualifies at mind symptomatic. Would be less impacted that someone that has severe symptoms severe symptomatic so it can be very different from a person to another. So as a clean clinicians it's at the same time very tricky that you have subjective. Symptomatics, but at the same time it's very relevant to to imagine the the burden of the patient. [00:05:40] Researcher: Yeah, that's what I would like to ask you actually, if like this sort of materials or any other way that you can imagine to? Facilitate from the patient's side the description of symptoms might help in reading further, let's say. Their perception, so go deeper into their subjectivity of the disease or not really, because everything is again very subjective. [00:06:13] ME10: So I will say, yeah, yeah. [00:06:13] Researcher: Because for example, sorry I was having another conversation with you, Yulia, and she will say that usually doctors have this case that help them asking patients if they the pain is zero to five or zero to 10 with like a smiling faces colours and this stuff. But what she was saying is that that kind of tool help them in understanding. [00:06:30] ME10: Exactly. Mm hmm. [00:06:38] Researcher: Quantitative information related to the symptoms why there is a complete lack in terms of qualitative description of the symptoms. [00:06:40] ME10: Mm hmm mm hmm. [00:06:48] Researcher: I mean and then her opinion was that materials can help in that direction. So what I'm asking to you is if that kind of tool is helping to have quantitative scale of the pain which is again like can be subjective, but if that kind of scale and answer is integrated with some qualitative description of the pain. My dad's, like, create a sort of like wall definition or like wall description of of the disease might be that useful

in your opinion. [00:07:22] ME10: Yeah, in my opinion it's very useful because. You for specific diseases, for example inflammatory diseases, you have different kinds, so different qualities of pain. So you have pains that are more like punching pain or pulsing pain, which are more associated, for example in case of inflammation. And then you have the burning pain, the stinging pain. Which are more associated with. We could say acute processes, so acute diseases. So it is something that is important and the fact that again patient go through this introspection procedure. [00:07:54] Researcher: Mm hmm. [00:08:07] ME10: They learn to qualify a bit better this pain, which could help. I I think substantially to to make the diagnosis a bit preciser. But what I also liked about this workshop is in fact that the different persons. Found how to qualify qualitatively the symptoms, but also we could say their experience and also quantitatively because for example the size of the forms or also. What was very or the numbers, the numbers of the different forms they used had a meaning. [00:08:47] Researcher: Hmm. [00:08:50] ME10: So they also qualified them quantitatively as we do with those pain scales and such kind of things. So I think, yeah, it is it is something that is I would say for a complete diagnosis it's it's very good to have both. So yeah, I found it interesting. [00:09:11] Researcher: Do you have or do you know any other like tools, scales or yeah like support that are used to describe symptoms or in general the disease more qualitatively instead of quantitatively? The doctors can use or even without patients, maybe from an expert point of view with other expert. I don't know what might be the context. [00:09:35] ME10: So is the. I would say the tool that I know the best is the Socrates tool. I wrote it in the yeah. [00:09:42] Researcher: Yeah, the one you pointed in the in the document, yes, I just opened the page and not really like went into that, but I will definitely do. [00:09:46] ME10: Exactly. Yeah, it is. It is an acronym. So it's an acronym for site of the Pane. So you look at the site you look on set. So here you really have. [00:09:54] Researcher: K. Yeah, mm hmm. [00:10:03] ME10: We could say also a time component which also sometimes. Was mentioned during the workshop, so I also found this interesting. Not always, but some of the the persons needs structures that were related with time. [00:10:23] Researcher: Mm hmm. Mm hmm. [00:10:26] ME10: That's interesting. Then you have also the character of the pain, and here you have the qualitative. [00:10:32] Researcher: Exactly, yeah. [00:10:33] ME10: Factor, but yeah you do. I do not exactly. Know if there is any scale because you know when it's qualitative, I don't think you can speak about the scale, but there is no tool, for example, to have not a scale, but you know, like a list of different qualitative pain we could say. [00:10:46] Researcher: Mm hmm. [00:11:00] ME10: Probably because it's subjective also, and it's maybe best that the person's patients come up with their own words when they describe it. [00:11:03] Researcher: Yeah. [00:11:13] ME10: Probably, but this is something I do not really know. Then you have the different ones. So yeah, afterwards the acronym you have R for yet radiation where it's radiate and so on. I I will let you look at it if you want. [00:11:16] Researcher: Yeah. So this sakrat, sorry. How who does use this scale? I mean, how? Who usually? [00:11:34] ME10: Technically, it's what we learn to do in an amnesty to do a complete anonymous when someone has a pain or discomfort, or even you can use. [00:11:37] Researcher: OK. OK. OK. If like enough general question that you are trained to ask patients because for example, what you were saying about the qualitative of pain, if it's ageing or stop being this sort of question, is there a specific list or is something that a general knowledge that comes from your study? [00:11:50] ME10: Yeah. Yeah, exactly. No, that's. Yeah, exactly. That's that's what I mentioned to you. You do not really have a specific list. [00:12:10] Researcher: OK. [00:12:12] ME10: You you learn some kind of qualitative pain, like I said, like touching, pulsing. Dumps. In Dutch. Or you also have other kind of pains, like stinging, burning you. You learn that they are more associated towards acute. [00:12:27] Researcher: OK. [00:12:34] ME10: Diseases or inflammatory but. [00:12:38] Researcher: There is not like any specific reference on that. OK. [00:12:38] ME10: Yeah, more than that. No, there is no specific reference, it's yeah. [00:12:43] Researcher: OK, thank you. This is very, very useful. Thank you for for sharing with me. I don't know if you have any other point you want. No. Sure, sure. I mean, it's not like. [00:12:49] ME10: Not a as far as I know. As far as I know, this is also important to precise. [00:12:55] Researcher: I don't know if you

have a sort of list or other other points that you wanted to to go through, or as you prefer. [00:13:03] ME10: Yeah. We can. What what I liked with this workshop is that in literature we know that it's a frequent disease, so UTI particularly among women and that it can be recurrent for quite a lot of women. So women that experience one UTI are very are very exposed to recurrence of the UTI. In the following six months, or even in the following year, so it's something we know it's very frequent and. With literature, we also know that it's high burden. But to have this workshop, it's also nice to see to see the expression of the burden so that patient expressed. Really. Yeah, it is a burden because of the instability. We do not really know how it's going to evolve if it's going to be worse. If it's going to be better, it's a huge burden. Because. Of the quantity of pain or because of the presence of such and such symptomatics. So this is also something that I found interesting. [00:14:14] Researcher: Have you spot any like different symptoms from the one you are usually? Trained or you usually recognise based on your experience. [00:14:25] ME10: Yes, the the one that surprised me a bit was the swollen stomach, because this is not something I learned we could say. [00:14:32] Researcher: Mm hmm, I read your comment. Uh huh. [00:14:37] ME10: Yeah, I was thinking about it. Maybe they are confounding factors and maybe for example, menstruation, because I know that for so this is more for genital disease. So vaginal disease that they are associated with specific type points of the menstrual for example. [00:14:44] Researcher: Mm hmm. [00:14:58] ME10: So I don't know about UT, is it probably could be the same, but this is something I just say probably and if it is the same so it could be a confounding factor is that you have at the same time the menstruation and it's because of this that you have this wound stomach. But this is the second point I would like to mention about this is the fact that swollen stomach. [00:15:02] Researcher: Mm hmm. Bye. [00:15:23] ME10: What does that really mean? In a sense, you have the physical. Examination of your stomach and you see that it's swollen. But you also have the feeling of small, swollen stomach. And this, for me was not very clear in the workshop if. The woman patient reported more. So the physical examination of their stomach, so they saw that the stomach was swollen, or if it was more the feeling of of a swollen stomach. So this could also be interesting to precise a little bit, but I don't know if you already have the answers about this, but. [00:15:49] Researcher: The feeling OK. No, I don't actually. This perspective of actually seeing the symptoms from the, from the feeling of the symptoms is something that I didn't like considered since still you were mentioning for the first time. So that's an interesting point of of you and something that would my ask in case this emerge again in the next session definitely. [00:16:15] ME10: OK, OK. [00:16:25] Researcher: And do you see on the other hand any any like specific association between materials and symptoms that surprised or impressed you positively or negatively? [00:16:26] ME10: OK. Yeah. I miss look on my notes I think. Yeah, there was one. Something for fever using fur and for example fur. So this is very subjective, but fur is for me something that is, you know, like smooth. It's something that is comfortable. So it's not very intuitive for me to use something comfortable to qualify something that is disagreeable, like fever. So this is something that surprised me. I think there was other things. [00:16:53] Researcher: Mm hmm mm hmm. Mm hmm. Yeah. [00:17:17] ME10: That I wrote on the document. I don't know if I have it in the note but. [00:17:19] Researcher: Yep. It's OK. I mean, if you wrote it down, I will. I will go again through that. It was just like there was something like that came to to your mind. [00:17:32] ME10: Yeah, this was surprising because most of the time I was more. How quick can we say this more amazed by how they represented their symptoms? And it was like, Oh yeah, that's a nice representation. So I was relating more to the representations than really like, oh, this is surprising, but yeah. [00:17:42] Researcher: Mm hmm. Mm hmm. OK. Yeah, yeah, yeah. Something that you wouldn't have done in in that way. OK. OK. [00:17:56] ME10: Yeah. Excellent. [00:18:00] Researcher: And on the other end is do you see any limits or possible problems in? Asking people to speak about symptoms or disease experiences through material or using materials to represent this kind of information. [00:18:20] ME10: Yeah, you you have to be able to have a good sense of abstraction, so to really. Take take out the form, take out the. The colour take out the the also the you know the size you you you really need the presentation of the one that did the the artefact

because if you do not have it you are going to misinterpret it's it's a bit like. [00:18:45] Researcher: Mm hmm. Mm hmm. Mm hmm mm hmm. You mean from the perspective of patients who have to build stuff or from the perspective of who does read the analysis in the end and and need to understand. [00:19:02] ME10: I think a little bit of both to be completely honest. So I would say it's so when. Yeah, someone did that artefact with ideas in mind. And if you do not have this person that explains you what exactly what it means. Then you would interpret it, and if you give free room to interpretation, then you have the risk of interpretation bias and so on. So it's it's a challenge. But I I think it's more or less the same in the clinical life when you have a patient that comes to to the office and you you see. That the patient seems to be tired seems that the the disease is a huge burden and such kind of things. It's also interpretation. When you see the you know the how do you say this in English? It's like the the. Corporal big behaviour, no body language. Body language. Sorry. It's so easy. In fact, if you see the body language, it's also interpretation. But I I think you need both. And you need to to assess both and to use both. But in. Yeah, the balance is not always easy to take into account. So I would say the principal risk is this interpretation risk. [00:20:11] Researcher: Mm hmm. Mm hmm. Mm hmm mm hmm. Yes. [00:20:35] ME10: But yeah, I would say it's this. [00:20:38] Researcher: OK. And you. Do you have in mind any other information that should be asked or faced during the workshop to try to understand better the experience, the symptoms and any other information useful for you as doctor? [00:21:00] ME10: So what? What I what I noticed is also something that might be a misconception. I don't know if it was just because I read the paper and was not present during the workshop, but. [00:21:12] Researcher: Hmm. [00:21:14] ME10: The difference between incontinence and urge of peeing because one of the patient, for example, described incontinence as something in movements because of the urge of peeing. [00:21:18] Researcher: OK. OK. [00:21:44] ME10: More than movement, movement being more representative to this urge of peeing, so I don't know. You had both like urge of ping and incontinence as I do not remember exactly. [00:21:55] Researcher: Yes, I I saw your comment asking where I took symptom from. [00:22:01] ME10: Mm hmm mm hmm. [00:22:01] Researcher: I have not like the the name of the the the paper now, but I can provide it to you you with that. So I basically look for. [00:22:07] ME10: Mm hmm. [00:22:11] Researcher: Research on UTI describing symptoms from UTI and so I took all the lists from there. Then there were some empty labels during the workshop, so I asked people during that phase to add if there was anything like use I mean. [00:22:15] ME10: OK. Yeah, yeah. [00:22:28] Researcher: That worth to notice. And so they added some labels. I see the difference you citing and I would also say that sometimes. People. Especially when it came to work also on physical variables. [00:22:51] ME10: Mm hmm. [00:22:51] Researcher: They kind of like sometimes associated similar symptoms together. That's not that. They were not like seeing the difference or perceiving the difference, but. They kind of like group them to treat them equally in terms of representation, which might be a problem. I mean it or on the other hand, I think is more related to what you were saying before. So there a bit. [00:23:07] ME10: Yeah. Yeah, OK. OK. [00:23:18] Researcher: And actually lack of familiarity on working in this kind of way. So of course it's something out of normal. You're not usually trained or familiar with associating symptoms to shapes and whatever. So. [00:23:31] ME10: Yeah, yeah, yeah, obviously, yeah. [00:23:32] Researcher: Sometimes was also difficult to to facilitate the activity because everyone was going like in different directions. So try to merge the the the energy in the same direction. But I I I see what you do saying and that's also why I always try to keep an expert with me during the workshop because it's always useful to have like feedback from the definition of the disease or like. Expert point of view on what also participants say because as as you noticed, there was participants who took part in the worship thinking of having the disease and then they ended their worship with another disease in mind. So was useful to have the the expert in there also what emerged. And I actually discovered in this run of interview with the expert. [00:24:02] ME10: Yeah. Yes, I'm not having it. [00:24:24] Researcher: Is the fact that all I mean a lot of participants were trying to push to have? Anxity. And like this sort of feelings as a dizzy, as a symptom. While I've been say that that's more a consequence of the symptoms. So because you have urgency and

going to the bathroom, you are anxious to leave your home. So to walk, to go to work or for to go with friends, whatever. And so that where the anxiety starts. [00:24:38] ME10: Yeah. Mm hmm. [00:24:57] Researcher: So more as a consequence like second kind of yeah, consequence of of the disease. But was interesting because actually patients, I mean people were treating them on the same level of like urgency or even. [00:24:57] ME10: Yeah. Yeah, but it it's it's still. Yeah. [00:25:13] Researcher: Stomach or like any other symptoms. [00:25:14] ME10: Yeah. But it's still interesting because. Even though those are consequences, those are still symptoms that are associated with it so. We cannot part them. It's something you know is related to. So it's it. It's needed to be taken into account together with the other symptomatics knowing that it's a consequence, but still it's something that I found interesting. [00:25:45] Researcher: I'm mean, say if I'm wrong, but that doesn't help the doctor to understand the sort of disease most probably. Or maybe it's a sort of way to understand how urgency is. They need to go to the bathroom. I don't know. [00:26:00] ME10: So what? What it helps it's to understand the burden once again. It's to understand how much it affects the person because it could be also that you have. [00:26:04] Researcher: OK. [00:26:12] ME10: Some anxiety issues beforehand, but even if you have some beforehand. Having a recurrent UTI in association with it could amplify the anxiety, so you know that the burden will be higher. By someone that is very anxious that has anxiety disorder, then someone that is we could say very stable. That has a very stable personality or does not have these anxiety problems. So this is something that amplifies the burden of the disease. So yeah, it still needs to be considered, but yes, it's not a direct symptoms. It's more indirect, but it is also interesting because. [00:26:59] Researcher: Yeah. [00:27:01] ME10: A lot of person mentioned cleanliness and such kind of things so. How you clean yourself and also after sexual intercourse, which is prevention, that is very often mentioned and recommended to avoid Utis and it works quite well. And this is also something that has. That is linked strongly linked to the microbiota. We know we have evidence that microbiota, if you have a healthy vagina microbiota, which is. [00:27:33] Researcher: Mm hmm. [00:27:40] ME10: We can say in between when you look at the rectal and **** area and you have the vagina and afterwards you have the retrof, you know that it's in between. So if you have a healthy microbiota, it helps a lot to. There is actually one paper that's that's so an association with healthy microbiota and less UTI for example, so. [00:28:03] Researcher: Mm hmm. [00:28:03] ME10: We know that it's very linked and it does not surprise me that you had some of the participants that were confused between the two because it's very close. It's very related. You have specific symptoms where you can really discriminate between the both, but you also have unspecific ones and you are not able to really discriminate between the two. And this is also something I noticed. Someone mentioned mentioned Candida. [00:28:21] Researcher: Mm hmm yeah. Mm hmm. [00:28:28] ME10: And candy doses. And she also took. Spoke about antibiotics. And here it was not very clear for me if she was just saying antibiotics but was actually taking antifungals. [00:28:45] Researcher: Mm hmm. [00:28:45] ME10: But she didn't know that it was antifungals, or if it was. In fact, a mistake because you should treat candidates as a list, so you should treat it with antifungals instead of antibiotics. If you take antibiotic, you're just going to kill more you you know you. Vaginal microbiota and not kill at all the the Candida, so it could. It could even worsen the the disease, but here it depends on what the doctor did, but. Yeah, I will not judge. It's just that. [00:29:21] Researcher: Yep, no, no, sure. [00:29:25] ME10: This is a mistake that we commonly find with patients is that they associate antibiotics, killing all microorganisms, which is not the case. Not the case. And should be well explained because if you look at UT is you the most common one is the share shackle, which is a bacteria and afterwards you have other bacteria. You almost have no yeast. [00:29:53] Researcher: Mm hmm. [00:29:53] ME10: Only in specific conditions and viral. It's very rare, too. So viral it's, I don't know any to be completely honest, but yeah, still, I'm a medical trainee, so I'm not very experienced, but I mean. The majority is like our bacteria and if you look at vaginal infections, you have all kinds of infections. You really have Candida, which is one of the most recurrent, which is a yeast you have chlamydia, which is a bacteria. An intracellular one, which is a bit specific, different, but it's still a bacteria, so you use antibiotics and you also have virus like you know,

hairpins, virus and such kind of things. So you have a large variate and also parasites. Also, parasites. You have one parasite that's called Trichomonas, and this one is. [00:30:43] Researcher: Mm hmm. [00:30:50] ME10: I think it's 10% of all virginity. So vaginitis is when you have an inflammation of the vagina. So it's kind, it's quite often the case. So you really have a large variety and this is very confusing people. As I read in the in the workshop. And this is also something that made me realise also, oh, OK there are. [00:31:09] Researcher: OK. Yeah, yeah. [00:31:14] ME10: Confusing factors for persons. [00:31:16] Researcher: Well, maybe keeping the topic of the worship, the focus on one sort of disease, it it can help better because I started being focused on urinary tract infections that I tried to open a little bit to what do I define. But I've been told that's a wrong description of intimate infection. So I've been suggested that maybe I can refer to. [00:31:20] ME10: Yeah. Mm hmm. Yep. [00:31:42] Researcher: Volvo vaginal infection to have it more general. Well. [00:31:47] ME10: But I I find I find that it's it's great to keep it as an intimate infection and that you keep it like that. But it depends on what you want to do and if this kind of things. [00:31:53] Researcher: OK. [00:32:00] ME10: You should be aware of the fact that people will most probably be confused about the difference of bacteria. The difference of between the two diseases, but it would be also very interesting to see what people think about it and if it's something very common. If it's something that you only see in a few people this or so. [00:32:22] Researcher: OK. So you mean like keeping the focus quite open and then see also how people relate to maybe similar symptoms or what is described as the same symptoms but from different perspective of different diseases something like that? [00:32:26] ME10: Mm hmm. Yeah, but once again, it depends on what you like to do. If you would like to focus really on UTI, you can focus on Uti's. You will still have people that experience both, meaning Uti's and also you know, like vaginal infections or genital infections, so. [00:32:41] Researcher: Yeah, sure. [00:32:56] ME10: It's not something that will exclude all persons that have a genital infections, but if you would like to open the wrench, I find it interesting too to also to to see the proportion of people that have both. [00:33:06] Researcher: OK, OK. [00:33:11] ME10: Or one only one. It could be interesting to. [00:33:11] Researcher: Mm hmm. Yeah. Then it really depends from recruitment. But yeah, yeah, no, I I see what you mean. [00:33:19] ME10: Yeah. Also, yeah, yeah, obviously. [00:33:22] Researcher: I don't know if you have anything else to add or that I will not find in your notes, yeah. [00:33:26] ME10: I'm looking through my notes I think. Yeah, I think there was this timeline thing that I found interesting. The IT really that some patients reported this timeline of the symptomatics and this is one clue often that the person is first has a recurrent infections. Because the person knows how it comes up, how what follows and such kind of things, yeah. [00:34:04] Researcher: Yeah, kind of recognise the steps. [00:34:07] ME10: Which is very valuable. At the same time but. Should always consider all these. This person has a recurrent infection, so it is huge problematic. It is a burden for for him or her. But you you look at women mainly and. What I wanted to say about this session and the the one that surprised me and I was not thinking about this. It's one person mentioned that she often had Uti's after sexual intercourse, and she was ashamed of it because she didn't talk about it because for her it was like she was having too much sex because she didn't know that it was something. [00:34:54] Researcher: Mm hmm. Mm hmm. Mm hmm mm hmm. [00:34:58] ME10: I would not say normal, but something that can occur. [00:35:01] Researcher: Nothing. [00:35:03] ME10: So this is something that's really surprised me in a sense. [00:35:08] Researcher: Yeah. I mean, she was young when that happened. And then, of course, *** understood what was UTI and whatever. But yes, that's actually something that came up from another session as well. And this participant was mentioning, like, the lack of having a sister because could, like, refer yes to someone and ask questions instead of, like, going to anyone else because she was feeling. [00:35:28] ME10: OK. [00:35:33] Researcher: Sort of like guilty of the fact of having UTI. Yeah, no, that's that's true. [00:35:35] ME10: Yeah. Yeah, this is also something very challenging. [00:35:39] Researcher: That's part of people not being aware of the disease itself, and sometimes their body too. I have a very last question you of probably like speak with the people who got the experience of UTI, both male and female, even if they're, I read more female affected by the disease because of body condition. [00:35:42]

ME10: Yeah. Yeah. Mm hmm. [00:36:04] Researcher: Do you think is your perception different when? Male. Reports symptoms and they are like feelings, perceptions, physical and mentally, but probably most physical to female because of your of your sex. [00:36:23] ME10: So you mean if I if I have one patient that is female and report so UTI symptoms and one male patient that report UTI symptoms, the difference between the two are? [00:36:37] Researcher: Yes, difference in term of like understanding or perceiving or like in the way you interact with them because of course I suppose you know very well from the literature and your study what's the the perception of both symptoms. But of course I suppose as male you can like. I don't know is this actually this is actually a question better understand what may report or not really. [00:37:07] ME10: And you mean that I better understand as a male clinician, what male reports? Oh. [00:37:12] Researcher: Mm hmm mm hmm or not understand, I suppose you always understand in. I mean in terms of like perceiving or like relate to what they're saying. [00:37:18] ME10: OK. OK. And it's difficult to say because. [00:37:28] Researcher: You don't know they have. [00:37:29] ME10: I I don't. I don't really think there is any difference on my side. There's more like a knowledge difference in a sense. When you have a male that has a UTI. So a male patient, it is almost always classified as what we say, complicated UTI. So there, there is a huge difference because of that. [00:37:34] Researcher: K. [00:37:53] ME10: You you have to to treat the person in a different way. You do not really have. I don't know if there is evidence now in the literature, but if you have a complicated UTI, normally you should treat with antibiotic and now it is more and more suggested for healthy young woman and without risks that you should avoid antibiotics and treat with alternative methods, for example. [00:38:08] Researcher: Mm hmm. Mm hmm. [00:38:22] ME10: This is because of, you know, the increasing resistance rate and such kind of things, but. [00:38:27] Researcher: Yeah. [00:38:30] ME10: About nails it's it's difficult because it's not classified as the same for the moment, so. [00:38:36] Researcher: Yes, I see what you mean. Mm hmm. OK. [00:38:39] ME10: Obviously because it's classified as complicated. Directly classified as complicated. It's something different because as a clinicians, if you know it's a complicated one. Because of the term also complicated, you are going to, you know, treat. [00:38:55] Researcher: Mm hmm. [00:39:00] ME10: More treats more like. Using more antibiotics, for example, doing more investigations and such kind of things. [00:39:06] Researcher: Yeah, yeah, yeah. [00:39:11] ME10: Then if you heard the term uncomplicated, which is often treated empirically, we do not even know which bacteria is causing you know the infection. But we give this antibiotic because you know, we know that it works in a Tata T percent of times and such kind of things. But I would say the main difference is here it's not because of the sex per SE, it's. [00:39:11] Researcher: OK. Mm hmm. [00:39:35] ME10: It's because of the classification. [00:39:37] Researcher: Yeah. [00:39:39] ME10: Because I do not see any difference and I do not relate to that because I've never had one to be completely honest. So. [00:39:40] Researcher: OK. Exactly. That's what I completely see. What you mean the other like kind of sub question was do you like have a different experience when you? Know because you experience yourself the disease people are reporting because, for example, luckily I have other diseases but never like seized this nudi. So when I was running workshops sometimes of course I know what, like, bloated stomachs means or like other like urgency to go to pee. But. [00:40:08] ME10: Yeah. [00:40:18] Researcher: I never have the experience of that symptoms because of UTI, so I always think that might be different from my perception of that symptoms. So even in thermos like we're using material and blah blah blah. So if you think that as a expert you relate differently to diseases that you actually personally experience and to the one that you only read about and studied of course. [00:40:44] ME10: Yes, obviously. So this is something, it is a bias, but it is you know it's a very human bias and it's better to be aware of it because if you're aware of the bias you, you know you can tackle it. So it's better to admit it than you know deny it. But yeah, I have personally celiac disease, so I cannot eat any gluten. And I had a period. [00:40:56] Researcher: Sure. Mm hmm. [00:41:08] ME10: Now, until diagnosis, it lasts around. Five months, I think where I had symptoms and if you have celiac disease, you can have a wide range of symptoms. You can have intestinal symptoms which are like a bloating, diarrhoea or Constipation. Depends. You can also have what

is very surprising of psychological symptoms like. Kind of a light depression. Can happen. This is most probably due of this gut brain axis that is more and more studied, but we do not really. Know actually what's happening, but it is something that I lived I experienced. So when I hear patients having the same symptoms, obviously I think about that. So it is a bias. See, it's just if you know it, you're not going to have this, you know, we say in French. If iTunes, it's like a tunel effect, you know, you you consider one diagnosis and not all the other ones that are possible. Sorry. Yeah. [00:42:09] Researcher: Mm hmm. Mm hmm mm hmm. Let's go straight into that. Mm hmm. No. Yes, yes, I got it. [00:42:19] ME10: Yeah, I don't have to to say it in English. I don't know the name in English, but yeah, so. Yes, obviously it's it impacts also in a in a way you you always have empathy towards the patient, but if you experience yourself the disease, you will have automatically a bit more and maybe lean a bit more towards this feeling. Side so yeah, it is something that that happens and I can relate to relate to that, but. I I've never had a celiac patient until now or just talking with celiac people. I know that I will lean toward this, but yeah, so I hope it answers your question. [00:43:07] Researcher: Yeah, yeah, yeah, sure. No, this is this was actually more a curiosity or trying to like contextualise some information so. Yes, thank you very much. You for your comments and this super interesting conversation and the time you spent reading the analysis. I hope somehow it's been useful to to you as well. [00:43:30] ME10: I don't. I don't know if it's useful per SE. When I was reading it, but I was very I found it very interesting and also a few points like I mentioned this point where this woman was ashamed of having a sexual intercourse and having this problem after sexual intercourse. This is something that is very relevant in a sense because I wanted to mention this, but. [00:43:30] Researcher: And. Mm hmm. [00:43:55] ME10: I forgot it's the very intimate. Symptomatics that you can have is something very challenging in clinic because. You often let the patient speak about what they feel, what they have, but you also have this hidden agenda. So patients that have some symptomatics, they are ashamed of, they don't want to talk about, so it can even sometimes happen that you have a patient that comes, seems to be very fine and does not really want to talk directly about those kind of things and. [00:44:14] Researcher: Hmm. [00:44:31] ME10: Waits for you to ask the question and it's very it's at the same time very awkward and challenging because. [00:44:33] Researcher: Mm hmm. Mm hmm mm hmm. [00:44:37] ME10: You have to identify this and afterwards explicitly ask the question or at the end of the consultation, say, is there something else you want to talk about? And there are such kind of techniques, but still it's something very challenging and I was never. [00:44:46] Researcher: Mm hmm. Mm hmm mm hmm. [00:44:55] ME10: Expecting that from the UTI point of view that it could, because it's linked with sexual intraprocess was very interesting. So yes, I think it it brought me some nice inputs. [00:45:01] Researcher: Mm hmm. Oh, that's good to hear. I'm glad for that. I'm glad for that. [00:45:09] ME10: Yeah, yeah, yeah. And they really liked this patient centred. Also a point of view to to really try to understand better what happens in a given disease, yeah. [00:45:20] Researcher: Thank you. Thank you.

ME11

[00:01:11] Researcher: Ok quindi anche in un momento di consulto, lei considera più queste variabili? Diciamo, posso definire di contesto? [00:01:16] ME11: Me me le faccio, me le faccio, mi faccio raccontare il. Il l'acronimo per tutto quello che si deve chiedere a un paziente del dolore, si chiama Socrate Eh. [00:01:31] Researcher: Mhm. [00:01:32] ME11: Non so se lei abbia già incontrato. Esatto che Said on Search Direct Al cara te lo metterei piccolo, ah relieving faction ah aggravato in factors. Tu quelle cose lì. Insomma, il SOCRATES. Lo chiedo, ma il carattere del dolore mi mi dici relativamente poco? [00:01:58] Researcher: Ok, OK, grazie. [00:01:59] ME11: Anche se lo chiedo. [00:02:01] Researcher: Ok, quindi è un'informazione che comunque chiede, anche in forma quantitativa, non non è indice perché comunque è una variabile soggettiva. [00:02:07] ME11: No, no, non puoi chiedere informazioni quantitative. Esatto e descrittivo, la forma è il watt si, il viso Ronan Score per il dolore lo chiedo eccome. Ma anche questo è relativamente poco discriminante, ma il carattere non può essere quantificato e un carattere noti che non sono uno che è soggetto alla dittatura della misura. [00:02:31] Researcher: Ok. [00:02:37] ME11: Considero che il carattere

sia qualcosa di estremamente importante in vari campi. [00:02:42] Researcher: Mhm. [00:02:43] ME11: Ah, c'è un carattere della relazione, un carattere di un romanzo, un carattere di un pezzo di musica? Penso che anzi Eh. 1 1 dei degli elementi importanti, appunto della della musica sono state abituato a considerare che il carattere non certo pezzo che va rispettato, quindi rispetto al il carattere e mhm. [00:03:05] Researcher: Per carattere posso chiederle cosa intende? [00:03:13] ME11: Laura emotiva che circonda un'esperienza. Ehm. Sereno, Eh cupo? Ah, ecco, con questo tipo di cose che nell'esperienza artistica sono certamente eh importanti nel nella definizione, cioè nel dolore, hanno relativamente poca, a poco valore per me, ma non dico che non l'abbiano per i pazienti e non dico che studiando le cose che lei sta studiando non vengano fuori cose nuove anche per me che in fondo faccio questo mestiere da quarant'anni, ma ci sono sempre cose nuove che imparo. [00:03:48] Researcher: Mhm. Ah, certo, sicuramente una prospettiva interessante. Io in realtà l'ho ho trovato, e cioè la conoscevo tramite la. Il ciclo di conferenze che avete fatto? Parole che curano l'anno scorso, quindi comunque ho diciamo riconosciuto il il tentativo di portare delle pratiche diverse rispetto alla narrazione di quella che è la malattia è quello. [00:04:13] ME11: Sì. Ma ha sentito la mia conferenza? [00:04:30] Researcher: Sì, sì. Ho partecipato ai vari incontri, ad esempio conoscevo già, cioè avevo sentito, però è stato molto utile poi approfondire anche la parte di medicina narrativa e con con l'incontro che avete fatto e quindi lei vede queste pratiche più utili da un punto di vista, diciamo del paziente o comunque per andare a conoscere quelle informazioni contestuali che diceva prima. [00:04:32] ME11: Ecco. Della relazione. Ecco, io vedo molto utile l'approccio di medicina narrativa per la relazione e la soddisfazione del paziente. [00:05:06] Researcher: Ok. [00:05:07] ME11: La mia sul sul carattere del dolore era una riflessione, non è la riflessione centrale del nostro, di quello che ci stiamo dicendo, ma dicevo, ah, non mi stupisce che in fondo non non siamo stati capaci di sviluppare un linguaggio specifico del carattere, perché in realtà il carattere si dice poco. [00:05:31] Researcher: Ok. [00:05:32] ME11: Sul dolore. [00:05:33] Researcher: Ok, lei fa quindi come carattere in inscrive anche la definizione o comunque la descrizione qualitativa del dolore potrebbe andare in quella direzione? [00:05:43] ME11: Esatto, no. È la descrizione qualitativa, perché non è quantificabile il carattere. [00:05:45] Researcher: Ok, OK. Mhm OK. E invece a livello di pratica alternative, come dice, per instaurare una relazione o comunque rendere il paziente soddisfatto di questo tipo di relazione c'è ne sono alcune che vede più eh. Diciamo soddisfacenti o come che ha riscontrato maggiormente, utilizzate intuitivamente anche da parte del paziente, dipendentemente dalle malattie o anche non dipendentemente dalle malattie. [00:06:18] ME11: Ma come? Evidentemente considero che l'approccio ah l'interesse che il paziente vede che tu gli porti è uno degli elementi fondamentali per sentirsi ben accudito. Se tu ti occupi solo della sua malattia, il grado di soddisfazione sarà fin lì. Se ti interessi di sapere chi è lui, al di là della sua malattia, ah, si instaura un'altro rapporto che qualitativamente molto diverso, anche se quantitativamente non lo è, cioè il tempo che tu dai a un paziente è sostanzialmente lo stesso, ma la qualità della relazione per il fatto che tu ti interessi chi è lui o lei, al di là della malattia, questo cambia completamente. [00:07:08] Researcher: Ok, quindi questa pratica nella sua visione piu utile per 1 ° di soddisfazione del paziente che per ricevere informazioni quanto medico o possono essere combinate queste due. [00:07:20] ME11: No, no, per me è il. Se se devo fare una. Se il mio lavoro è fare una diagnosi o capire cosa significa una malattia per un paziente, ah. Gli aspetti quantitativi sono in generale sufficienti e mi permettono di fare molto bene il mio lavoro. Se il mio mestiere è di accompagnare il paziente in un cammino di cura, non dico di guarigione, ma di cura, Eh. L'approccio narrativo è indispensabile per costruire un rapporto di ehm, un canale di comunicazione largo con il paziente nel quale lui si sente sicuro, si sente accudito? Nella maniera giusta, anche se il mio gesto non cambiera tutto quello che ne può scaturire, in particolare accompagnarla attraverso le complicazioni, accompagnarlo attraverso un deterioramento, eccetera. Quello che cambia moltissimo e cambia molto anche nella fiducia dei dei pazienti e della famiglia, ma questo è il mio progetto, non è il suo. Noi stiamo parlando del suo progetto. [00:08:40] Researcher: Ma questo ha a che fare anche con un tipo di Eh. Risposta diversa al trattamento secondo lei poi? [00:08:49] ME11:

Non lo escludo, ma al limite non mi interessa il. I vantaggi dell'approccio che ho utilizzato con la biografia di riconoscere in realtà la biografia non è altro che la validazione dell'individualità di un paziente, della sua unicità a fronte di minacce identitarie enormi, che sono quella di essere standardizzato dalla malattia, di essere uniformi in vestiti, orari, cibo e tutte queste cose, Eh ti, lui ti elegge, ti ti sceglie come guardiano, ha della sua identità e questo è fondamentale per il rapporto di un attimo solo. [00:09:40] Researcher: Prego. [00:09:41] ME11: Ecco. Eh? Urgente, non è urgente, grazie ecco sì. [00:09:49] Researcher: Ok e infatti la mia domanda successiva, un po forse stava accennando rispetto il tempo impiegato per la lettura da parte sua, in generale del dottore, rispetto quella che è in questo caso la biografia, o comunque questo tipo di dati, nel senso che già rispetto alla mia pratica, che non vuole essere integrata durante la diagnosi, però il fatto di viene spesso visto come perdere tempo in fase anche di diagnosi e rispetto alla descrizione diciamo più lunga, sicuramente di pratiche ho del della malattia stessa che va poi a inficiare il tempo che si trascorre o che richiede Al. [00:10:10] ME11: In. [00:10:24] Researcher: Dottore, per che ascolti? Il paziente però lei dice invece mi sembra di capire che è un investimento di tempo che viene poi ricavato rispetto ad altro tipo di attività che svolge il medico. [00:10:34] ME11: Assolutamente, assolutamente è quello che la bellezza del nostro progetto e che di una grande semplicità non ti prende più tempo e ti aggiunge uno o due dimensioni Al alla comunicazione con il paziente. [00:10:50] Researcher: Ok. Questo però non ha bisogno di nessun tipo di diciamo Eh stimolo narrativo, nel senso che per lei è più importante quello che il paziente vuole dire, corretto, nel senso qualsiasi cosa racconti il paziente che è utile per il paziente, eh, oppure cerca comunque di ricavare delle informazioni. [00:11:09] ME11: No, no, no, io ci. Ma la verità è che stiamo parlando del mio progetto, non del suo. [00:11:13] Researcher: Sì. [00:11:13] ME11: Io adoro parlare del mio progetto, ma volevo dare del tempo per lei, Eh. [00:11:18] Researcher: No, perché non cioè nel senso, facendo riferimento un po Al alle analisi dei risultati, magari le lascio un po di tempo e anche senza risentirci, mi farebbe piacere che li commentasse quello che io cerco di fare. Allo stato attuale, nel senso, ci sono delle variabili che ricorrono nel modo in cui queste persone che ho coinvolto, che hanno esperienza della malattia, vanno a parlare o descrivere alcuni sintomi. Non sono, diciamo uno a uno o precise come un vocabolario, come nel caso ad esempio della visualizzazione che ormai ripercorre un po che sono delle variabili assodate. Nel caso della comunicazione, nel caso della fiscalizzazione, quindi nell'uso dei materiali non c'è ancora o non si sa se ci possa essere questa sorta di vocabolario che va a identificare specifiche qualità materiali per rappresentare e specifiche informazioni. Quello che io vorrei fare, oltre a un po, investigare il è un po aprire la definizione di sintomi che non derivi solo dalla letteratura, ma provi a considerare anche un po una sorta di ehm, con interpretazione dal basso, quindi un po uno scambio a livello partecipativo rispetto a quelle che sono le esperienze personali della malattia. Per rivedere se ci sono altri sintomi che possono essere considerati o altri modi di interpretare o comunque descrivere quelli che sono i sintomi attualmente riconosciuti. Il interesse da designer e anche un po quello di capire se eventualmente, appunto, ci sono delle variabili ricorrenti per rappresentare determinati C specifici sintomi per vedere un po se alla fine, invece, perché da altri esperti ho avuto feedback, ammetto diversi nel senso che mi è stato detto che c'è un problema soggettivo nel mhm descrivere quantitativamente il dolore a livello qualitativo manca un po una sorta di abitudine, ha parlarne e quindi cercare anche un po di capire come De alternativamente potrebbe essere descritto rispetto delle parole standard che magari vengono anche richieste dai dai dottori Eh se un. Eventuale piccolo kit delle forme semplici che derivano un po da quello che è risultata dai miei workshop l'associazioni più ricorrenti tra determinati sintomi e determinate variabili, potrebbe essere utile in fase di diagnosi, definizione del trattamento da aiutare, un po come fossero prompt, quindi stimoli e il paziente ha descrivere magari determinati dolori che possono appunto essere utili nelle fasi di diagnosi. Quindi diciamo che ti va un po in questa direzione. [00:13:54] ME11: Allora ho capito, allora ci sono due cose che mi piace molto della del del suo approccio. Uno lei si esprime estremamente bene, Eh? È molto precisa nel linguaggio mhm sa esattamente quello che sta cercando, ha sono invece scettico sull'approccio mhm. Eh? E spesso abbiamo

bisogno di cercare quello che è annett need. Ah, ecco, io non ho risentito un Yanmeng need per questo approccio eh, di descrivere i sintomi? [00:14:38] Researcher: Mhm. [00:14:39] ME11: Quanto ho sentito un'enorme Almeida ti raccontare chi siamo come elemento importante nella Eh, nel rapporto terapeutico per. [00:14:45] Researcher: Mhm. Vedo forse no? Prego. [00:14:53] ME11: Per per questo non mi sono particolarmente interessato a far descrivere meglio i sintomi. Perché in fondo Eh, perché ho bisogno che mi si descrivano i sintomi? Anzi, una volta che ho fatto la diagnosi sapere è come il paziente mentalizzata o fiscalità, anzi EI suoi sintomi o di raffigurarli, rappresenta li racconta eccetera. E non è un elemento che mi è parso fino ad ora un elemento fertile in termini di riflessione, ma son pronto a essere stupito. [00:15:35] Researcher: No, ma se è considerasse questa fase precedente rispetto lei la la la diciamo chiamata in causa dopo la diagnosi, nel senso che probabilmente quello che succede ai suoi pazienti, nel senso che c'è una diagnosi, ricordo forse citato ad esempio. [00:15:48] ME11: A me arrivano tutti con una diagnosi. [00:15:49] Researcher: Esatto, OK. Nel caso stiamo lavorando. [00:15:53] ME11: Ma ogni tanto ho dei pazienti con dolori in cui nessuno capisce niente. [00:15:59] Researcher: Ok un. [00:16:00] ME11: È un formulario che gli faccio riempire di descrizione del dolore a con con varie voci, cioè una quindicina, una ventina di domande su su questo Eh, e fino ad ora Eh questi Eh. [00:16:01] Researcher: Mhm. [00:16:22] ME11: Il carattere del dolore non mi ha aiutato. Quindi, siccome il suo approccio è la mhm materializzazione di questo carattere. Non non avrei necessariamente scelto quella direzione per rispondere a un Yanmeng niente, ecco. [00:16:43] Researcher: Mhm no è, è chiaro. Lei forse che mi può condividere questo questionario che fa ai pazienti che che non descrivono esatto? [00:16:49] ME11: Ma certo, ma certo, ma certo è, è proprio un questionario molto banale che ho scritto per non dimenticare niente EE per. [00:16:58] Researcher: Mhm. [00:17:00] ME11: Ma se dovessi dire mi è stato utile Eh, non son sicuro un attimo, solo. [00:17:10] Researcher: Ok, è sicuramente una sì.

ME12

ME12: Yeah, you might want to remind me a little bit. [00:00:14] Researcher: OK so. Yes, I will. Would you like to just quickly introduce yourself with your background and your work. So to contextualise the information please. [00:00:25] ME12: Sure, sure. Sure. So I'm an infectious disease doctor. I'm a professor of infectious diseases at the University Hospital of Geneva, Switzerland. I cover. General infectious diseases, but I also have a sub sub specialty in urinary tract infections. So outpatient clinic for UTI and lots of inpatient consults for yearning tract infection UTI. [00:00:56] Researcher: OK, thank you. I will share my screen. You should be able to access the the analysis I provided with you with I can send the link here in the conversation on teams. [00:00:56] ME12: OK, good. OK. [00:01:11] Researcher: But I also shared the screen so you can follow me. There is just to you if you want to have a look later on. [00:01:12] ME12: K. OK. Yep. [00:01:19] Researcher: Basically, is there a preliminary analysis of results? Of data I collected from three different sessions of workshop I ran for my PhD. So I'm doing a PhD in design focusing on data physicalization, so trying to use adapt materials physical materials to represent healthcare data. More specifically symptoms of urinary tract infections. To work with a small number of of people, specifically women. To try to redefine the symptoms, if anything new emerged, even describing those symptoms. Together with an expert that's kind of supervised, but not in the role of a supervisor, what is happening around the table? So how I do organise the workshop? Usually they last about 2-3 hours depending from the conversation, but there are about. [00:02:08] ME12: Mm hmm mm hmm. [00:02:20] Researcher: people woman because I'm working with a woman suffering from urinary tract infection. Now they might have one on the experience of the disease or suffering from recurrent infections. [00:02:34] ME12: Mm hmm. [00:02:34] Researcher: So we gather all together around the table. I first asked them, I mean a nice break to introduce themselves and then we work on defining symptoms. So I provide them with a set of labels which report some symptoms of urinary tract infection taken from the literature. There are also empty labels. So I asked them in case anything is missing to add what is missing based on their experiences. [00:02:47] ME12: Mm hmm.

[00:03:00] Researcher: Of the disease. And then I introduce some materials on the table. I think I'm. I'm working now with the. You need some units of cubes, spheres and triangular prism made in polyester form and wooden and they have like small they are available in small and big size so they are on the table. I asked participants to start interacting and like touching handling these units of material. [00:03:19] ME12: Mm hmm. Mm hmm. [00:03:32] Researcher: And then that point, I introduced the second set of labels with this time report physical variables of the materials such as colour, roundness, brightness. Orientation, weight and others. These are just some of of the labels to to make you understand. And because the shape of the label kind of combine the other of symptoms as a sort of puzzle. [00:03:58] ME12: Mm hmm. [00:03:59] Researcher: And I ask at this point participants to combine and select from the physical materials. So a variables that might be suitable in their opinion to represent that specific. Group of symptoms, for example, headache with the brightness or. Pain with the weight and these other stuff combination. What's interesting is because it is a group activity, everyone have to kind of explain others what is meant by that symptoms, what that symptoms produce in their body, in their mind. What's the effect? So someone else can also interact or add some more detailed definitions of the symptom. Or I also say recognising. Symptoms that happen to. To themselves to in in others description so like. Exchange. Experiences, but also practises in terms of like prevention sometimes or treatment or what happened to them in in, in the case of the disease and then so I asked them to combine these labels as I was saying and discussing on the on the reason of specific combination and then I leave everyone individually to build their own artefacts. [00:05:06] ME12: Hmm. [00:05:18] Researcher: So taking those objects and units based on the sort of vocabulary that you set with this combination of labels, create this sort of object that they use in the end to. Narrate and so share their experience of the disease with others in other in in the groups. So I ran through different session and the document mainly report what happened, what happened during the workshop, if there were some recurrence. [00:05:41] ME12: OK. [00:05:50] Researcher: Dermal association, but those are the definition of symptoms from from patients and so on. So I just stopped sharing the screen with you and I don't know if you have any like feedback or idea on the workshop. If you have a question, if anything was not clear to you. [00:05:58] ME12: OK. So far so good I think. [00:06:13] Researcher: OK, I can get it so. Some of the points that emerge within the analysis are related to the knowledge of the disease itself, so some of the participants attended the worship at the beginning. So how I I do recruit people is advertising the workshop and but also asking through personal contacts contacts. If there is anyone who suffer from the disease and it is interesting interested in taking part of that activity. So all the people attending are supposed to suffer from urinary tract infection, but what happened is that during the worship very often. I mean, not very often, but there are cases of people who attended the worship thinking of being affective or UTI, but actually was something different. There is one specific person who was suffering from Pandita and another a couple, two of person who were not suffering from from UTI. So this is one one point. Then there is the importance of the expert within the workshops so. In one session I wasn't able to recruit an expert who can join us for the activity and with expert I mean like pharmacists, gynaecologist medical experts in one of the session there was this PhD student working on AMR specifically. And so the activity made everyone working in the same direction, let's say. So everyone had the same like turn of speech and we are all together on the table, but at the same time the expertise able to provide the in this way some feedback on symptoms and what people reporting because sometimes it's not like accurate or they need some more explanation explanation. And when people participants. Understand the role of the expert, which is not hidden because we all introduce ourselves from the beginning, so it it it is quite. Like clear, they also start interacting with the expert, maybe asking more specific question related to to their personal experiences. Then there is this thing of trying to associate those symptoms with the physical variables. So what I'm also is a kind of like, I mean the primary goal of my research is try to see if new symptoms emerge or if any different description of the available symptoms. Symptoms can help in. Specify the treatment or intervene in sort of like prevention instead of like to the point when I

mean some of the participants were hospitalised because they just didn't consider symptoms or didn't know how to recognise them because maybe it was the first time or someone didn't have the time said to like properly go to the doctor or do anything. Because of the condition. So I arrive at the point that they needed to be hospitalised and given with some antibiotics. [00:09:09] ME12: Yeah. [00:09:17] Researcher: And and so I was saying this is the primary goal of the research. The second one as a designer, I would like to understand if there is any recurrency in associating or selecting specific future of materials to communicate and represent some data related to to symptoms. And I still need to go through. Other session and other information collected but. Spheres in general, for example, are used for mild symptoms. Or for symptoms like at the beginning or at the end of the disease, that's something that is evolving or actually disappearing. So somehow stay ready with is with mild symptoms or less intense. [00:10:06] ME12: OK, OK. [00:10:08] Researcher: Symptoms then we have a sort of evolution of edges and like pins shapes to represent the feeling and the urgency of like peeing. But also materials are. [00:10:25] ME12: That's a good, good idea. [00:10:26] Researcher: Quite. I quite interesting. [00:10:28] ME12: Did you come up with this? Because, yeah, did the women come up with the pin shape or did you come up? Yeah, man. Yeah. [00:10:33] Researcher: Yeah. Yeah, yeah, yeah, no, no, no, no, they definitely did. I was not, let's say, suggesting anything in terms of different shapes and material were available for them to use and to express the symptoms. But I intentionally left them open to express what they were feeling to. [00:10:38] ME12: Yeah. Mm hmm. Mm hmm mm hmm. Hmm. Mm hmm mm hmm. [00:10:55] Researcher: Yes, to express themselves, the idea is to take advantage of physical futures of materials to see if they can try to. [00:10:56] ME12: Yeah. [00:11:05] Researcher: Enriched their vocabulary related to expression and communication of of symptoms of related to intimates healthcare data. And have you ever? Like work with alternative method to represent symptoms or. Eired off. [00:11:28] ME12: Yeah, I don't think so. No, no. No. [00:11:33] Researcher: Do you usually ask specific question to? To people who come to you that maybe are not. [00:11:41] ME12: Yeah. [00:11:42] Researcher: At the first, let's say experience of UTI, that might be the the possibility of not being aware of the symptoms and the necessity to understand what kind of symptoms they suffer from. [00:11:48] ME12: Yeah. I think in my case I'm maybe less useful to you because almost everyone who comes to my clinic, they've had recurrent urinary tract infections. So they know that they it's not their first time they've had many, most of them have had many infections. The symptoms are not new. So but I I mean I think yeah in the hospital sometimes I see people who are having their first. Infection. But it's extremely rare. It's really rare, and as you know, probably very well. There are two kinds and urinary tract infections. There's the simple cystitis, which is just the bladder being inflamed. And then there's the pyelonephritis. Which is when the kidneys are involved, and it's a very different disease. It's like you say it requires antibiotics. It requires sometimes requires hospitalisation. It's much more severe. It's much more serious when the kidneys are involved and it. But it's much more rare. So you know when I'm seeing patients in the hospital, it's usually for pyelonephritis. It's not for the cystitis. The lower urinary tract symptoms which you know. Are well described by the ping. And everything. Yeah, but. [00:13:16] Researcher: Yeah. And is there there? So if you're saying your passions are, let's say, aware of the this is because they suffer from recurrent experiences, is still there any question that you ask them or is just like? [00:13:31] ME12: I do systematically. I ask everyone, what are their typical symptoms? I you know, because I I like to document that for every patient, what do they feel? Because as you must have learned by now, not everyone has the burning, you know, some people have different manifestations. So I do ask everyone, what are your symptoms? But I leave it very open. I let them tell me I don't suggest. You know, I just talk and not what they tell me. [00:13:57] Researcher: Mm hmm mm hmm. [00:14:00] ME12: Yeah. [00:14:01] Researcher: And you feel they do have, I mean. They looks able to describe the kind of symptoms and the kind of pain that symptoms provide to them, yeah. [00:14:14] ME12: Yeah, most of them, absolutely. I. Sometimes I have like some really old patients who have some dementia and they can't really talk, you know, but most of my patients are are very ex, you know, they're quite articulate. [00:14:20] Researcher: Mm hmm. Mm hmm mm

hmm. OK. And do they, I mean, if I can ask her if they do use metaphors to describe their symptoms or the kind of pain, the kind of effect of those symptoms on their body, or is there any like pattern, let's say that you do recognise? [00:14:29] ME12: Yeah, yeah. It is metaphors. Yeah, yeah. Yeah, OK. So they use metaphors. [00:14:49] Researcher: Mm hmm. [00:14:51] ME12: That one told me once that it was like an elephant was sitting on her bladder, you know, so a lot of pressure this the sense of this heaviness, you know? [00:14:55] Researcher: OK. Mm hmm mm hmm. [00:15:01] ME12: My own child, my daughter, who has. So I have three children and one of them had probably had a UTIA few years ago. She's a healthy girl, but she probably did have a UTI, she said. Mama, it's like, you know, when you have to sneeze, that's how it feels in my bladder, like, you know that like, I need to. [00:15:12] Researcher: Mm hmm. Yeah, that makes sense. [00:15:25] ME12: So I thought that was actually really an interest. Yeah. It really helps to understand. He kept feeling like she had to seize, but down there. And it's probably, you know, inflammation of the urethra, you know. But yeah. So I've heard things like that. What else? Yeah, mostly I like. I've heard, you know, like, there's something heavy sitting on me, whether it's an elephant, you know? I yeah. I mean it's maybe not not so concrete, but I've also heard a lot of women tell me again, this is more abstract. It's not necessarily about concrete symptoms, but I have had a lot of women. Evoke like the sword of Demo, please. You know, like there's a sword hanging over me. There's a sword that could fall on me anytime, because the symptoms could start anytime. I can't move it. You know, I don't know when I'm gonna get a new infection. So there's this sword that's hanging over me. [00:16:16] Researcher: OK. OK. OK. Yes. [00:16:28] ME12: Like the sword of Democrats? Yeah, but yeah. [00:16:30] Researcher: I mean that might be related to someone from the warship that actually mentioned anxiety and they wanted, I mean, they treated as a symptom. So I was speaking with other experts as well who were saying that it's more a consequence of the symptoms because they were saying, I mean, participant were saying. I feel anxious because I cannot leave home or go to work because I need every time I should. I mean, I might be able needed to. [00:16:37] ME12: Yeah. Yeah, yeah. [00:16:58] Researcher: To the to the toilet, and so there was other. Exactly. There was other experts saying that's more we don't consider that as a symptoms that more as an effect of of the symptom. [00:16:59] ME12: Bathroom, yeah. Yeah, yeah, yeah. No, that is true. That is true. It's. It's a manifestation of the. Yeah, I agree. I agree. [00:17:18] Researcher: And would you see any like benefit or on the other hand like problems in? Making available, let's say, some materials to express symptoms specifically related to UTI. [00:17:35] ME12: Benefit. Yeah, no problems, but I think I think it's a good idea to. I mean, I think it's a really nice idea to do it like that. I think just the act of taking the time of thinking about this with them, of creating, you know, putting, making available these materials, it's very validating already. You know, these are women who often are told you don't have anything. You know, you don't. Your culture's not really positive. There aren't enough bacteria, so you don't really have an infection. You think you have symptoms, but you don't, you know. So I think just the act of of. You know, going down this path with them and and and, you know, confirming that you think these symptoms are real and that they deserve a description by material or by, you know, any process really I think that in itself is very validating. [00:18:30] Researcher: I mean you mentioning this point? As something that so women coming to your office very often are undertreated or like not considered, maybe in like general kind of care, right is so even like providing them with specific assistance or. [00:18:48] ME12: Yeah, it's a bit specialised. [00:18:54] Researcher: Like. An occasion to be here is already something like that might have. The them. Is that correct? I mean if you can just contextualise. Yes. OK. [00:19:03] ME12: Are you? Yeah, yeah, yeah. Yeah, yeah, absolutely, absolutely. [00:19:11] Researcher: OK. And. I was thinking again about the description of disease and symptoms in general. If any one. Or do you remember anyone describing the disease by? Let's say. The opposite effect that is doing or like mentioning the normal condition and then trying to describe the difference from the normal condition and what is actually. Spending to them. [00:19:50] ME12: Like so you're asking do does this ever. [00:19:54] Researcher: I mean, if people no if people just behave this way, so trying to maybe describe what they do have saying what they normally how they normally

feel and what's the difference between like normal condition and like situation when they are affected by the symptom. If this had never happened or you ever notice that if you might have not noticed that. [00:19:54] ME12: Is this how I do it with patients? I haven't really noticed that. [00:20:22] Researcher: OK, OK, OK. OK. [00:20:22] ME12: They definitely concentrate a lot on what doesn't. You know what isn't normal. I think, yeah, I don't think they really start by discussing what is normal. But. [00:20:37] Researcher: OK. And then based on these results, I would consider to, I mean to have some units of material. To help, maybe available to doctor's office to. Support let's say patient in describing their symptoms. That might work specifically on qualitative of pain or diseases instead of like a quantitative information. [00:20:58] ME12: Yeah. [00:21:08] Researcher: I knew maybe not you, but it's quite common. Or someone use this sort of tables with smiles or with different colours to like help and support patient in describe their pain. Is that something that are you familiar with or avoid because you are more conversation with your patient? [00:21:17] ME12: E. Yeah, yeah. No, no, I think that sounds like a really good idea. You're. And you're actually making me think of something. I want to show you something that I actually use with my patients. The first time I see them. Wait right there. I'll show you. Let's see. Let's see this. OK, so it's kind of big. But it's really, really helpful. This is actually for medical schools. I think it's it's more for teaching, right, but it's really, really helpful in the clinic because it has, OK, so. So it has like the female bladder. [00:21:47] Researcher: OK. Yeah. Yeah. Yeah. [00:22:00] ME12: There's the. Yeah. Sorry. Yeah. There's the uterus underneath. And then here's if you have a male, this is the male bladder with the prostate underneath. But anyway. [00:22:12] Researcher: OK. [00:22:15] ME12: I'm I'm kind of thinking for you. Maybe if you're thinking about creating materials, it might be useful to create a material using your, you know, different. [00:22:17] Researcher: Hmm. [00:22:26] ME12: Textures different, you know tissues. But in the shape of a bladder so that they can say, yeah, this is how my bladder feels like. And I you squeeze it like a sponge or I don't know because or or it feels here like it's you know. [00:22:27] Researcher: Mm hmm. Mm hmm. Mm hmm mm hmm. [00:22:39] ME12: Yeah. I don't know. Maybe that would be helpful to these patients. 'cause I I have to be honest. They really like it. They like it that you know, I could take these things out and they can and I can open them. And you know, I mean, this was really expensive, but yeah. [00:22:48] Researcher: Yes. So you use it to explain. You use it to explain your patients. [00:22:57] ME12: But but it's really. [00:23:00] Researcher: Sorry, you use it to explain, yeah. [00:23:01] ME12: Yeah, yeah. Yeah, yeah, to. To explain. I I talk a lot. It's the first time I see a patient. We do a lot of education because, you know, often like I said, often they are being. Rushed by the doctor, UTI is considered an annoyance for a lot of doctors. It's just annoying, so they they try to just prescribe an antibiotic and get rid of the patient, you know? So a lot of times the patients come, they know their symptoms but they but they don't. You know, they haven't really gotten much education on what's really happen, what's really happening with the bacteria and the bladder so. [00:23:22] Researcher: Mm hmm. Sure. Yeah. [00:23:38] ME12: So I take a lot of time, a lot of what I do is just informing, and it's actually hugely impactful. I think it really does help when they understand what's happening. So it helps to save antibiotics and all of that, but OK. [00:23:46] Researcher: Yeah. Yeah. No, that's very useful to know. And one of the positive effect of the activity and working with material in a participatory environment with an expert is also to build awareness of the disease and symptoms. So sometimes they kind of create the shape of their disease, but they creating a sort of like timeline because I recognising this sort of objects. [00:23:55] ME12: Yeah. Yeah. [00:24:17] Researcher: Their needs and somehow attempts to reconstruct the, let's say, journey of the disease. Go kind of investigate or understand what causes my have affected or like led to to the disease. So I suppose if something still related with self-awareness and knowledge of the disease, what you do as well. [00:24:25] ME12: Yeah. Yeah. Yeah, yeah, definitely. Definitely, yes. Yeah. We're probably gonna get interrupted because I think the surgeons are gonna call me. I'm supposed to discuss patients at 3:00 with them. But in the hospital. [00:24:46] Researcher: OK. Yeah, yeah, yeah, it's OK.

A.6 Ethics approval letters

Ethics approval for all research activities described in this thesis was granted by the Brunel University London Ethics Committee. Separate applications were required to address the distinct aims, methods, and participant engagements involved in the different stages of the research. The following section presents the ethics approvals obtained for each activity, including the approval letter reference and a brief overview of the corresponding project submitted for review. [EA] denotes Ethics Approval, followed by a numerical identifier indicating the order in which the approval letters are presented.

EA1: The promotion of data literacy to raise awareness on antibiotic consumption and improve symptom description to enhance people's participation in prescription

Approval letter reference:
40219-A-Apr/2023-44766-1

Overview of the project for application: The project focuses on the promotion of data literacy to improve the relationship between citizens and doctors. More specifically, data literacy is meant to help raise awareness on antibiotic consumption and engaging people in bottom-up data collection to tackle antimicrobial resistance caused by urinary tract infections. This first group of interviews is planned to validate the literature and further explore possible directions of intervention, especially regarding the promotion of data literacy to raise awareness and engage people in collecting data. In this direction, open questions investigate what people should know to consume antibiotics responsibly, what data is required to make people actively participate in the prescription process, and what data is needed to enhance a better understanding of antimicrobial resistance and urinary tract infection diseases. The interviews are conducted online, with a duration of 45 minutes.

EA2: "Shape Your Symptoms" - a workshop involving women with experience and expertise in urinary tract infections and antibiotic resistance to improve agency through data collection

Approval letter reference:
44341-A-Feb/2024-49976-1

Overview of the project for application: Based on the findings from the literature review and expert interviews, the project considers designing a workshop format including different stakeholders who is introduced to the use of personal data to improve literacy skills, track information and define how to support symptom explanation during the diagnosis.

Approval for this activity was also obtained from the University of Applied Sciences and Arts, where WS1 and WS3 took place. See Letter of approval EA2(b).

EA3: "Shape Your Symptoms" 2.0

Approval letter reference:
49759-MHR-Oct/2024-52983-2

Overview of the project for application: The wok activity refers to a workshop format planned to be run multiple times with different people. Each session lasts about 2 hours and includes one or multiple groups of 5 people with different backgrounds, working together in the same room. The activity originated from a previous version of the workshop - application 44341, but this time participation was open to other genders than women. For this reason, the focus of the activity shifts and instead of UTI, the workshop allows participants to work more generally on symptoms related to any sort of disease. One healthcare expert is expected to join every session, as their presence demonstrated being useful and adding knowledge during the activity.

Approval for this activity was also obtained from the Berner Fachhochschule, where WS5 took place. See Letter of approval EA3(b).

EA4: Assessment of the research workshop method: “Shape Your Symptoms”

Approval letter reference:
49695-LR-Sep/2024-52885-2

Overview of the project for application: After running different sessions of the workshop, which is the core of the methodology of my PhD research, this activity serves to assess the method. For this reason, this application aims to provide me with permission to ask experts for feedback on my analysis of results.

EA5: Health-Self-Revealed: Exploring data physicalization practices

Reference:
50837-LR-May/2025-54217-2

Overview of the project for application: This application is the follow-up of the application 49695, which has been used to run my main PhD research. This application aims to extend the workshop format to conduct the activity at the EKSIG 2025 conference (https://eksig2025.mome.hu/) and integrate results into my final dissertation.

Approval for this activity was also obtained from the Moholy-Nagy University of Art and Design Budapest, where the Health-Self-Revealed workshop took place. See Letter of approval EA5(b).

College of Engineering, Design and Physical Sciences Research Ethics Committee
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

15 May 2023

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 15/05/2023 AND 30/01/2024

Applicant (s): Miss Ginevra Terenghi

Project Title: The promotion of data literacy to raise awareness on antibiotic consumption and improve symptom description to enhance people's participation in prescription

Reference: 40219-A-Apr/2023- 44766-1

Dear Miss Ginevra Terenghi

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- **Please ensure that you monitor and adhere to all up-to-date local and national Government health advice for the duration of your project.**

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to any conditions that may appear above.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Professor Simon Taylor

Chair of the College of Engineering, Design and Physical Sciences Research Ethics Committee

Brunel University London

Figure A: Letter of approval EA1

College of Engineering, Design and Physical Sciences Research Ethics Committee
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

21 February 2024

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 14/11/2023 AND 30/04/2025

Applicant (s): Ms Ginevra Terenghi

Project Title: "Shape your symptoms" - a workshop involving women with experience and expertise in urinary tract infections and antibiotic resistance to improve agency through data collection

Reference: 44341-A-Feb/2024- 49976-1

Dear Ms Ginevra Terenghi

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- **All previous agreed permissions in the letter of approval must still be adhered to for this amendment**

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to any conditions that may appear above.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Professor Simon Taylor

Chair of the College of Engineering, Design and Physical Sciences Research Ethics Committee

Brunel University London

Figure B: Letter of approval EA2

University of Applied Sciences and Arts of Southern Switzerland
Department of Environment Constructions and Design
Institute of Design

SUPSI

29 September 2023

This letter guarantees permission to run the activity "Shape your symptoms - a workshop involving women with experience of UTIs to improve data collection" at the University campus.

Institute of Design, Dipartimento ambiente costruzioni e design (DACD), University of Applied Science and Arts of Southern Switzeland (SUPSI), Via Flora Ruchat-Roncati 15, 6850 Mendrisio.

The detailed description of the activity is attached below. The permission is valid for the activity described in detail below. Any changes need to be notified by the researcher.

The workshop will be conducted by Ginevra Terenghi, as part of her PhD research.

This permission is valid from October 1, 2023 to the end of the PhD research, expected in April 2025.

Serena Cangiano

PhD Supervisor

Giulio Zaccarelli

Head of the Design Institute

supsi-location-permission.docx 1/1

Figure C: Letter of approval EA2(b)

College of Engineering, Design and Physical Sciences Research Ethics Committee
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

7 October 2024

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 07/10/2024 AND 30/03/2025

Applicant (s): Ms Ginevra Terenghi

Project Title: "Shape your symptoms" - version 2.0

Reference: 49759-MHR-Oct/2024- 52983-2

Dear Ms Ginevra Terenghi

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to any conditions that may appear above.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Professor Simon Taylor

Chair of the College of Engineering, Design and Physical Sciences Research Ethics Committee

Figure D: Letter of approval EA3

Hochschule der Künste Bern
Institute of Design Research
Fellerstrasse, 11
3027
Bern
hkb.bfh.ch

Ein Departement der
Berner Fachhochschule

Paola Pierri
Prof. Social Design
Deputy Head of the Institute of Design Research
Paola.pierri@hkb.bfh.ch

To Whom it Might Concern

This letter guarantees permission to run the activity "Shape your symptoms - a workshop to investigate the role of materials in supporting intimate and healthcare data collection to improve awareness and communication" planned for October 25th at the campus in Fellerstrasse 11, Bern.

The workshop will be conducted by Ginevra Terenghi, as part of her PhD research. The activity will be hosted by the MA Design during the course of Social Design and considers involving students of the University.

Date: 9.09.2024

Paola Pierri,

Prof. Social Design and Deputy Head of the Institute of Design Research

Figure E: Letter of approval EA3(b)

College of Engineering, Design and Physical Sciences Research Ethics Committee
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

23 September 2024

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 24/09/2024 AND 31/03/2025

Applicant (s): Ms Ginevra Terenghi

Project Title: Assessment of the research workshop method - "Shape your symptoms"

Reference: 49695-LR-Sep/2024- 52885-2

Dear Ms Ginevra Terenghi

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- **Please review and amend the following sections in your PIS: 'What will happen to me if I take part?' and 'What are the possible disadvantages and risks of taking part?'** (this point can be addressed outside of the BREO system)

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to any conditions that may appear above.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Professor Simon Taylor

Page 1 of 2

Figure F: Letter of approval EA4

College of Engineering, Design and Physical Sciences Research Ethics Committee
Brunel University of London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

9 May 2025

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 11/05/2025 AND 31/12/2025 31/12/2025

Applicant (s): Ms Ginevra Terenghi

Project Title: Health Self-Revealed: Exploring Data Physicalization Practices

Reference: 50837-LR-May/2025- 54217-2

Dear Ms Ginevra Terenghi

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**

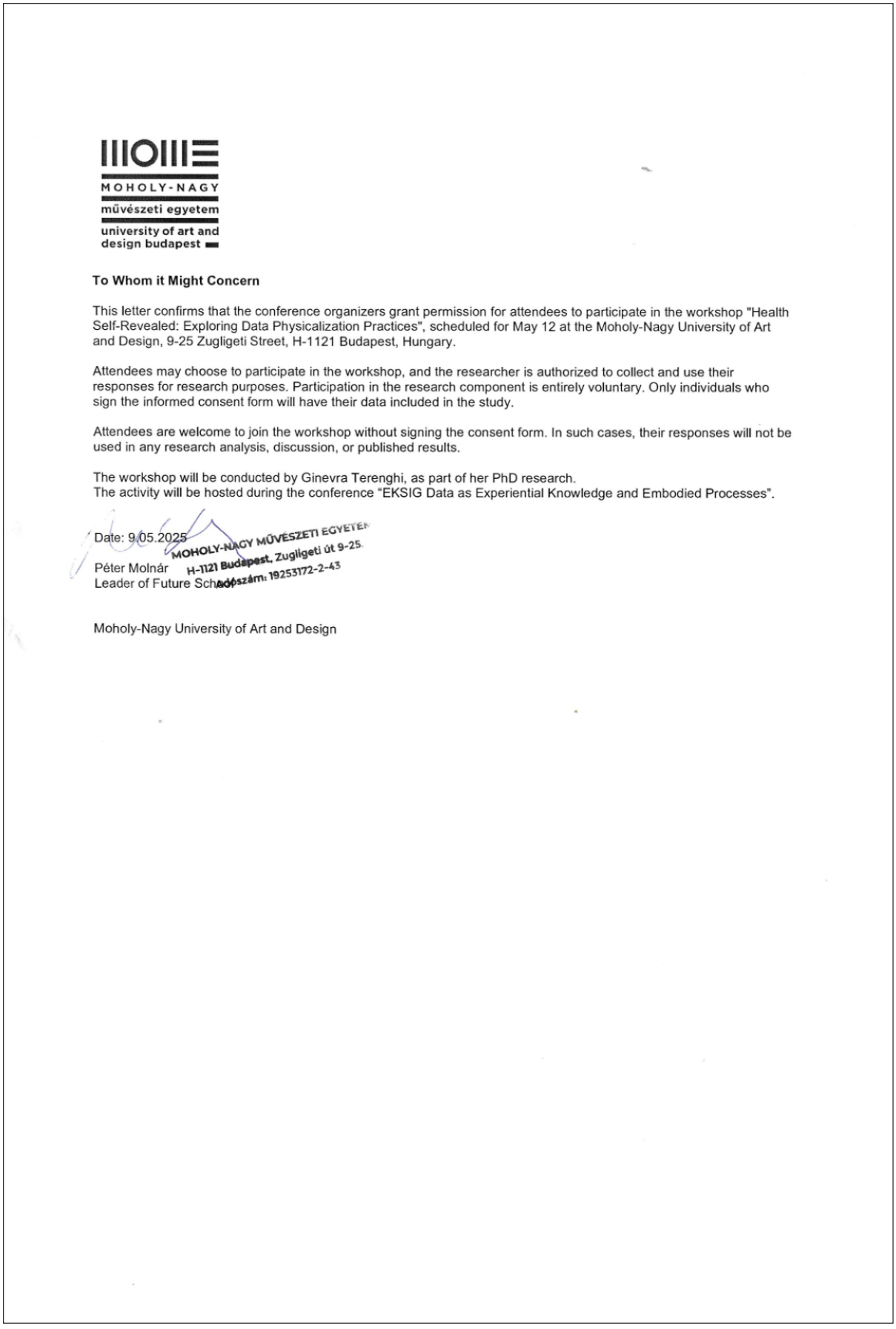
Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to any conditions that may appear above.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.



Professor Simon Taylor

Figure G: Letter of approval EA5



MOHOLY-NAGY
művészeti egyetem
university of art and
design budapest

To Whom it Might Concern

This letter confirms that the conference organizers grant permission for attendees to participate in the workshop "Health Self-Revealed: Exploring Data Physicalization Practices", scheduled for May 12 at the Moholy-Nagy University of Art and Design, 9-25 Zugligeti Street, H-1121 Budapest, Hungary.

Attendees may choose to participate in the workshop, and the researcher is authorized to collect and use their responses for research purposes. Participation in the research component is entirely voluntary. Only individuals who sign the informed consent form will have their data included in the study.

Attendees are welcome to join the workshop without signing the consent form. In such cases, their responses will not be used in any research analysis, discussion, or published results.

The workshop will be conducted by Ginevra Terenghi, as part of her PhD research.
The activity will be hosted during the conference "EKSIG Data as Experiential Knowledge and Embodied Processes".

Date: 9.05.2025

MOHOLY-NAGY MŰVÉSZETI EGYETEM
H-1121 Budapest, Zugligeti út 9-25.
Adószám: 19253172-2-43

Péter Molnár
Leader of Future Sch...

Moholy-Nagy University of Art and Design

Figure H: Letter of approval EA5(b)