

To share or not to share:

Public attitudes towards disclosing personal and identifiable medical data and information.

First Author: Professor Dorothy Ai-wan Yen (corresponding author)

Affiliation: Brunel University London

Email: dorothy.yen@brunel.ac.uk

Postal address: Brunel Business School, Brunel University London, Kingston Lane, Uxbridge, UB8 3PH

Telephone number: +44(0)1895 267318

Second Author: Professor Han Dorussen

Affiliation: Essex University

Email: hdorus@essex.ac.uk

Third Author: Dr Steve Pickering

Affiliation: University of Amsterdam

Email: s.d.pickering@uva.nl

Fourth Author: Dr Martin Hansen

Affiliation: Brunel University London

Email: martin.hansen@brunel.ac.uk

Fifth Author: Professor Thomas Scotto

Affiliation: University of Strathclyde

Email: To be updated.

Six Author: Professor Jason Reifler

Affiliation: University of Southampton

Email: J.Reifler@soton.ac.uk

To share or not to share:

Public attitudes towards disclosing personal and identifiable medical data and information.

Abstract

In the summer of 2023, we surveyed 2,355 members of the public in England to gauge their opinions on the acceptability of the NHS sharing their personal versus anonymised data or information with other key entities operating within the public health system. These include hospitals, GPs, pharmacists, social care providers, health insurance companies, pharmaceutical companies for research purposes, and city or county councils.

Notably, 84% of respondents indicate it is either acceptable or very acceptable of the NHS sharing personalised data and information with hospitals and GPs. In contrast, the majority of respondents (50%+) find it either unacceptable or very unacceptable of sharing such information with pharmaceutical companies for research purposes or with councils, whether it was personal or anonymised. Interestingly, higher levels of acceptability were observed when the term *information* was used rather than *data* with GPs and hospitals.

Our findings extend previous understanding by suggesting that, when there are perceived potential personal benefits, people are more willing to share personal rather than anonymised health information/data. This is a new finding that has not been considered before in the discussion of patients' health information/data sharing. We discuss the managerial implications and provide specific recommendations to the NHS, insurance companies, pharmaceutical companies, and local governments on how they could improve their communication with the general public regarding the sharing of health data and information.

1. Introduction

People are very sensitive about sharing their personal information due to privacy concerns (Perera et al., 2011) and this is especially the case for data or information related to their personal health. In the UK, individuals have the right to access their health data, request corrections or deletions, and exercise other data subject rights provided by the GDPR (General Data Protection Regulation). Healthcare providers and other entities are data controllers or data processors and have legal obligations to ensure compliance with GDPR requirements and respect individuals' rights regarding their health data (Astrup, 2018). Nevertheless, there has been opposition to recent efforts by the NHS to create a data platform that will make information sharing easier (Guardian, 2023). The issue of trust has been brought further to the forefront of late by the Kate Middleton hospital privacy breach scandal.

Healthcare providers must obtain patients' consent prior to sharing any health data or medical information with other entities. Whiddett et al. (2006) explain that, in general, patients' willingness to share data/information depends on three key factors: 1) the identity of the recipients, i.e., those with whom their data is shared; 2) the level of anonymity, i.e., whether the shared health data/information could be traced back to them as individuals; 3) the type of information, i.e., how personal and sensitive people consider a particular health record to be. Applying Utility Theory, which

explains people's purchasing decisions on a comparison of the potential utility or value of all available alternatives (Fishburn, 2013), Esmailzadeh (2017) adds perceived value – a trade-off between overall cost and benefits – as another indicator of whether people would opt-in to exchange health information. For example, while cost is highly related to perceived risks, such as losing privacy, data/information leakage, and storage system security breakdown, the perceived benefits include the completeness and accuracy of their medical record and the improved communication between doctors involved in providing care delivery (O'Donnell et al., 2011; Kalkman et al., 2022). Esmailzadeh (2017) also shows that perceived benefits tend to have a greater impact on perceived value than perceived risk, showing why it is important to explain and emphasise the benefits associated with sharing health data or medical information in communications. These may include immediate benefits, such as increased convenience or easier access to services, as well as benefits for the public good, for example, an improved public health system in the future. (ONS, 2023).

In the UK, people have very mixed feelings towards the sharing of their medical information and health data. Since the NHS ranked as one of the most trusted public institutions, in comparison to the police force, the parliament, the court and the prime minister (Dorussen et al., 2024), the source credibility effect would suggest that communication initiated by the NHS is more likely to be favourably received by the public. However, recent NHS data-leaking scandals and the lack of a well-planned data storage security system have led to controversial debates and oppositions, despite the promise of pseudonymisation, that replaces identifiable information with artificial identifiers or pseudonyms (Boiten, 2021). While we know that people are happy for their data to be used for research purposes, but uncomfortable if a commercial organisation is involved (Wellcome Trust, 2016; Ghafur et al., 2020; Aggarwal et al., 2021), we know very little about the public's attitude towards data sharing with other relevant healthcare entities. These include hospitals, general practitioners, pharmacists, social care providers, health insurance companies, pharmaceutical companies, as well as local councils - who all play an integral role in ensuring public health and contribute to sustaining a resilient public healthcare system, despite some of their profitmaking purposes. This prompts us to ask our first research question, to gain a general understanding on this matter:

- RQ1: With which entities are people more willing to consent to the NHS sharing their health data/information?

Extant research tends to discuss people's attitude towards sharing of health records in relation with the process of pseudonymisation, focusing the debate on the sharing of anonymised and non-personal data/information (e.g., Ghafur et al., 2020). However, very little has been said about people's attitude towards sharing personal and identifiable health records (Chico et al., 2019). While marketing studies reveal that consumers are willing to opt in and share their personal data with companies for better price, tailored contents and latest information that are deemed of value (Ackermann et al., 2021), we question whether this is the same when discussing the sharing of their health records. Would people find it more acceptable to share their personal and non-anonymised health records when the personal benefits are clear to them? Hence, we ask:

- RQ2: How does the level of anonymity (personal versus anonymised) affect people's attitude towards sharing health data/information?

Thirdly, although data (raw facts and figures without context) and information (data that is processed and given context) are regarded as different concepts in the fields of information science, data science and knowledge management (Ackoff, 1989; Rowley, 2007), the two words are often used nearly as synonyms in everyday communications. From a semantic viewpoint, while data and information denote different stages in the hierarchy of understanding, their interchangeable use arises from their close relationship in pragmatic applications (Beynon-Davies, 2009; Ackoff, 1989). For example, in healthcare communications, data from patient records is processed to generate information for diagnosis and treatment plans. Yet the practical focus is on the resulting actionable insights, leading to both terms being used interchangeably. For NHS, understanding and leveraging this distinction is crucial for crafting more effective communication campaigns and strategies. Since there has been no research that directly compares the use of the two words in assessing people willingness to share their health data/information, we propose the following research question:

- RQ3: Does the use of words (*data* versus *information*) create any significant difference in people's sharing attitude?

2. Methods

To evaluate the willingness of respondents to share their personal health records, we employed an online survey experiment between April and July 2023. Respondents were drawn from YouGov's UK online panel through quota sampling. The data were sampled and weighted to be representative of all adults in England. Administered by YouGov, 2,335 responses were collected. The age of the respondents varied from 18 to 98 with the median respondent being 50 years old. In total 2,335 persons were surveyed with near equal distribution between men (1,135) and women (1,200).¹

Using across-group sampling, respondents were randomly allocated to one of four groups that were given a unique treatment that differentiated between sharing data or information on the one hand and adding 'after data/information have been fully anonymised' on the other. The respective treatments were:

- Group 1: The NHS holds important **data** regarding your health. Do you consider it acceptable or unacceptable for the NHS to make your personal **data** available to the following organisations? Group 1 consisted of 562 respondents.
- Group 2: The NHS holds important **data** regarding your health, **after data have been fully anonymised**, do you consider it acceptable or unacceptable for the NHS to make your personal **data** available to the following organisations? Group 2 consisted of 570 respondents.
- Group 3: The NHS holds important **Information** regarding your health. Do you consider it acceptable or unacceptable for the NHS to make your

¹ Ethical approval was given by *Brunel University* (35290-LR-Jan/2022- 37313-1) and the experiments were pre-registered on April 4, 2023 with *As Predicted Wharton Credibility Lab* (#128236)

personal **information** available to the following organisations? Group 3 consisted of 580 respondents.

- Group 4: The NHS holds important **information** regarding your health, **after information has been fully anonymised**, do you consider it acceptable or unacceptable for the NHS to make your personal **information** available to the following organisations? Group 4 consisted of 621 respondents.

The outcome variables are the answers on the willingness to share data/information for the following entities: (1) hospitals in case you are admitted for procedures, (2) your GP (general practitioner), (3) your pharmacist (e.g., Boots) to dispense your medication, (4) your social care provider to assist in your home care, (5) your health insurance company, (6) pharmaceutical companies for research purposes, and (7) your city and/or county council.² The order by which organisations were listed varied across respondents. Respondents were asked to answer on a five-point scale: very acceptable, acceptable, neither acceptable nor unacceptable, unacceptable, and very unacceptable.

To examine any differences in the acceptability of sharing health records with different entities, we use the Wilcoxon matched-pairs signed-rank test. To test how the treatments affect the willingness to share health records, we apply the Wilcoxon rank-sum test – also known as the Mann-Whitney two sample statistic – on the unmatched data. Since we conduct a relatively large number of tests on our data, we use a strong criterion to reject the null hypothesis that the distributions are equal. Accordingly, we rely on 99% confidence levels ($p < .01$) to denote statistically significant differences between the distributions.

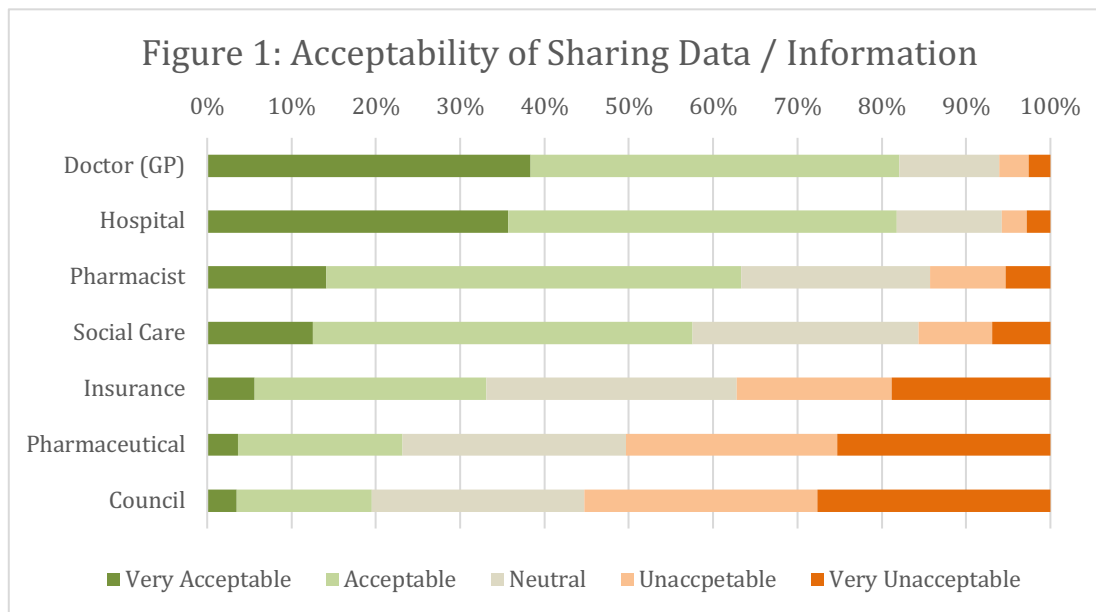
The survey data include responses about the sociodemographic characteristics of our respondents either asked directly in the survey or given as profile variables collected and provided by YouGov. Sociodemographic measures include age, gender, place of residence, level of education and income. YouGov sampled and weighted the responses to be representative for the population in England. The random allocation of respondents to different groups means that there are no significant differences across these sociodemographic characteristics in the experimental design. The surveys also asked whether the respondent belongs to an ethnic minority and their levels of trust in health and government institutions. Regarding this measures there are no significant differences across groups either. Unfortunately, the low number of respondents from an ethnic minority does not allow us to explore further possible differences in their responses.

3. Results

In Figure 1, we report on how acceptable respondents consider it to be to share information comparing the different entities in the public healthcare system. We combined the responses from all four groups ($n = 2355$); in other words, whether the respondents were asked about sharing data or information or whether they would be

² Note that we added some brief information on how the health records would be used by some, but not all, entities. In our opinion, the additional information was sometimes needed to help respondents to better understand the questions. Arguably, information could have been added for all entities or removed altogether. The results of the experiments are, however, consistent apart from those for insurance companies where they may suggest some lack of understanding on how insurance companies use health records.

made anonymous. The first finding that stands out is that in evaluating the acceptability of sharing health records, respondents clearly distinguish between different entities. More than 80% of the respondents find it either acceptable or very acceptable to share health data/information with hospitals and GPs. This acceptability drops to in terms of sharing their health records with pharmacists (65%) and social care workers (58%). The acceptability drops even further with insurance companies (33%), pharmaceutical companies (23%) and city and county councils (20%). Based on the Wilcoxon signed-rank tests, the distributions of the responses for all entities are statistically distinct with 99% probability.



The survey experiment allows us to compare the different responses based on people's attitude towards sharing anonymised versus personal (non-anonymous) information/data. Figure 2 shows the effect of the first treatment contrasting the acceptability of sharing health records that are either made anonymous or not. The treatment makes a clear difference, where respondents often find it *more* acceptable to share personal (non-anonymised) data/information than to share data that are made fully anonymous. The preference for personal rather than anonymous data sharing holds for GPs, social care providers and even insurance companies, where the Wilcoxon rank-sum test shows that the differences are statistically significant at 99%. For hospitals, the Wilcoxon rank-sum test indicates that the difference is only statistically significant at 95%. Only when asked about sharing health records with city or county councils do respondents express a preference for making them fully anonymous. The difference for councils is statistically significant at 99%.

The percentage of respondents who find it either acceptable or very acceptable to share health records with insurance companies or social care providers increases with 15% and 13% respectively when the treatment is personal rather than anonymised data/information. These large differences result partly from the larger number of respondents finding it (very) unacceptable to share their health records with these entities. In the case of GPs and hospitals where only few people object to sharing, the differences are approximately 3%. In contrast, 13% less respondents

object to sharing health records with city and county councils when they are made anonymous.

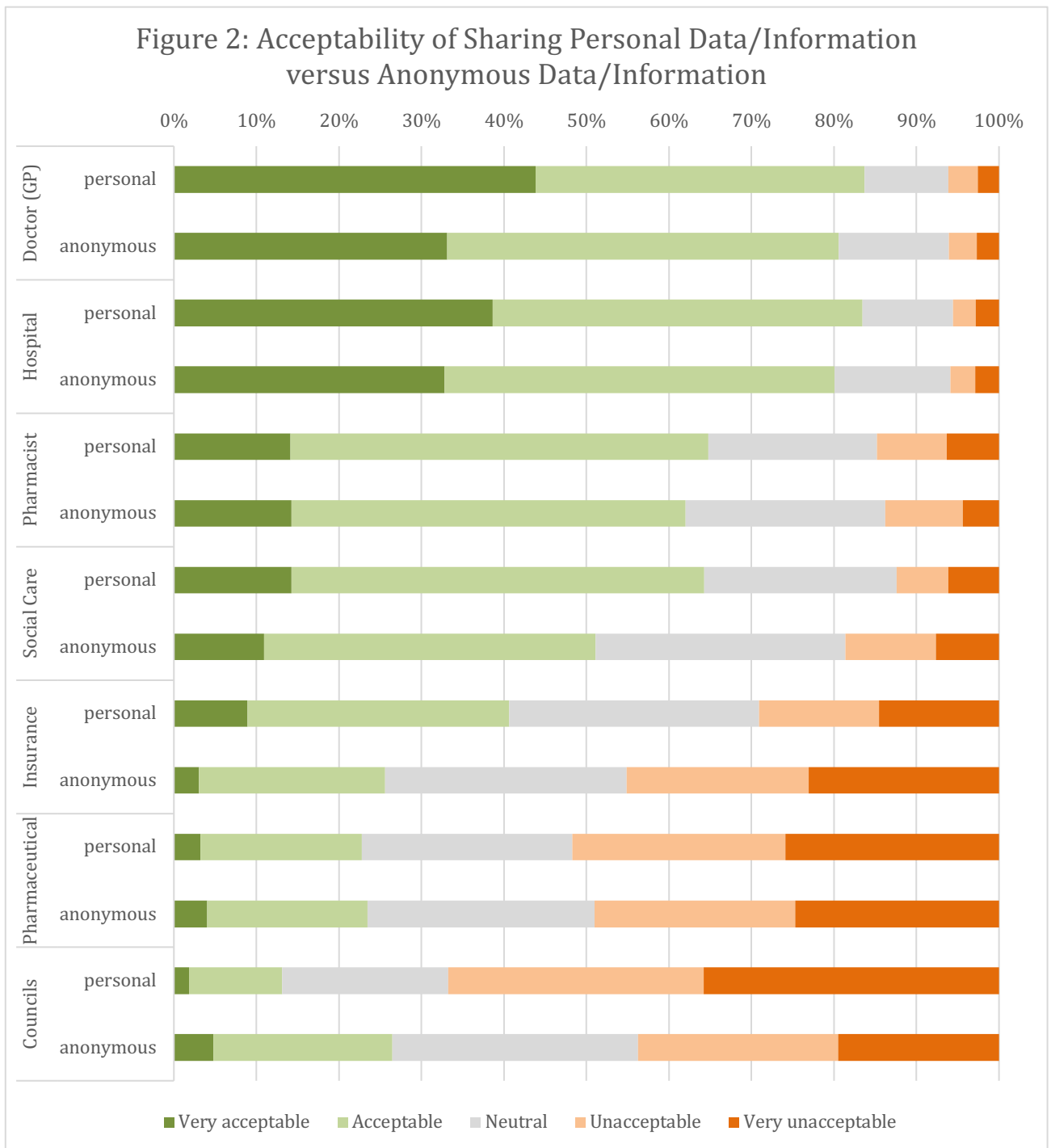
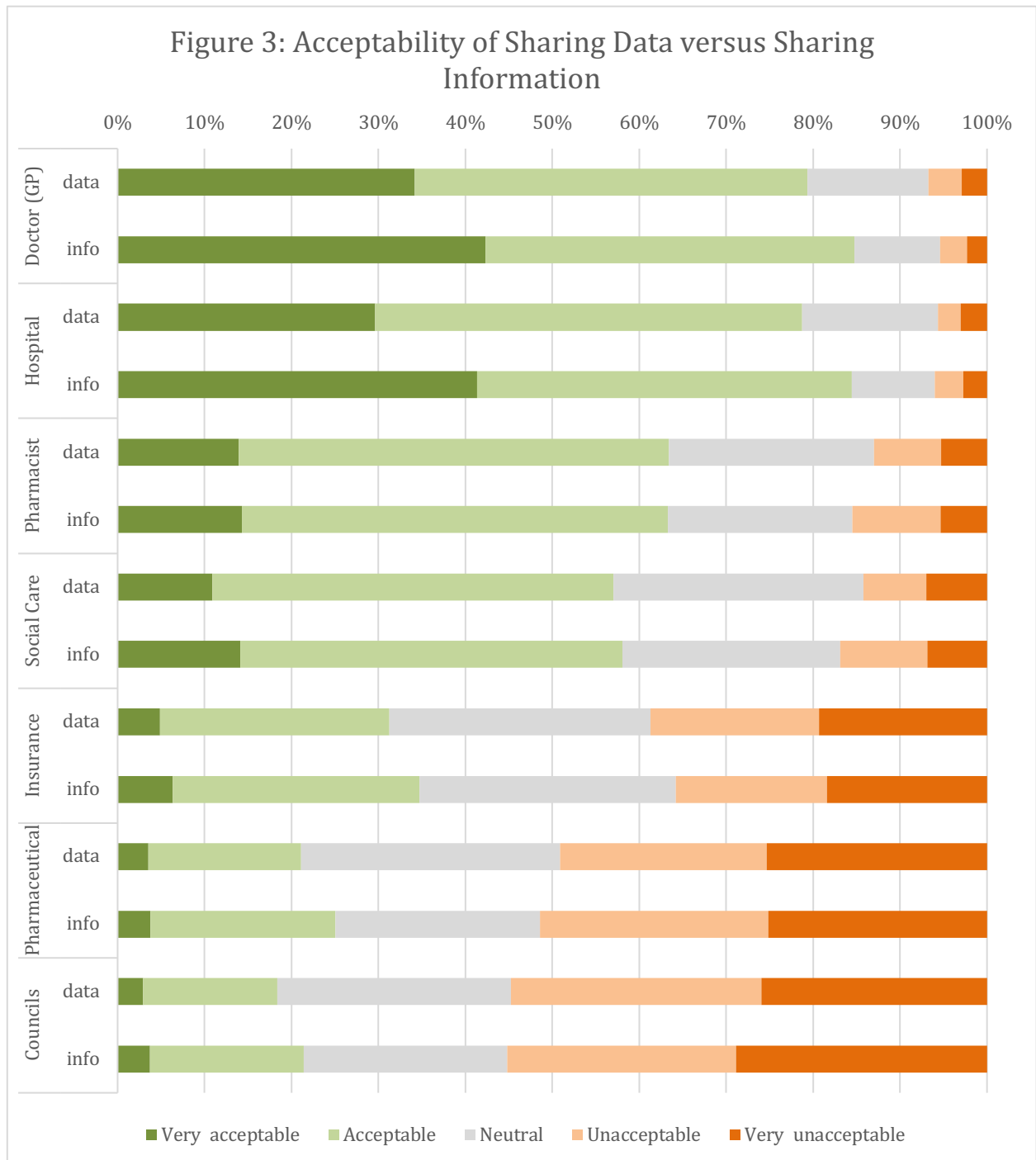


Figure 3 shows the results when the treatment is sharing *data* or *information*. Generally, the treatment does not have a clear impact on the acceptability of sharing health records. The Wilcoxon rank-sum test does not allow us to reject the null hypothesis that the samples for information and data are similar for councils, pharmaceutical and insurance companies, social care providers, and pharmacists. A notable exception is that respondents in the information groups (3 and 4) are more

willing to share their health records with hospitals and GPs, compared to respondents in the data groups (1 and 2). In these cases, the differences are statistically significant at 99%. When the term information rather than data is used, the percentage of respondents finding it (very) acceptable to share records with GPs or hospitals increases by about 5.5%. These differences result mainly from fewer respondents finding it neither acceptable nor unacceptable to share (the neutral answer category).



4. Discussion

Our findings show that people hold very different attitudes on how acceptable it is for the NHS to share their data/information with different entities. Conceptually, these entities can be categorised into three different clusters. People find it very acceptable to share data/information with hospitals and GPs (Cluster One) and are fine with sharing data/information with pharmacists and social care workers (Cluster Two). However, they hold a negative attitude towards sharing data/information with entities in Cluster Three, which includes health insurance companies, pharmaceutical companies, and city and county councils; specifically, sharing data/information with councils is regarded as unacceptable (see Table 1 below). The differences between the three clusters suggest that people evaluate the acceptability of sharing health records based on how sharing their health information/data could increase the quality of the healthcare they expect to receive. This echoes previous studies that discuss the importance of perceived benefits in patients' evaluation of whether or not to share their healthcare data/information (Kalkman et al., 2022; Esmailzadeh, 2017).

Table 1: Acceptability of Sharing Health Records

		Data (n= 562)	Anon Data (n= 570)	Info (n= 580)	Anon Info (n= 621)
Cluster One	GP	81%	78%	87%	83%
	Hospitals	80%	77%	87%	83%
Cluster Two	Pharmacist	66%	61%	64%	63%
	Social care provider	62%	52%	66%	50%
Cluster Three	Health insurance company	40%	23%	41%	29%
	Pharmaceutical companies	21%	21%	24%	26%
	City and/or county council	12%	24%	14%	29%

Note: Percentage of respondents finding it either acceptable or very acceptable to share data / information for each of the four treatment groups. Number of respondents per group unweighted.

When comparing the responses towards sharing personal versus fully anonymised data/information, the results become even more interesting and relevant. We found that people find it more acceptable to share personal (non-anonymised) data/information with hospitals, GPs, social care providers and even insurance companies. Arguably, in their dealings with all these organisations, respondents could expect direct benefits from providing personal and identifiable access to their health data/information. This is a new finding that challenges existing understanding, which often assumes that when sharing patients' health information/data, it must be kept anonymised or go through pseudonymisation (Boiten, 2021; Ghafur et al., 2020). This could be because sharing personalised data/information allows hospitals, GPs and social care workers to provide better and more customised care, and insurance companies can quote cheaper health or life insurance. This speaks to the explanation offered by Ackermann et al., (2021) for why consumers are willing to share their personal information with companies for perceived benefits that are relevant and of value to themselves. Notably, such benefits disappear when the data cannot be linked to them directly. To maximise the perceived benefits of better care and more tailored and relevant service (O'Donnell, 2011), sharing personal and non-anonymised data/information is clearly necessary. On the contrary, sharing personal and non-anonymised data with city and county councils is regarded by many

respondents as unacceptable, since sharing such data adds no personal benefits to them as individuals (Esmailzadeh, 2017). Yet, respondents appear to recognise that fully anonymised data has a purpose in planning health care and sharing anonymous health information/data with the councils is considered more acceptable.

Our findings also show that people find it more acceptable to share health *information* rather than *data* with GPs and hospitals. The differences are small but still statistically significant. When being admitted to a hospital or being treated by a new GP, it is reasonable for respondents to perceive direct benefits when these organisations know about their personal health; for example, to be able to provide the best care in case of an emergency. The perception of benefits appears to be prompted more strongly by using the term *information*. The NHS and other healthcare providers are therefore recommended to consider the use of the word “information” instead of “data” in future communications in England. *Information* adds context, meaning and value to data, thereby converting it into useful material for decision-making processes (Ackoff, 1989).

Nevertheless, it is important to note that since we had across-group sampling, every respondent was only exposed to the questions related to either *data* (groups 1 and 2) or *information* (groups 3 and 4). Since none of the respondents were required to compare or discuss the differences between *data* and *information* when answering the questions, it was not necessary to define each word in the questionnaire. We did not ask the respondents to interpret the differences between *data* and *information*. Instead, they were asked to express how acceptable they found the terms as they would encounter them in everyday healthcare communications. In other words, their interpretation of the word *data* or *information* is unprompted and based on their own semantic understanding, which reflects the ecological validity of our study. Saying that, we would recommend future studies to explore the nuanced differences between the two words, following our finding that respondents in England are more sensitive about sharing their data than their information.

4.1. Managerial Implications

Based on the discussions of our research findings, we advise the following:

For the NHS:

- Stop using *data* and *information* interchangeably in communication. We find that the word *information* is better received maybe because it is less abstract.
- Clearly explain the benefits of information sharing to the general public, especially how the act of sharing their health records will benefit them directly. While people appreciate and understand the benefits of sharing their information with hospitals and GPs, more effort is needed to outline the benefits for sharing their personal and anonymised information with pharmacies and social care workers. This will increase positive attitudes.

For Insurance companies:

- While sharing personal rather than anonymised data/information is considered necessary, people do not seem to hold a very positive attitude towards sharing their data/information with insurance companies. Insurance companies are advised to highlight the direct benefits of providing such

information. The reluctance to share highlights a potential reputational issue that insurance companies and the sector need to fix moving forward.

For Pharmaceutical companies:

- It is evident that people prefer not to share either data or information with pharmaceutical companies for research purposes, whether it is personal or anonymous. This may be because people cannot see how the sharing of their data/information provides a direct benefit to themselves. In future communications, pharmaceutical companies are advised to clearly explain how the sharing of data/information can benefit the general public in return.

For local governments (councils):

- While ranked as the least favourite in terms of data/information sharing, this should be a wake-up call to local governments. City and town councils are advised to work on increasing citizens' understanding about why their health information/data may be required. They are advised to offer explicit explanations regarding how information and data are used to enhance the infrastructure and the services offered by the local governments for the benefits of the general public.
- Moving forward, local governments are also advised to collect only anonymised data/information where possible and only collect personal data/information where absolutely necessary. This is likely to have a positive effect on rebuilding trust over the longer term.

4.2. Conclusion & Limitations

Our research has important implications for how to best manage issues regarding the sharing of health records across entities operating within public health in England. The perceived direct personal benefits determine the acceptability of sharing health records. Making these benefits clearer thus encourages the public to allow their health information/data to be shared effectively and completely. Whenever the direct and personal benefits are less clear, there is more reluctance to share health records regardless of anonymisation or whether *data* or *information* is used in communications.

Although our findings are important, our research has some limitations which should be taken into consideration. The experimental research design allows us to identify so-called average treatment effects. Thus, we can show that anonymisation and wording have an impact that varies across entities. However, we cannot evaluate any variation of the impact across respondents – the so-called heterogeneity of treatment effects. Research (e.g. Aggarwal et al., 2021) has found that minorities are particularly concerned about sharing their health records, and unfortunately our research cannot explore this further.

Another limitation is that we only consider anonymisation to address privacy concerns. However, any concerns about privacy may also pertain to the secure storage of data or strict adherence to data-protection regulation. Adding further treatments would have overly complicated the research design, and we opted for treatments that in our opinion the respondents could grasp immediately. Our main

goal was to evaluate how data sharing was communicated rather than to gauge confidence in the practices of different entities to manage health records.

Our survey experiments have allowed us to identify some important elements that underpin the acceptability of sharing health records. The limitations of our research, moreover, provide valuable avenues for future research.

5. References

- Ackermann, K. A., Burkhalter, L., Mildenerger, T., Frey, M., & Bearth, A. (2022). Willingness to share data: Contextual determinants of consumers' decisions to share private data with companies. *Journal of Consumer Behaviour*, 21(2), 375-386.
- Ackoff, R. L. (1989). From data to wisdom. *Journal of applied systems analysis*, 16(1), 3-9.
- Aggarwal, R., Farag, S., Martin, G., Ashrafian, H., & Darzi, A. (2021). Patient perceptions on data sharing and applying artificial intelligence to health care data: cross-sectional survey. *Journal of Medical Internet Research*, 23(8), e26162.
- Astrup, J., 2018. GDPR The Transfer of Data Power. *Community Practitioner*, 91(5), 36-39.
- Beynon-Davies, P., 2019. *Business information systems*. Bloomsbury Publishing.
- Chico, V., Hunn, A., & Taylor, M. (2019). Public views on sharing anonymised patient-level data where there is a mixed public and private benefit. *NHS Health Research Authority, University of Sheffield School of Law*.
- Dorussen, H., & Hansen, M. E., & Pickering, S. D., & Reifler, J., & Scotto, T., & Sunahara, Y., & Yen, D. (2024). The influence of waiting times and sociopolitical variables on public trust in healthcare: A cross-sectional study of the NHS in England. *Public Health in Practice*, 7(100484), 1-7.
- Esmaeilzadeh, P., 2018. Healthcare consumers' opt-in intentions to Health Information Exchanges (HIEs): an empirical study. *Computers in Human Behavior*, 84, 114-129.
- Fishburn, P.C., 2013. *The foundations of expected utility* (Vol. 31). Springer Science & Business Media.
- Ghafur, S., Van Dael, J., Leis, M., Darzi, A., & Sheikh, A. (2020). Public perceptions on data sharing: key insights from the UK and the USA. *The Lancet Digital Health*, 2(9), e444-e446.
- Guardian, 2023: <https://www.theguardian.com/society/2023/nov/30/nhs-england-faces-lawsuit-patient-privacy-fears-new-data-fdp-platform>.
- Ipsos MORI Social Research Institute. (2016, March). The one-way mirror: Public attitudes to commercial access to health data. <https://www.ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf>
- Kalkman, S., van Delden, J., Banerjee, A., Tyl, B., Mostert, M., & van Thiel, G. (2022). Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *Journal of Medical Ethics*, 48(1), 3-13.
- O'Donnell, H.C., Patel, V., Kern, L.M., Barrón, Y., Teixeira, P., Dhopeswarkar, R. and Kaushal, R., 2011. Healthcare consumers' attitudes towards physician and

- personal use of health information exchange. *Journal of General Internal Medicine*, 26, 1019-1026.
- Office for National Statistics (ONS), released 29 June 2023, ONS website, article, What we know from engaging with the public on data: June 2023
- Perera, G., Holbrook, A., Thabane, L., Foster, G. and Willison, D.J., 2011. Views on health information sharing and privacy from primary care practices using electronic medical records. *International Journal of Medical Informatics*, 80(2), 94-101.
- Rowley, J. (2007). The wisdom hierarchy: representations of the DIKW hierarchy. *Journal of Information Science*, 33(2), 163-180.
- Whiddett, R., Hunter, I., Engelbrecht, J. and Handy, J., 2006. Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics*, 75(7), 530-541.