



"SCOPING OUR FUTURE RESEARCH PRIORITIES"
PROJECT FUNDED BY THE TENTH ANNIVERSARY TRUST
MOTABILITY
MARCH – OCTOBER 2015
Full Report

PROJECT MANAGEMENT TEAM

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The Trustees of the Tenth Anniversary Trust wished to access knowledge and expert insight to create a long- term research agenda that would ensure that Motability remained relevant and accessible to its customers for the next 50 years.

Motability has excellent customer relationships and a robust mechanism to obtain and respond to feedback from its customers. However the Tenth Anniversary Trust has a wider remit pertaining to research into the broader topic of mobility and therefore wished to extend its understanding of this concept with both customers and other key stakeholders.

The key challenge was to understand the lived experience of individuals with mobility needs and to identify priority areas for future research investment. The challenge was addressed by scoping the views of those who manage their own disability and those who support them personally or professionally.

This report describes how this key challenge has been met and the related outcomes identified.

The Brunel University London team was ideally placed to lead this research as they held the relevant expertise as occupational therapists, inclusive designers and automotive engineers.

Study website: <https://mobilityresearch.wordpress.com/>

ACKNOWLEDGEMENTS

The project management team would like to thank Joanna Lewis & Tony Rogers who kindly provided advice and guidance to the project team from the conception of the project through to its conclusion. In addition, thank you to the staff at Motobility Operations, the Donnington 'Motobility Roadshow' and the Exeter 'One Big Day' event for their assistance in facilitating access to participants. Finally and most importantly, our thanks go to the 102 participants who kindly shared their lived experience of managing mobility, either as a person with a disability or through providing support as a carer or a mobility related professional. All participants have been represented by pseudo names and approximate ages in order to protect confidentiality.

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01 INTRODUCTION

Within the UK there are over 600,000 people with disabilities currently leasing a car, wheelchair accessible vehicle, scooter or powered wheelchair through the Motability scheme. Since its inception in 1977, Motability has supported almost 4 million disabled people and their families to become mobile.

The Motability scheme enables clients to have a new car every 3 or 5 years, with or without adaptations. In order to qualify for these scheme clients must be in receipt of the Higher Rate of Mobility Component of Disability Living Allowance, an Enhanced Rate of Mobility Component of Personal Independence Payment or an Armed Forces Independence Payment equating to £57.45 or an individual may also be in receipt of a War Pensioners' Mobility Supplement, equating to £64.15. The benefit a client is in receipt of will be paid directly to Motability in return for a fully insured, taxed and maintained car. Some vehicles do require a deposit but this is dependent on the make, model and adaptations required. Additionally, at 16 if you are in receipt of the higher rate of disability allowance you will be eligible to learn to drive and get your first motobility vehicle (<http://www.nidirect.gov.uk/learning-to-drive>)

Mobility is 'the ability to move or be moved freely and easily; for people with disabilities this may involve the use of adaptive equipment, techniques and technology such as walking sticks, walking frames, wheelchairs, powered wheelchairs, cars, adapted cars, wheelchair assisted vehicles or any combination of the afore mentioned. There are many significant social, economic and technological changes affecting people's mobility and it is important to seek the nature of the current and future needs of mobility challenged individuals.

Through identifying what a client with mobility needs wants psychologically, socially and physically will enable Motability to gather a holistic view of its clients. A collaborative research approach from Brunel University between Inclusive Design teams and Occupational Therapists has enable psychosocial needs and practical needs of clients to be determined. In accordance with current best practice in undertaking research, and in relation to requirements of the Health & Social Care Act, the project management team were committed to co-designing research together with the customers/service users and other key stakeholders, thus empowering the client to influence change.

KEY CHALLENGE

The Motability Tenth Anniversary Trust is a registered charity, whose principle objectives are to “promote and support the objectives of Motability by making grants and investing in research and special projects to facilitate mobility”.

How can the Trustees of the Tenth Anniversary Trust access knowledge and expert insight to create a longer-term research agenda that will ensure that Motability remains relevant and accessible to its customers for the next 50 years?

OBJECTIVES

In order to identify the priorities for Motability’s research agenda, a scoping study was undertaken to establish:

- the ‘lived experience’ of managing mobility today and,
- the future research priorities that Motability customers and other key stakeholders feel justify further investigation.
- to identify if a car club scheme would be a valuable addition to the mobility service

DELIVERABLES

- 01 Identify and document the current and future mobility needs of people with disabilities in the form of key values, meanings and metaphors.
- 02 Identify and document if a car club scheme would be a valued addition to the Motability service.
- 03 Collate and provide the recorded transcriptions of the interviews with the stakeholders.

ABOUT THE PROJECT TEAM

Details of the project team leads can be found on the project website www.mapsproject.com

SUMMARY OF FINDINGS

The 102 stakeholders who participated in this project represented those with lived experience of managing mobility. This experience was gained either through experience of managing their own disability or through supporting others personally or professionally.

Key Findings:

- 01 — The stakeholders' value system centred around:
equality and empowerment; freedom; health and fitness;
independence; social identity and security.
- 02 — Stakeholder values will be upheld through adhering to their identified **requirements** when designing future mobility products and services.
- 03 — A **values and requirements framework** has been produced as a checklist to support future products and service design. This encapsulates issues relating to:
 - equipment and services
 - usability
 - inclusivity
 - trust, support and services
 - finance
- 04 — Stakeholders' proposed solutions to current mobility challenges have been prioritised by stakeholders in a **prioritised wish list**.
- 05 — 53% of stakeholders welcomed the proposal of a car club scheme but only 24% said they would consider using it. Advantages and disadvantages of the proposal and the type of further detail required to conduct a fuller survey was identified.

02 LITERATURE REVIEW

INTRODUCTION

For people with disabilities, difficulty travelling is associated with limited life opportunities¹. While many quantitative studies and reviews have been undertaken on how mobility aids and devices and adapted vehicles can promote engagement in activities and participation in the community^{2, 3, 4, 5} very little has been written from the perspective of the user about how people with disabilities manage their mobility, and their vision for what could enhance mobility in the future. This review examines the small number of qualitative studies that have attempted to examine the lived experience of managing mobility. The studies in this field focus mainly on the use of mobility aids such as powered wheelchairs or motorised mobility scooters, and can be broadly classified as research examining; i) the experience of wheelchair use, ii) wheelchair user perspectives on barriers and facilitators to community participation, iii) effectiveness of wheelchair interventions and iv) usability problems in public transport among people with mobility limitations. The majority of these studies have been published by occupational therapy public health and urban transport researchers. Importantly, only two of the 15 studies reviewed have been conducted in the UK. Pyer and Tucker⁶ examined the transport, mobility and leisure experiences of British teenagers, and Bromley, Matthews and Thomas⁷ examined city

¹ Dodson, J., Gleeson, B., & Sipe, N. (2004). *Transport disadvantage and social status: A review of literature and methods. Urban Policy Program (Vol. Monograph 5, pp. 1-55). Brisbane, QLD: Griffith University.*

² Norweg, A., Jette, A.M., Houlihan, B., Ni, P., & Boninger, M.L. (2011). *Patterns, Predictors, and Associated Benefits of Driving a modified vehicle after spinal cord injury: Findings from the National Spinal Cord Injury Model Systems. Arch Phys Med Rehabil, 92(3), 477-483. doi: 10.1016/j.apmr.2010.07.234*

³ Pettersson, I., Ahlström, G., Törnquist, K. (2007). *The value of an outdoor powered wheelchair with regard to the quality of life of persons with stroke: a follow-up study. Assistive Technology 19(3): 143-153.*

⁴ Salminen, A.L., Brandt, A., Samuelsson K, Töytäri O, Malmivaara A.(2009). *Mobility devices to promote activity and participation: a systematic review. Journal of Rehabilitation Medicine, 41(9), 697-706. doi: 10.2340/16501977-0427.*

⁵ Sund, T., Iwarsson, S., Anttila, H., & Brandt, Å. (2015). *Effectiveness of Powered Mobility Devices in Enabling Community Mobility-Related Participation: A Prospective Study Among People With Mobility Restrictions. Physical Medicine and Rehabilitation, doi: 10.1016/j.pmrj.2015.02.001.*

⁶ Pyer, T., & Tucker, F. (2014). *With us, we, like, physically can't: Transport, mobility and the leisure experiences of teenage wheelchair users. Mobilities, 1-17. doi: 10.1080/17450101.2014.970390*

⁷ Bromley, R.D.F., Matthews, D.L., & Thomas, C.J. (2007). *City centre accessibility for wheelchair users: The consumer perspective and the planning implications. Cities, 24(3), 229-241. doi:10.1016/j.cities.2007.01.009*

centre accessibility among wheelchair users. The majority of the studies were conducted in Canada and Scandinavia.

THE EXPERIENCE OF WHEELCHAIR USE

Seven studies have examined the lived experience of using a wheelchair. Wretstrand, Petzäll and Ståhl⁸ focussed specifically on wheelchair seated passengers perceptions of safety in special transportation services, while the other six examined wheelchair user's experiences in general. These six studies^{9, 10, 11, 12, 13, 14} all found wheelchairs provided opportunity for participation and continuity in life for people who acquired mobility problems in later life. Some of the themes raised across these studies included the 'wheelchair as part of me', managing varied social responses from community members, the humility, humiliation and frustration of using a wheelchair, the need for careful planning and developing strategies to manage everyday life, and feelings of both freedom and confinement. Of particular concern was the research by Pyer and Tucker⁶ which revealed that teenagers in the UK experience multiple layers of transport disability, disadvantage, anxiety and dependency. The study by May et al.,¹³ drew on the experiences of participants to call for changes to environmental design (the need for more scooter-friendly spaces), and for improved training of users, and public education to further promote independence and reduce barriers for mobility aid users.

⁸ Wretstrand, A., Petzäll, Jan., & Ståhl, A. (2004). *Safety as perceived by wheelchair-seated passengers in special transportation services. Accident Analysis & Prevention, 36*(1), 3-11. doi: 10.1016/S0001-4575(02)00108-2

⁹ Barker, D.J., Reid, D., & Cott, C. (2004). *Acceptance and meanings of wheelchair use in senior stroke survivors. American Journal of Occupational Therapy, 58*, 221-230.

¹⁰ Barlew, L., Secrest, J., Guo, Z., Fell, N., & Haban, G. (2013). *The experience of being grounded: a phenomenological study of living with a wheelchair. Rehabilitation nursing, 38*(4), 193-201. doi: 10.1002/rnj.96

¹¹ Korotchenko, A., & Clark, L. H. (2014). *Power mobility and the built environment: the experiences of older Canadians. Disability & Society, 29*(3), 431-443.

¹² Kylberg, M., Löfqvist, C., Phillips, J., & Iwarsson, S. (2013). *Three very old men's experiences of mobility device use over time. Scandinavian Journal of Occupational Therapy, 20*(5), 397-405. doi: 10.3109/11038128.2013.779321

¹³ May, E., Garrett, R., & Ballantyne, A. (2010). *Being mobile: electric mobility-scooters and their use by older people. Ageing & Society, 30*, 1219-1237. doi:10.1017/S0144686X10000334

WHEELCHAIR USER PERSPECTIVES ON BARRIERS AND FACILITATORS TO COMMUNITY PARTICIPATION

Five studies were identified that examined mobility aid user's perspective on barriers and facilitators to community participation. Earlier this year, Ripat and Colatruglio¹⁴ published a study that examined the environmental barriers to community participation for wheeled mobility device users in cold weather climates such as Canada. On-line focus groups were led over several days with eight individuals who identified that winter barriers included weather, policies and attitudes. Strategies to overcome these barriers included going out as little as possible, having to rely more heavily on family and friends, taking extra precautions and contacting local authorities to manage safety concerns. These research participants also identified that life resumes in spring, and summer, but that winter participation is a right. Similarly, Meyers et al.,¹⁵ identified a range of personal, interpersonal and environmental barriers that 25 wheelchair users came across when attempting to access a range of destinations such as shops, banks, and health professionals' offices accessing the community in two North American cities. Through surveys and interviews, the research team identified that while civic destinations were generally accessible, workplaces and the homes of friends and family were harder to gain entry. Further investigations to improve assistive technologies that promote mobility were called for.

While all the studies targeting barriers to community mobility noted that a major barrier is the attitudes of community members, few examined any practical solutions to overcome this, or any of the physical barriers that exist. However, the research by Herrera-Saray et al.,¹⁶ concluded that user input is essential in the design of assistive devices, as well as the built environment, and that design 'from and for' the user is essential. Pierce¹⁷ and more recently, Bromley, Matthews and Thomas⁷ also called for a stronger

¹⁴ Ripat, J., & Colatruglio, A. (2015). *Exploring winter community participation among wheelchair users: An online focus group. Occupational Therapy in Health care, 1-12.* doi: 10.3109/07380577.2015.1057669

¹⁵ Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoening, H. (2002). *Barriers, facilitators, and access for wheelchair users: substantive and methodologic lessons from a pilot study of environmental effects. Social Science and Medicine, 55(8), 1435-1446.* doi: 10.1016/S0277-9536(01)00269-6

¹⁶ Herrera-Saray, P., Peláez-Ballestas, I., Ramos-Lira, L., Sánchez-Monroy, D., & Burgos-Vargas, R. (2013). *Usage problems and social barriers faced by persons with a wheelchair and other aids. Qualitative study from the ergonomics perspective in persons disabled by rheumatoid arthritis and other conditions. Reumatología clínica, 9(1), 24-30.* doi: 10.1016/j.reuma.2012.05.010

¹⁷ Pierce, L.L. (1998). *Barriers to Access: Frustrations of people who use a wheelchair for Full-Time Mobility. Rehabilitation Nursing, 23(3), 120-125.* Retrieved from doi/10.1002/j.2048-7940.1998.tb01763.

voice for people with disabilities in the development of policy and planning and access decisions. Bromley et al., 7 identified several strategies to improve the physical environment of UK city centres for use by people in wheelchairs including dropping kerbs, increasing pavement quality, removing steps and providing more disabled parking bays that are better monitored, and incorporating the concept of universal design when upgrading the environment.

EFFECTIVENESS OF WHEELCHAIR INTERVENTIONS

Two studies were identified that examined the impact of receiving a mobility aid from the recipient's perspective. Sund and colleagues⁵ conducted pre and post interviews to examine changes in frequency, ease/difficulty, and number of mobility-related aspects of participation in daily life among 180 people from Denmark, Finland or Norway who received a powered mobility device. Compared to baseline scores, the participants had higher levels of participation in shopping and going for 'walks', and reported that activities such as going to restaurants/cafes/pubs, shopping for groceries, other shopping, posting letters, and going to the bank or the chemist's became much easier. However, this research used a standardised tool to collect the data rather than examining the participant's own perspective on the changes brought about by the receipt of a mobility device. In contrast, Barker, Reid and Cott¹⁸, studied the experience of 10 older stroke survivors who had been prescribed a wheelchair, and the factors that influenced their community participation. The participants viewed their wheelchairs as enablers to community participation, and that without a wheelchair they would simply be house-bound. The remaining themes identified by participants related to personal and environmental facilitator and barriers as discussed above.

¹⁸ Barker, D.J., Reid, D., & Cott, C. (2006). *The experience of senior stroke survivors: Factors in community participation among wheelchair users*. *Canadian Journal of Occupational Therapy*, 73(1), 18–25. doi: 10.2182/cjot.05.0002

USABILITY PROBLEMS IN PUBLIC TRANSPORT AMONG PEOPLE WITH MOBILITY LIMITATIONS

In this final section of the review, only one study was found relating to the views of people with mobility difficulties in using public transport. Carlsson¹⁹ conducted focus groups and interviews with 20 people from two Swedish towns concerning the usability problems faced by people with functional limitations when using urban buses. The difficulties encountered were summarised as relating to the functional limitations the individual needed to manage and the environmental barriers associated with bus stops (including no seats, lack of information about the timetable and buses stopping) and the buses themselves (such as access to entrance, handrails, and space for mobility aids).

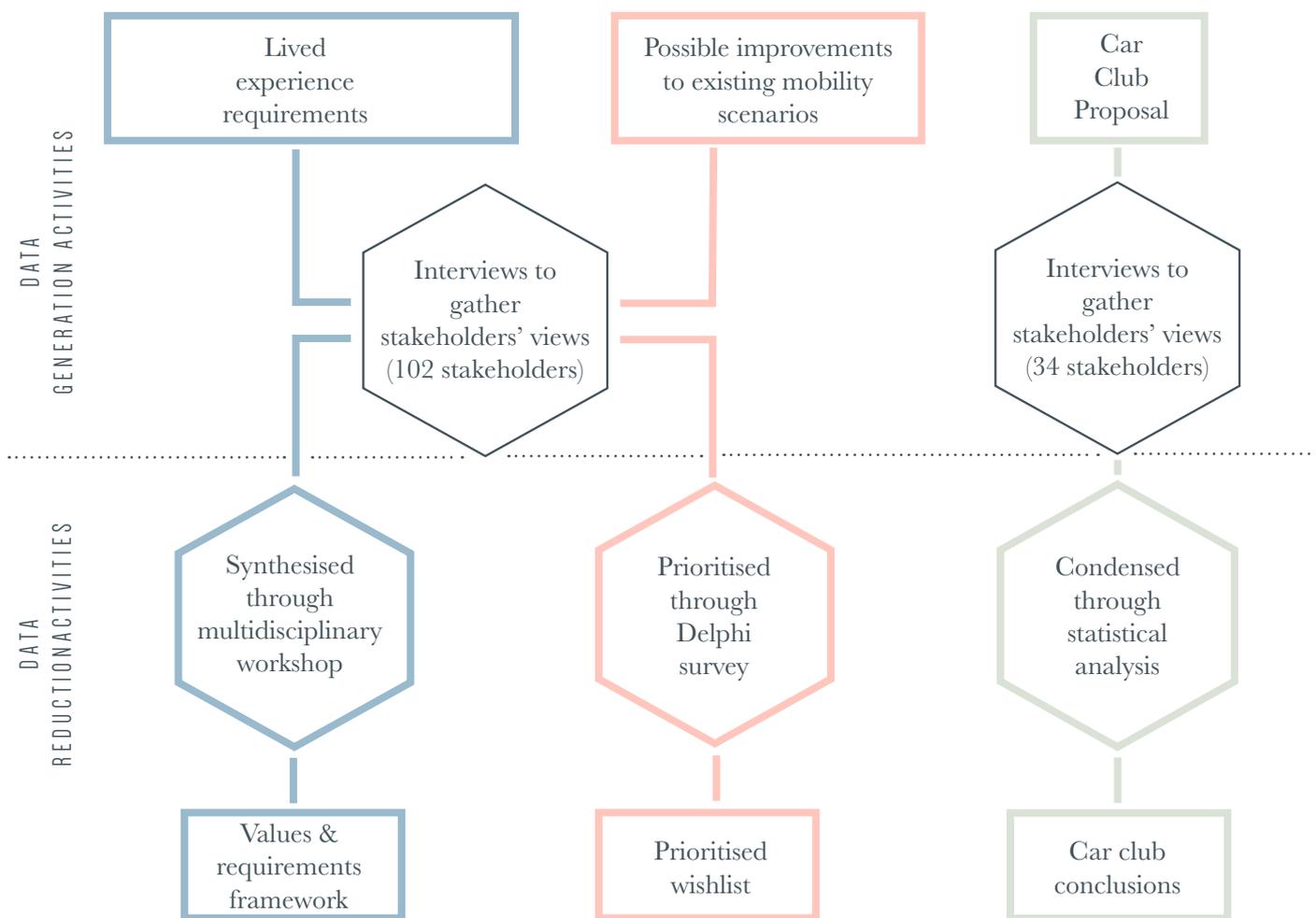
SUMMARY AND RESEARCH AIMS

While this review has identified research exploring facets of the experiences of mobility aid users internationally, only two studies were identified involving British participants. Research undertaken to date has also focused on the experience of using specific devices such as powered wheelchairs or motorised mobility scooters. However, none of the studies reviewed considered mobility in a broader context that encompasses the ‘whole of journey’. There is a gap in the literature in understanding people’s experiences of their total mobility experience, including use of personal mobility devices, cars, taxis and public transport to access their neighbourhood, or traverse the country. Furthermore, people with mobility limitations have rarely been asked to share their views on what they value and what they require to be considered when such products and services are being developed. These complex issues could usefully be summarised into a simple framework that could be used to vet any future new product or service design proposed. Finally it is important to ask those who have the lived experience of managing mobility, what solutions they would like to see to their mobility challenges, both now and in the future. A research program was therefore developed to assist the Trustees of the Tenth Anniversary Trust to access knowledge and expert insights to create a longer-term research agenda that will ensure that Motability remains relevant and accessible to its customers for the next 50 years. In this component of the research program, our team sought to gather the ‘lived experience’ of how people with mobility problems in the UK manage their mobility today as well as their ideas for managing in the future, in the form of key values, meanings and metaphors.

¹⁹ Carlsson, G. (2004). *Travelling by urban public transport: exploration of usability problems in a travel chain perspective*. *Scandinavian Journal of Occupational Therapy*, 11(2), 78-89.

03 METHODOLOGY

RESEARCH PROCESS



The scoping study was undertaken with key stakeholders in order to co-design the study with those who were experts by experience. The definition of the stakeholders included the ‘person, groups or institutions with an interest in the project’s performance and in the outcome of proposed actions.’²⁰ The scoping study focused on gathering and prioritising the views and insights of the full range of stakeholders.

Initially we observed the mobility challenges of people with disabilities (ethnographic phase) and through that process iteratively developed, discussed and agreed with 10 stakeholders, the topics to be included in the interview schedule.

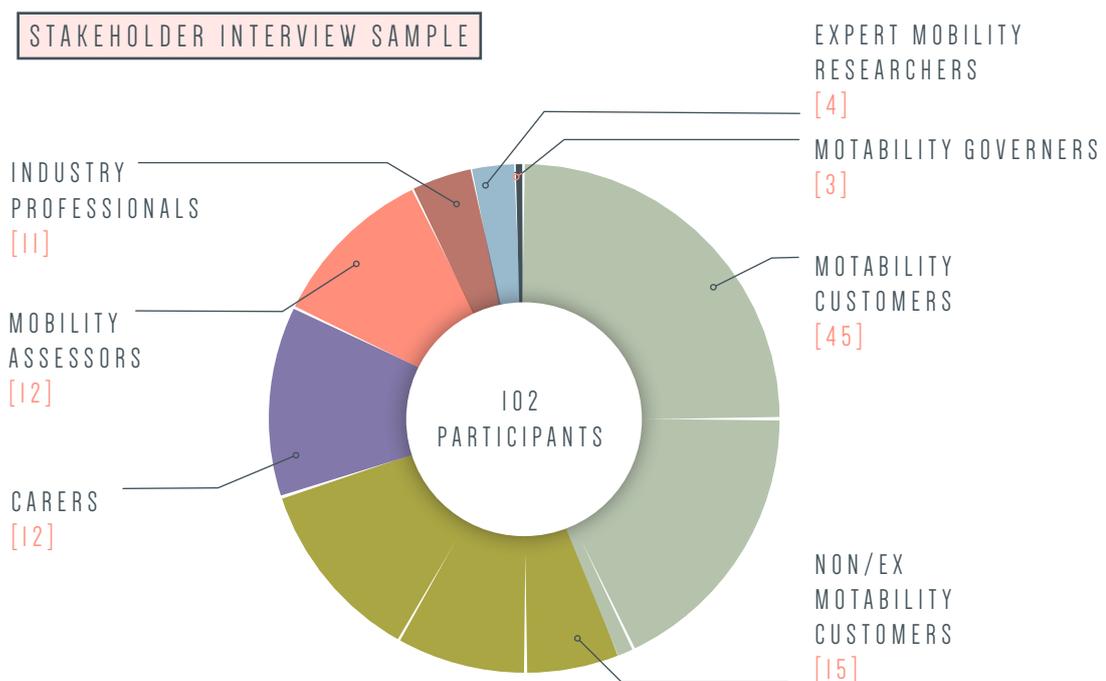
²⁰Newcombe, R. (2003) *From client to project stakeholders: a stakeholder mapping approach*, *Construction Management and Economics*, 21:8, pp. 841-848.

MacArthur, J. (1997) *Stakeholder analysis in project planning: origins, applications and refinements of the method*, *Project Appraisal*, 12:4, 251-265.

Vos, J.F.J. and Achterkamp, M.C. (2006) *Stakeholder identification in innovation projects-Going beyond classification* *European Journal of Innovation Management*. 9(2) pp161-178.

Once we had completed this pilot stage, the interview questions were agreed as fit for purpose. We then proceeded to collect interview data from the full sample of stakeholders (phenomenological phase). Interviews were offered as face-to-face, by telephone, or Skype depending on preference; they were undertaken at a time and place of the participants choosing. In total, 102 interviews were conducted with the stakeholders; over half of were conducted face to face. The in-depth analysis of the interview data was undertaken in parallel by both a health researcher and design researcher in order to maximize the benefits of using both perspectives.

The findings from both sources were merged at a workshop facilitated by the project management team (synthesis phase). In addition those items which were identified as solutions were also identified and then prioritised through an online Delphi survey (consensus approach).



STAKEHOLDER SAMPLING

In order to fully explore the issues of importance we used a mixed sampling method incorporating both the core views of motability stakeholders who were the most common stakeholder view included as well as those who represent individual extreme views e.g someone who is housebound. We underpinned selection by using a theoretical framework to identify key informants (Appendix A).

Motability customers were well placed to offer expert insight into the impact of their mobility challenges through their ‘lived experience’ of managing their mobility challenges.

Other groups that had a valuable contribution to make included; carers, family members, professional carers, Governors of Motability; professionals working in mobility centers; mobility researchers and organisations who have an active role in supporting individuals’ mobility needs such as automotive industry representatives and the Research Institute for Consumer Affairs (RICA).

The sample size was determined by the funders who requested 100 interviews were undertaken. Of these they required approximately 40-45 to be Motability customers.

APPROACH TO RECRUITMENT

A purposeful sampling approach was taken to the recruitment of stakeholders. This involved a researcher actively selecting samples among those who have certain traits or qualities to answer the research question. Participants were recruited through a combination of snowball sampling (interviewee recommends another potential interviewee), opportunity sampling (attendees of events where interviewees may attend), as well as recommended contacts from Motability or the project management team's or researchers' professional contacts.

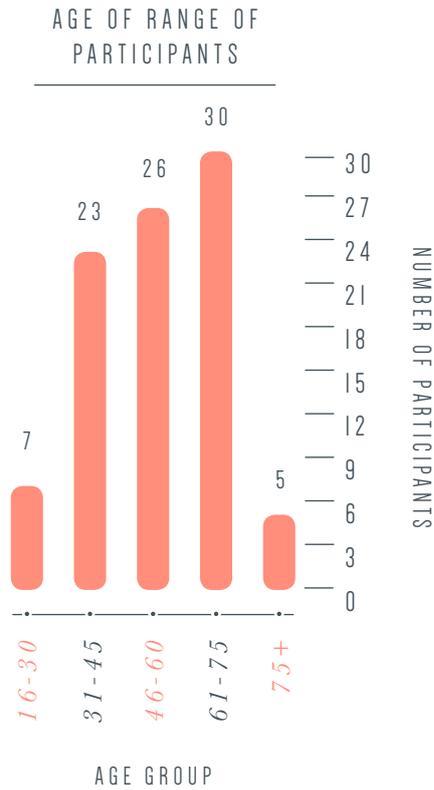
Another key source was via from the Motability Operations customer database. A data sharing agreement to contact Motability customers was established between Motability Operations and Brunel University London. This enabled Motability Operations to send Brunel University London a telephone list of participants eligible to take part in study. In order to ensure participants were appropriately informed about the purpose of the study and how Brunel University London had received their data an opening telephone script was written and approved by Motability Operations (Appendix B)

DETAILED BREAKDOWN OF OBTAINED STAKEHOLDER SAMPLE

<u>PARTICIPANT TYPE</u>	<u>TOTAL INTERVIEWED</u>
<u>MOTABILITY CUSTOMER</u>	<i>45</i>
Driver of adapted car	33
Wav driver	2
Passenger with disability	4
Powered wheelchair user	3
Mobility scooter user	3
<u>NON/EX MOTABILITY CUSTOMER</u>	<i>15</i>
People with disability as passenger & car driver	12
People with public transport preference	1
People who are housebound	2
<u>CARERS</u>	<i>12</i>
Family carers	9
Professional carers of motability customers	3
<u>HEALTH & SOCIAL CARE PROFESSIONALS & DRIVER ASSESSORS</u>	<i>12</i>
Occupational therapist driving assessor & other driving assessors	9
Occupational therapist - local authority / police / local authority	3
<u>EXPERT MOBILITY RESEARCHERS</u>	<i>4</i>
Expert mobility researchers / rica	4
Members of the uk mibility forum expert panel	0
<u>INDUSTRY</u>	<i>11</i>
Mobility equipment providers / mobility facilitator	9
Automotive companies / insurance companies	2
<u>MOTABILITY</u>	<i>3</i>
Mobility governors	3

DEMOGRAPHIC INFORMATION

Participants varied by age with the majority of participants interviewed aged 61-75 years. Only 7 participants were in the youngest age group, (16-30) similarly, only 5 participants were aged over 75 years. No participants between 16 and 18 agreed to participate.



ETHICAL CONSIDERATIONS

Ethical Approval was granted by the Brunel University London Ethics Committee (Approval no. 15/04/STF/36). Brunel University London also provided indemnity and oversight of the proper conduct of the study.

OBTAINING INFORMED CONSENT

Before consent was obtained, information was provided to explain the purpose of the study (Appendix C). For those participants who were interviewed face to face, written consent was obtained. For those participants who were interviewed by telephone, recorded verbal consent was obtained. If participants wanted further information they could access the project website <https://mobilityresearch.wordpress.com/>. Interviewees were not informed that Motability are funding the research in order to avoid participant bias in responses. However if participants directly asked who was funding the research, researchers explained it was Motability's Tenth Anniversary Trust.

SECURE DATA STORAGE

Brunel University London ensured data was stored security through establishing a secure, password protected intranet site. Only the research project management team and researchers had access to the folders.

OBSERVATION AND INTERVIEW QUESTION DESIGN

The interview questions were developed and tested with 10 stakeholders in the co-design phase. Observations of individual's mobility in various environments and iterative discussions informed the development of the questions. Initially the following questions were posed:

We utilised a theoretical framework to underpin the design of the interview topics to ensure the interviews remained comprehensive (Appendix D). Through consultation with pilot participants, the focus of the interview questions were developed. The following issues were felt to be important and therefore warranted inclusion:

- Stakeholders wanted to start the interview by sharing something of themselves and the context from which they were answering the questions.
- Stakeholders felt it was important to delineate how their mobility was experienced across three very different environments:
 - the home environment,
 - their local area
 - when travelling further afield.
- They wanted the opportunity to explain what they valued about mobility, what was working well and how that was achieved.
- They wanted to share what was a mobility challenge and their ideas on how those challenges could be overcome.

In the second stage of the data collection, another aspect was identified as important to capture in more depth;

- how mobility was experienced both when the person with a disability was on their own as well as when they were with others and how they would like to ideally find these two experiences.

Two parallel sets of questions were developed a) those who had a disability and b) for those who supported someone with a disability personally or professionally.

A final question was added at the request of the Tenth Anniversary Trustees to enquire if a car club scheme would be of interest if it were added to the Motability Scheme service.

The final interview schedule can be found in Appendices E. Information was also available in Welsh to allow Welsh speaking participants to give consent (Appendix F)

APPROACH TO DATA ANALYSIS OF INTERVIEWS

Thematic Data Analysis was carried out using the qualitative software package Nvivo 10²¹. Nvivo identifies implicit ideas within the data beyond explicit words or phrases to produce themes and issues addressed in the interviews.

The approach is useful to examine the underlying ideas, assumptions, and conceptualisations at the latent level beyond the semantic content of the data. The approach was in keeping with published guidance on thematic quality control requirements²² (Appendix G)

THEMATIC ANALYSIS PROCESS

Framework Analysis was used to analyse the qualitative data, with themes being developed inductively from participant's narratives²³. In the first instance, the data underwent a familiarisation process in which a number of transcripts were carefully selected in order to acquire an overview of the data. This selection was based on a review of the initial proposal and the key deliverables and reflected the range of stakeholder views. Using a case and theme approach, the data was line by line coded, with key phrases and themes being summarised using Nvivo codes. Where necessary notes and memos were produced which recorded initial thoughts as well as analytical impressions of the data. These were linked to the relevant transcripts using Nvivo 10.

The familiarisation process continued until the diversity of the circumstances and characteristics of the data were understood and a number of initial themes had been identified which reflected the views of stakeholders.

²¹ *Nvivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012*

²² *Braun, V and Clarke, V.(2006) Using thematic analysis in psychology. Qualitative Research in Psychology 2006;3: 77-101pp.*

²³ *Ritchie, J. and Lewis, J. (2003) Qualitative research practice: a guide for social science students and researchers. London. Sage.*

Once this process was completed, the data was then reviewed by two researchers, to ensure rigour, before similar themes/codes were grouped. These themes then formed the basis of the conceptual framework. A classification system was developed within Nvivo which enabled the analysis to explore across the different stakeholder groups and by gender, age, ethnicity, and UK Country.

Framework matrices were developed within Nvivo 10 based on the identified themes. Six thematic matrices were produced which contained the main themes and all the relevant sub themes. The main themes represented in the matrices were as follows: stakeholder values; inclusivity; usability; equipment & facilities; trust, support & service; finance. This conceptual framework was then applied to the remaining transcripts.

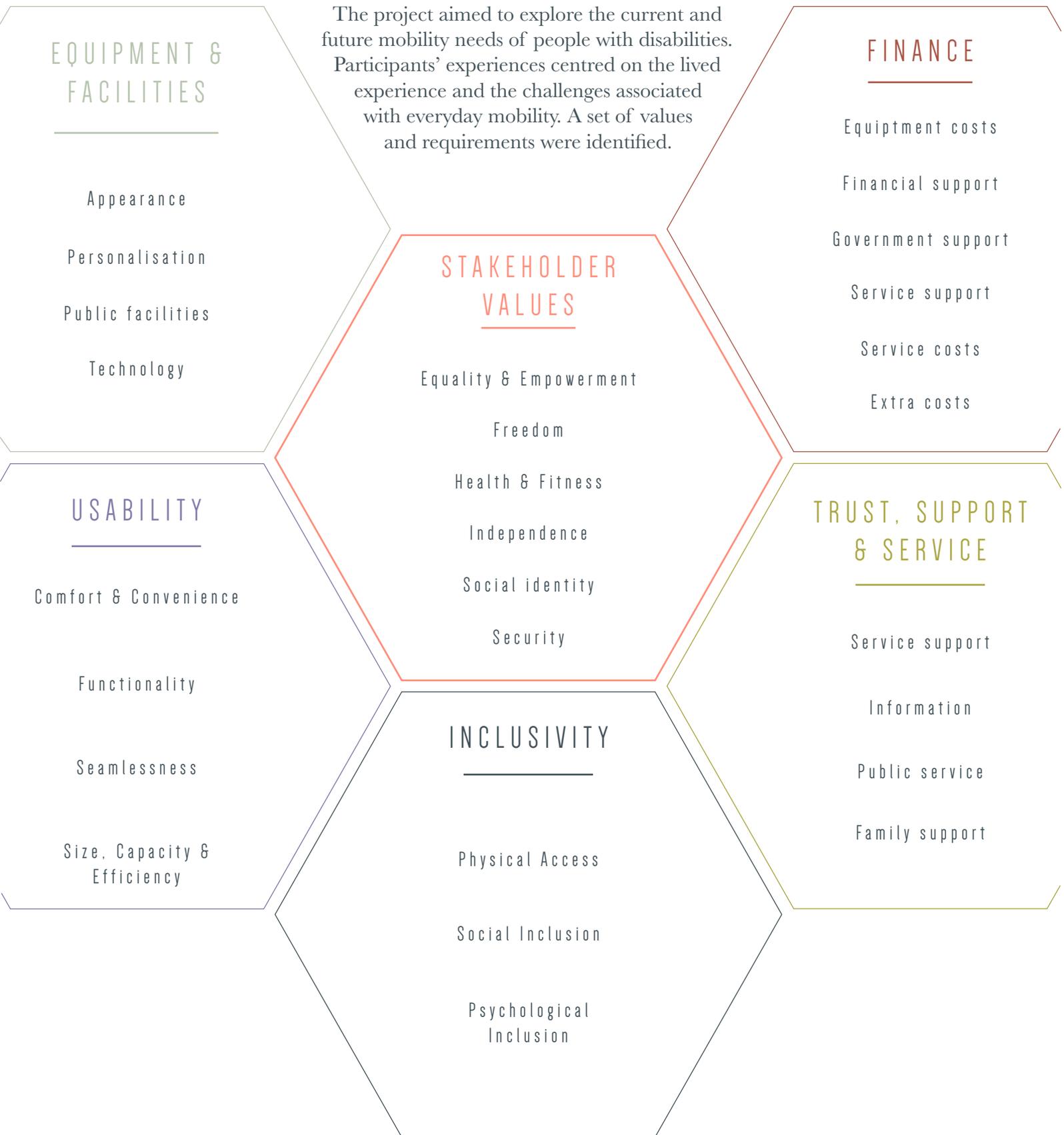
Each participant was allocated a row with the themes and subthemes displayed in separate columns in the matrices. Codes that did not fit into the matrix were retained under a separate thematic folder and then reviewed once all the transcripts had been analysed. A separate folder was also produced for the Delphi items.

WORKSHOP METHOD

Ten researchers regrouped all themes and subthemes individually before coming together to share and agree the final synthesis of the overall findings.

04 FINDINGS & RECOMMENDATIONS

VALUES & REQUIREMENTS FRAMEWORK



STAKEHOLDER VALUES

See Appendix H for long list of example quotations

EMPOWERMENT & EQUALITY

“It’s empowering because through my chair I can do anything the exact same as anybody else. So it’s my game changer, it makes me equal.” - Elizabeth, 54
Driver of adapted car



FREEDOM



“Your car is your freedom, your car is your legs. I use a lot of taxis and access to work and I keep on encouraging people to drive because not only can you get to work then you can visit your family, you’re not isolated, you can do lots of social activities. I’d be lost without my car. When I got out of hospital my dad had a car sitting there and I learnt how to drive and that was my freedom.”

- Megan, 38
Driver of adapted car

HEALTH & FITNESS

“This is a manual chair so that I can wheel it when I want, so I can keep reasonably fit, but then if I’m carrying shopping I flick the lever and it’s then motorised so I’ve got the best of both worlds.”

- Patrick, 52
Wheelchair User



INDEPENDENCE



“I’m a very fiercely independent person so... In fact after my injury friends and family wanted me in the local area and that’s not what I wanted so I went completely somewhere where I was completely away from everybody to make sure that I did everything for myself.[...] It goes back to what I said about the independence side of things. I built everything into my life, A, to be as healthy and fit as I can, to be as normal as I can and to achieve those things I’ve bought the various bits of kit to fulfill those two criteria, really.”

- Celine, 38
Driver of adapted car

SOCIAL IDENTITY

“They found the suitable powered chair for their son, purchased it from the show and now he’s gone on to have greater independence out of school, and in school. As a teenager it’s very important to engage with his peers... and gone on to play powered chair football as well, so it’s kind of opened up a whole new social life.”

- John, 36
Equipment provider



SECURITY



“I feel more safe knowing that it’s going to be serviced every year by them and yeah, I’m a bit sort of... It’s the security of if something goes wrong, it can go straight to the garage without costing me anything because obviously I’ve done from a damn good wage working at the hospital of nearly £2,000 a month and now I’m just living on benefits now.”

- Daphne, 67
Driver of adapted car

STAKEHOLDER VALUES

Key Insights & Recommendations

EMPOWERMENT & EQUALITY

Feeling empowered, achieving equality and maintaining normality were all highly valued by individuals with disability and their family carers. Normality can be viewed as a politically incorrect term but the stakeholders regularly expressed their desire to feel 'normal'.

For one male participant, the independence provided by his car gave him a sense of normality. Indeed, he noted that it was one of the few occasions when he felt he was on a level playing field with others. In contrast, another participant stated that the key purpose, when making equipment choices, was to achieve a 'normal life'. For family carers, particularly those with children, it was particularly important that their child and their family had a sense of normality. Equipment and wheelchairs were seen as essential to achieving this sense of normality as they facilitated equality in terms of engagement in schoolwork, sport and clubs.

It was also important to participants that the home looked 'normal' as illustrated in the narrative of a female wheelchair user. The woman described how, after the accident that left her with a spinal injury, both her and mother was keen to ensure that adaptations to the family home did not look 'disabled'.

It was also important for families that equipment enabled children to be a part of everyday life. This is illustrated by a parent with a disabled child who spoke about the importance of her child being involved in everyday life, but also in participating in activities with other children. A key factor for this family was that the child, who was in a wheelchair, had equipment that would raise her up to the same level as other children. Getting the right equipment was seen as a key factor in the child having a 'normal' childhood and facilitating play and social interaction with their peers. Being equal was equated with being empowered; value was placed on being 'on a level playing field' in every aspect of life.

In contrast some families, with very young children were against getting specialist equipment in order to maintain a sense of normality for as long as possible. For example, one family with a young child, were using a pushchair as opposed to a wheelchair so that they didn't have to use a specialist wheelchair adapted vehicle. They wanted to maintain normality as long as possible.

These findings about the need to feel normal resonate with those results identified in the subthemes of appearance and functionality. When using any equipment, wheelchairs or adapted cars, they must maximise the feeling of normality while still allowing the person to be empowered through equal

access and engagement in every aspect of life. The commencement of equipment use is also interesting in terms of timing; the desire to wait as long as possible before commencing use has to be balanced with the desire to be able to engage and participate. Cars, unless they are special adapted vehicles, represent normality and are readily adopted by people with disabilities and their carers, whereas other specialist equipment, wheelchairs and specialist adapted vehicles maybe resisted for as long as possible. Parents may resist using wheelchairs and equipment for children with disabilities for as long as possible but research has also shown that resistance can also be more common in later life: it has found that those who to come to need a wheelchair later in life have more difficulty making the transition and may have more psychological difficulty integrating wheelchair use into their lifestyle.

FREEDOM

Participants valued the freedom that their car afforded them. Their car felt like their legs; allowing them to be mobile whenever they wished. The ability to drive a car was valued immensely as it helped reduce dependence on others and it maintained participants' capacity to work. They particularly valued the freedom to get 'out and about' so they could socialise with friends and family. This prevented them feeling 'stuck at home', where they would feel lonely and isolated.

The use of a car has been identified in studies as an important factor in protecting people from loneliness. Driving cessation has also been shown to have a direct effect on health decline. The car can be viewed as an effective means of enhance public health; it protects individuals from the health risks associated with loneliness and isolation. The car can be seen to contributing indirectly to enhanced work force inclusion, which in turn increases the economic and social status of the driver and society. In addition, by reducing dependency on others, the physical, psychological and economic impacts are achieved for the person with disability as well as for their family and friends.

HEALTH & FITNESS

For a small number of participants, maintaining health and fitness was highly valued, despite the challenges of being a wheelchair user. Indeed their narratives revealed that many of them had been very active prior to becoming a wheelchair user. Enjoying activities that ranged from windsurfing, horse riding, mountain biking and climbing. These participants saw no reason why they should be less active since becoming disabled and they prioritised and valued being fit.

One participant with a spinal injury, spoke about their motivation for maintaining their health and fitness. For this individual, their motivation stemmed from the hope that if they were able to maintain their fitness, they would be able to benefit from any future developments in health care that could restore their mobility. For this individual, maintaining health and fitness also acted as a coping strategy. Focusing on becoming fit and maintaining their health was instrumental in helping the individual adjust to the reality of their disability in the immediate aftermath of the accident, as it was an element of their old life that remained a constant.

As previously discussed, participants maintained their fitness by limiting the amount of equipment they used in their daily life, as well as switching between manual and powered wheelchairs.

The importance of physical fitness is vital to both health and the ability to function. A certain level of fitness is needed to maintain the ability to conduct transfers and undertake activities of daily living. Balanced with this is the strain that the use of a manual wheelchair places on joints and the injuries that can occur. Fitness of those with disabilities is often poor and normal wheelchair use on its own is not sufficient exercise to maintain health and function.

I N D E P E N D E N C E

Independence was a key value to emerge from the narratives of participants with disabilities. Two female participants both identified driving as the potential key to regaining their independence. Both of the women felt that driving would help reduce their dependence on others when outside the home. For these individuals, the ability to drive and having access to their own car was seen as essential in order to maintain their independence. Family carers also prioritised facilitating and maintaining the independence of their disabled family members. Indeed their narratives revealed the strategies they employed to help the person they cared for to maintain a level of independence. Similarly, families caring for a disabled child were also looking towards future independence. Their narratives highlighted how fostering and maintaining independence in their child was a key priority.

Families with a disabled child felt this was best achieved through the choice of equipment their child could access. Similarly, professional carers spoke about how their work was geared towards facilitating and maintaining independence for their clients. Two professional carers, working in a residential facility, spoke about the training they provided for the residents to illustrate this. The training was geared towards the individual's goals and was aimed at facilitating independence both in and outside of the home.

Individuals with disabilities valued being independent, with a number of

them choosing equipment that would facilitate this. Indeed, one married couple, where both of whom were disabled, spoke with pride about the level of independence they had achieved. In contrast, other participants felt that they had lost their independence since becoming disabled, although they were hopeful it was something that they could regain again, with driving being central to this possibility.

SOCIAL IDENTITY

The narrative of an equipment provider recounted how he had assisted a family looking for a suitable wheelchair for their child; he describing how the powered wheelchair selection had facilitated the child's ability to become a football team member. Doing, being and becoming are all interlinked; they are core components of building a positive social identity. By identifying the equipment that would meet all the child's physical needs, the wheelchair provided the child with an opportunity for increased participation and engagement with his peers. Another family described the lengths they went to keep their child involved in the scouts, including hauling the wheelchair across fields using ropes so he could stay involved with the social activities of his peers.

These families' motivations bode well in terms of supporting their children to achieve a positive sense of self. Those that can maximise their quality of life through for example through wheelchair sports have been shown to be able to develop a strong sense of self, where the wheelchair as part of a of an integrated positive persona .

SECURITY

People with disabilities valued the security afforded by the Motability Scheme. They felt that the service looked after them; they appreciated feel safe and personally assured that all aspects of their needs would be promptly dealt with. When driving their car they felt secure and that was experienced as a very positive feeling.

RECOMMENDATIONS

Specialist equipment and mobility aids are experienced differently at different stages in life; successful acceptance and integration into an individual's lifestyle can be facilitated through the related improvements experienced in quality of life.

When designing equipment, wheelchairs and adapted cars, the feeling of normality needs to be maximised for the customer to embrace their use, while still ensuring a high level of functionality can be achieved.

Membership to a car club could be prescribed by a GP as a means to prevent loneliness, deduce social care dependency and maximise working capacity?

The combined option of a hybrid wheelchair that can be switched between manual and powered has the potential to promote health, maintain function and increase quality of life whilst reducing the effects of joint overuse. Although these are available on the market, the development of a lower cost version would be welcomed.

Self-management information on how customers can enhance their fitness and improve their transfer techniques could be offered at the stage of wheelchair leasing/purchase. These self-management packs could be developed in partnership with mobility experts and customers.

Consider extending the driving lessons service for young people to additionally cover newly disabled adults and older adult drivers. This could include habilitation (skill not learnt before) and/or rehabilitation (returning to previously learnt skill).

Lobby for driving assessment screening and referral to Mobility centres for driving rehabilitation to become part of mainstream NHS and local authority occupational therapy services; keeping disabled people driving saves money and improves quality of life.

EQUIPMENT & FACILITIES

APPEARANCE

“Someone rang up and said: I’ve got a newly disabled, young guy who has been here for 6 weeks who won’t go out with his scooter, because he doesn’t want to look like his grandmother. Are there any scooters that look like Vespers?” I said, “No, no such thing; there are no trendy scooters, they all look like mobility scooters.”

-Emma, 50
Disability Rights Advocate



ADAPTATION / PERSONALISATION

“Every time you change your shoes for whatever occasion, so you’re going to pub, you look lovely like that, you’re going to a wedding, you put on some sort of smart lacings perhaps, you go out for a run, you put on your trainers, you go into the countryside you put on your wellington boots. I don’t know. Think about how many pairs of shoes you’ve got in your closet, really and truthfully Jim needs to change his wheelchair for every one of those events because one doesn’t cover all.”

-Fiona, 53
Family carer



PUBLIC FACILITIES

“I think there’s a lot of parents that are like me who get very, very frustrated that they can’t change a child who’s doubly incontinent anywhere and you have to take towels and this that and the other to put on the floor and to change them anywhere, that is frustrating.”

-Gina, 44
Family Carer



TECHNOLOGY

“He’ll say: “I need to go to so and so ... I’ll just get it up on Google maps and it tells me the best way to get there on a bus,” or the best way to get there on a train and how long it’s going to take and what to change and things like that. He just uses technology for whatever he needs to do really.”

-Sarah, 42
Family Carer



EQUIPMENT & FACILITIES

Key Insights & Recommendations

APPEARANCE

The appearance of equipment, for use both in the home and outside was a central concern for individuals of all ages. It acted as a visual reminder of their difference and it influenced how people reacted to them. Some did not go out or would not take their equipment with them when they went out because they were embarrassed. The appearance of their equipment had an impact on their self identify and self esteem. The standard NHS wheelchair was very negatively perceived. The health professionals and researchers held similar views to those people with disabilities about the unattractive mainstream provision. Participants with disabilities wanted equipment and products that were mainstream, desirable, fun to use, and that did not make them feel different.

The service and equipment providers felt that there were new attractive products on the market and that aesthetically, equipment had improved in recent years. They were aware of those products coming on the market and were more optimistic about these ‘trendy’ and versatile products being developed. The Ogo wheelchair and Kenguru smartcar were cited as two such products.

PERSONALISATION

Individual requirements about what was deemed desirable or aesthetically pleasing changed across the life course. In general young people were not keen to use scooters as they felt these were for designed for older people, whereas older people preferred scooters to wheelchairs, as they did not want to be seen as disabled. The view from young people was that there were no trendy scooters on the market that would suit them although some were aware that Honda has made some progress in this design area. Participants also wanted wheelchairs that could be customised to their own taste that could be adapted for different purposes, and would allow them to participate in the lifestyle activities they enjoyed. They wanted to be seen for themselves, so people saw them as person, not them as a ‘wheelchair user’.

PUBLIC FACILITIES

Even when toilets were deemed accessible, the narratives of participants highlighted a range of issues including the lack of hygiene, the space being cluttered by bins and other items or handrails that were incorrectly located,

preventing some individuals from using the toilet. The baby changing facilities were too small for changing a child who was doubly incontinent and the parents or carers had to resort to laying them on the floor using towels, which they had brought with them.

Any mobility touch point needs be fit for purpose and public toilets seemed to be the main public facility of concern. For adults with disabilities, the toilets needed further improvement in terms of facilities and hygiene. Parents and carers considered their adapted car as an alternative changing facility; if the windows could be switched to black out or blinds closed and a changing kit designed for the boot of the car they would find that an effective space.

Other types of facilities were fit for purpose as long as the access was well designed. These issues are dealt with elsewhere under the topic of accessibility.

TECHNOLOGY

Technology was seen as a key factor in facilitating and maintaining independence. This was illustrated by a family with two older children, both of whom had a visual impairment. The family spoke about how smart technology in phones such as Google maps was helping their eldest child become independent of the family when out and about. Those using newly designed products welcomed the technology that had allowed such innovations as wheelchairs that could be adjusted from indoor to outdoor (by altering the camber of the wheels). Powered wheelchair users were keen to see lower cost longer life battery packs developed and driverless controls developed so that they did not have to use the control when on long outdoor journeys, particularly in cold weather when their hands would become too cold even when wearing gloves.

Researchers felt that the range of technology that was being developed was not shared sufficiently widely in clinical practice thereby limiting purchasers' choice of what was available.

RECOMMENDATIONS

Develop an online information stream to share attractive new product designs with customers

Explore opportunities for customers to test and review attractive new products as they come on the market

Invest in ‘trendy’ scooters for young people

Design a wheelchair that can be adapted for different types of lifestyle participation and presents the person not the wheelchair as the impact.

Consider creating or linking with a wheelchair rental club for off road/all terrain wheelchair use.

Develop a changing kit for use in the boot of a car.

Lobby for more wheelchair accessible toilets in public places and for hygiene standards to be improved.

Investigate potential for driverless powered wheelchairs and mobility scooters.

USABILITY

COMFORT & CONVENIENCE



“ The person in the wheelchair is always a little bit of a distance away from the driver and the passenger, so it’s quite difficult. I mean my little one can’t feed herself or give herself a drink or anything like that, so if you’re driving along and there’s two of you in the car, one of you leans back to give a drink and if they’re a distance away it’s very difficult to do that. ”

- Carol, 38
Family carer

FUNCTIONALITY

“ I’ve actually put one of them bike alarms on mine, so it’s almost like a mini siren, and also because the horn on the wheelchairs are rubbish. ”

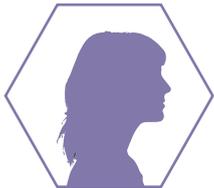
- William, 70
Powered wheelchair user



FUNCTIONALITY

“ We wouldn’t want to go back to a car with gears, so we’d need an automatic, but they don’t do that many automatics. There’s very few cars that come in automatic. But you have to put a certain amount there, up front, to have an automatic and it can be quite expensive. ”

- Julia, 51
Driver of adapted car



SEAMLESSNESS

“ I think I’d tell them to look at a few cars, try a few cars, have some adaptations as well, because you have the car for three years and things do change as the years go by, you need to make sure really that that car is going to be suitable for you for the next three years. So I’d tell somebody to look at the car and see how that feels, drive the car and look at it from the point of view is it going to be alright for me in two years, three years’ time? Is it going to have everything I want then if my condition or whatever it is deteriorates. ”

- Kathryn, 50
Driver of adapted car



SIZE, CAPACITY & EFFICIENCY

“ With my wife and I both being disabled, and both using walking frames now, we also need a boot that’s big enough to carry two of them without needing the car lift. ”

- Norman, 71
Driver of adapted car



EFFICIENCY

“ You’d need some kind of fairly robust off-road scooter and I’m not exactly a little guy either. I’m 16, 17 stone at least and that would mean I’d need something certainly with a reasonable amount of power that would get you up the hills. ”

- John, 37
Driver of adapted car



USABILITY

Key Insights & Recommendations

COMFORT AND CONVENIENCE

Ease of access into the car for wheelchairs and scooters was a usability criterion for some individuals which could introduce difficulties in terms of comfort and convenience of use. Some individuals cited regret at changes to vehicle design which meant the loss of a flat rear boot deck, which made lifting heavy equipment into the rear of a vehicle over a lip was difficult for some individuals. [needs more quotes and an expanded discussion]

FUNCTIONALITY

Functionality and usefulness of equipment and services on offer was one core consideration not only for individuals with disabilities but also for their families, professional working with them, and also equipment providers. Participants' narratives revealed that for an equipment to meet their daily needs it had to be 'multifunctional', 'adaptable', 'space saving', 'lightweight' and 'robust'. Such qualities become specifically key for mobility equipment where the nature of the activities implies constant change in the equipment's immediate environment and therefore demands a greater level of flexibility and multifunctionality (e.g. from home to car to public spaces). Some participants particularly wanted lightweight equipment that was suitable for travelling. Holiday was one specific scenario where difficulties with transporting and use of the equipment needed was regularly reported. This is interesting considering the leisurely nature of this scenario where individuals would naturally expect comfort and relaxation as an inherent part of their holiday experience.

SEAMLESSNESS

Frequently people reported making compromises in terms of the equipment or vehicle they used, this was particularly the case where the individuals conditions and needs had changed since acquiring their equipment or vehicle. This change in conditions and therefore needs could be rather common and needs certain level of flexibility and seamlessness when going through either scenarios of deterioration or rehabilitation. In many cases such changes were unavoidable and to certain extent unpredicted as individuals were not aware of the full extent and implications of changes and new physical or cognitive challenges they might face. One example was an individual who had a back operation and found driving in their Motability car extremely uncomfortable due to their new post-operation physical state but was unable to change their car due to the three year lease. For this woman, surgery had resulted

in her vehicle no longer meeting her needs due to increased pain. She had approached her local dealer and had been told she was unable to change the vehicle, leaving her no option but to compromise and leave her car standing and let her daughter do the driving. This not only increased the woman's level of dependence, it also meant that she was paying for a vehicle that was now effectively unusable.

Other participants also reported having to compromise on their choice of vehicle, balancing their need for a WAV vehicle with the need for day to day practicality. This frequently meant having a smaller vehicle than was practical for a wheelchair driver in order to have a large enough boot space for shopping and luggage.

SIZE, CAPACITY AND EFFICIENCY

The issues of size and capacity are two interrelated topics representing another key element of usability and mentioned by various groups of participants. Size and capacity impose an inherent challenge in the design of various mobility equipment and services. It could be argued that plus size trend is more strongly represented within the disability community, partially due to inherent difficulties with keeping physically active. This results in the increased size of certain disability equipment making them bigger and bulkier, having a knock on effect on storage and capacity issues making mobility equipment practically unfit for use in certain environments. In many cases participants mentioned issues with limited storage space and capacity of their vehicles while also referring to their vehicles as already rather big and bulky. As already discussed, some wheelchair adapted vehicles posed challenges in terms of usability in towns and cities in relation to parking.

This was also reflected in the narratives of a mobility researcher and also an occupational therapist who noted that scooters can be a challenge not just in terms of storage but that they also have to be practical to use on a daily basis in public spaces where width of pavement and size of shops and pathways could have a major impact on if and how a mobility equipment gets used on a day to day basis. One key issue raised here was lack of clarity and information on such barriers at point of purchase suggesting a successful purchase did not necessarily lead to successful day to day use of an item but to rather limited use due to issues of size, space and capacity.

RECOMMENDATIONS

Potential for the service to offer more flexibility in terms of responding to the users' changing conditions and access needs giving a chance to renew and adapt the leased car within the three year period

Introducing a line of products and accessories improving comfort and convenience of use in Motability's range of vehicles and equipment in order to help users further personalise and adapt their mobility equipment and give them further support

Develop a range of portable home-use solutions that could be used in various similar environments such as hotels and various short or long stay scenarios.

INCLUSIVITY

PHYSICAL ACCESS



“ I find most access needs are about space at the end of the day and like all disabled people I am the least disabled when I am at home yes because that is the environment that I control and it is as near as possible it is ideal for me. ”

-Mike, 41
Disabled Mobility Equipment Provider

PHYSICAL ACCESS

“ Because of the Wheelchair Accessible Vehicle we have got currently, we are having to terminate our contract early. The one thing I hadn't realised was that where we are, and I can fully understand why the council do it, they've got height restrictive barriers on car parks, especially car parks that are next to beaches, because they don't want travellers and holiday homes parking over night or for days; it would be nice if Motability could have more vehicles that are under two metres high. ”

-Sian, 37
Passenger with disability



SOCIAL INCLUSION



“ Ever since I've been able to drive I just love it. It's one of those few times when I feel I'm on a level playing field with everybody else because if I'm sat in my car on the road, on the motorway or wherever, there's no external indication that I have a disability or anything. I'm just another road user. ”

-Keith, 58
Driver of adapted car

SOCIAL INCLUSION

“ It's also really challenging if me and Jacob go anywhere together and in particular somewhere like London. With cabs they won't take two wheelchair users a lot of the time, kind of by law they don't take two wheelchair users but some will let you on. ”

-Sarah, 39
Driver of adapted car



PSYCHOLOGICAL INCLUSION



“ If I plan my journey they're very helpful. But if I wanted to go on the spur of the moment it varies as to whether I get enough help. I was once at East Croydon Station stuck on the train waiting for the ramp and the train nearly pulled away with me still on it. ”

-Magda, 34
Driver of adapted car

INCLUSIVITY

Key Insights & Recommendations

PHYSICAL ACCESS

Physical access and accessibility were key issues highlighted in the narratives of the participants with disabilities. Their narratives revealed the wide range of equipment and adaptations being used by individuals on a daily basis to keep them as mobile as possible, and give them access and control. The analysis indicated that for the majority of participants with disabilities the home environment was less challenging than the external environment. Regardless of the extent to which the individual had chosen to have their home adapted to meet their needs, participants felt that access within their home was within their control. The element of ‘control’ or lack of it, was a main factor affecting accessibility and differentiating between the home and external environment; making the home where the individual felt “least disabled”, while once they “leave the front door” physical access became a major daily life concern.

Interestingly and in line with the above, most notions of physical access referred to external environments. These environments could be grouped under two main categories; mobility services environments and other services environments. Car parks, taxis, planes and public transport (specifically buses and train) were the relevant mobility environments and services where participants reported most physical access concerns. Shops and local amenities, hotels and public toilets were the other service environments most commonly mentioned in regard to physical accessibility issues. Access to shops and public buildings was identified by individuals across stakeholder groups as being particularly problematic. In both categories, these physical access issues had a detrimental impact on the individual’s day to day life activities, choices and planning and their overall quality of life. In some cases, the level and complexity of physical access challenges associated with a service environment was perceived so high, the individuals had made the decision to totally disengage and not use that service. In some other cases, participants mentioned their day to day struggle resulting in dissatisfactory experience.

In both mobility environment and other service environments, ‘space’ considerations played a key role in providing physical access resulting in a satisfactory or a failed experience. Height was a more specific issue mentioned in some cases people reported.

The analysis also revealed differing attitudes to the use of equipment within the home environment, with some participants choosing to use the range of equipment on offer to help them get around the home. In contrast, other participants with disabilities had chosen to minimise the amount of adaptations

and equipment they used in the home environment. The reasons for this choice were complex, and related to the individual's personal preferences, some individuals expressed a preference to live life as 'normally' as possible, while other individuals expressed a wish to maintain their level of fitness. They felt this was best achieved by limiting the equipment used or by splitting their time between a manual and powered wheelchair. The appearance of equipment also influenced individual decision making processes regarding the use of equipment. Some individuals had made a conscious decision not to use the equipment on offer because they perceived it to be aesthetically displeasing. These issues will be explored in more depth in relation to the corresponding themes. The nature of the housing was also a major factor in the accessibility of the home. This was illustrated by an Occupational Therapist who spoke about her experience working in the community and the difficulties she encountered adapting older properties.

Even where homes had been adapted, participants noted that some challenges remained. Areas identified as remaining difficult included the height of furniture and toilets which made transferring difficult, access issues in narrow corridors and hallways and accessibility in kitchens remained a significant issue for a number of individuals. Space was also highlighted as a factor that could impact negatively on access and accessibility with the home. This was particularly relevant for individuals who used a wheelchair within the home, as the lack of space had a negative impact on turning circles and manoeuvrability, as illustrated by a female wheelchair user.

The lack of a consistent standard in terms of 'accessibility' in holiday accommodation prevented some people from going on holiday while others noted that it was stressful because they weren't sure until they arrived whether their specific needs were going to be met. It was also found that some holiday providers would not confirm the availability of accessible rooms until a booking had been made.

SOCIAL INCLUSION

Accessibility of a certain equipment, service or environment is not only dependent on physical access to it, but also based on its perceived social inclusivity. While physical access plays a fundamental role in whether people with disability can engage in a certain activity or not, the social connotations and implications of an activity also play a major role in the quality of the

experience and the individual's willingness to engage with an activity. The narratives of participants with disabilities and both family and professional carers' indicated that people with disabilities faced social exclusion and negative attitudes in their everyday life. Their narratives recall experiences of abuse, being laughed at and mocked or being discriminated against in terms of the provision of services. Participants felt strongly that this negative attitude was evident in the lack of consideration shown to disabled people by individuals parking in disabled bays, over drop kerbs and on pavements. As well as in the more explicit actions and responses to disabled people in the community. In such cases, the key reasons behind individuals with disability's decision regarding engaging with a task was the social inclusion rather than physical access. In both cases, whether the individual dismissed the experience altogether due to such social barriers, or went through a stressful and unpleasant experience, the lived experience was far from ideal, desirable and equal.

The root causes to this were mentioned as lack of understanding, awareness and empathy and misinformed and negative perceptions of disability. This is specifically noticeable in cases where an individual's multi-faceted, complex disability was and not necessarily visible or noticeable in the first sight as most people seem to judge a person with disability's level of 'entitlement' to care, support and empathy based on the first visual judgement. It was felt that media representations of disabled people were contributing to the negative attitude, with disabled people being portrayed as 'scroungers.' In contrast, some individuals felt that attitudes towards disability had changed for the better, compared to those in previous generations.

The enabling role of well designed and suited mobility solutions could go beyond physical access and have a major impact on social inclusion and participation of an individual with disability. This was well reflected in the narrative of an equipment provider who recounted how he had assisted a family looking for a suitable wheelchair for their child. By identifying the equipment that would meet all the child's physical needs, it had also provided the child with an opportunity for increased participation. Increasing the opportunity for the child to engage with his peers and participate in sporting activities. This not only gave him a sense of normality, both in and out of school, it also enabled him to be independent of adults

PSYCHOLOGICAL INCLUSION

As already noted, issues of accessibility and inclusivity go beyond mere physical access. This not only depends on the level of social acceptance and engagement but also on an individual's perceived psychological suitability and fitness to engage with a task or activity; including their emotional and mental state and their assessment of psychological barriers and difficulties they might face. Within current mobility experiences, there are examples where tasks and activities incur a considerable amount of stress, anxiety and lack of clarity on an individual, psychologically discouraging or excluding them from engaging with an activity. One individual for example mentioned how they needed to plan in advance for their transport to make sure they will receive the support they needed at the train station while if they wanted to 'go on the spur of the moment' there would be no guarantee they could get enough help. The individual then went further ahead to mention one occasion where they were stuck on a train at a station, waiting for the ramp while the train nearly pulled away with them still on board.

RECOMMENDATIONS

Develop a range of portable home-use solutions that could be used in various similar environments such as hotels and various short or long stay scenarios. Develop a set of psychosocial inclusivity metrics in order to ensure customers receive full support and care at every stage and ensure Motability's range of products and services are not only physically accessible but also psychosocially inclusive

TRUST, SUPPORT & SERVICES

SERVICE SUPPORT

“ If I go into a car showroom, I have to buy the car, pay £500 to get the hand controls and then drive it to see if I like it. So I don't actually get much choice in it. I get to choose whether I can transfer in and out of the car and I can sit beside someone else as they drive it but I don't get the same choice as everybody else. ”

- Rupinder, 45
Driver of adapted car



MOBILITY SUPPORT

“ From the point of view of practicality and mobility, I like the fact that I know if there's any problems with the car I can phone up the mobility assistance and they will get to you as soon as they possibly can and they will prioritise you because you have got a disable person in the car, so that takes one worry away, that I know that whatever happens, if we have an issue with the vehicle they will take care of that and take care of us. Everything is under one roof and you just have to speak to one person. So a bonus really having it all like a one stop shop basically. ”

- Marilyn, 35
Family Carer



INFORMATION

“ I think people are coming up with loads of things every day really, like coming to this I've already seen a few things that people have already come up with which is amazing. I'm a physio myself and I think you only know what's out there when you go to see it for yourself because even as a professional you only know what you've seen already. ”

- Ella, 26



PUBLIC SERVICE

“ They don't get charged any extra, they still get charged the normal rate like you do with an ordinary customer, but they always take about fifteen minutes extra to deal with those type of customers. ”

- Paul, 70
Driver of adapted car



FAMILY SUPPORT

“ I rely on my daughter for a lot of things. Say like if I need to go to the shops or anywhere she will take us. ”

- Karina, 59
Driver of adapted car



TRUST, SUPPORT & SERVICES

SERVICES SUPPORT

Support from other services such as hotels, airports and supermarkets or lack of it, was seen as an integral element which in some cases resulted in extremely negative or positive experiences and seemed to have a fundamental impact on decisions regarding future engagement with the service. For example, in some cases individuals reported their disappointment with hotel services where claims regarding accessibility were made but in reality only elements of service were accessible while it was branded and confirmed as a fully accessible service. The level of support offered and the service provider's attitudes became absolutely key in such cases as some individuals seemed to be more forgiving towards lack of full access but expected better support and courtesy to acknowledge and compensate for such shortcomings. One person with disability mentioned in cases like this after discussing physical access issues in a hotel the response might be something like "Well we have had other disabled people here and they don't complain", which he did not appreciate.

INFORMATION

As previously noted, lack of information underpinned a number of the themes and subthemes. Lack of information posed a barrier in relation to Motability, but it was also a barrier in terms of selection and use of equipment and services, and usability and inclusivity of an individual's mobility experience. The lack of information was highlighted by all stakeholder groups such as individuals with disability, family carers and also researchers and equipment providers.

In some cases this information was directly related to new equipment and devices or options available in regards to their adaptation. For example, one family carer who also worked as a professional physiotherapist mentioned difficulty with keeping up to date with latest available equipment and adaptations and mentioned as a professional she would only know about things she would have seen already, implying that up to date information relating to equipment is also not filtering through to professionals. This suggests that information is difficult to find or is not readily available. Such narratives could indicate a lack of accurate up to date information available for people with disabilities and their carers.

Another issue was in regards to provision of up to date information not only about equipment itself but regarding various stages and aspects of engaging in an activity or using a service such as information on accessibility of public buildings and spaces. In most cases some sort of planning and physical or

psychological preparation was needed in order to finish an activity successfully and pleasantly, and participants suggested better more accurate and up to date information provision would reduce the level of stress and concern in unfamiliar areas and situations improving the quality of such experiences and also social participation.

Credibility of information was another issue beyond availability and clarity of information on existing equipment and services and their implications on day to day life procedures. One equipment provider suggested this was due to rather small number of professionals who work in media and generate content about products in this specific sector, as major marketing and design agencies tend to work out of the sector, so this resulted in very few credible sources of information. Undoubtedly, there will be some individuals with disabilities who will have the personal resources and family support to enable them to access the required information, yet others lack those skill and appear to fall through the net.

PUBLIC SERVICE

While physical accessibility of public services has been the focus of improvements, there are other aspects of the public services which were brought up as an indicator of disability. For example one individual with disability mentioned how they would not get charged extra on public transport and would pay the normal rate like an ordinary customer but how it always took about fifteen minutes extra for the staff to deal with them as a specific type of customer. Others mentioned they not only appreciated the effort in public spaces to improve the accessibility but also appreciated when public services promoted the fact that they had improved access, published the information on the website or invested in staff training.

FAMILY SUPPORT

Family support was commonly brought up by participants where elements of trust, reliability and interdependence were high. Individuals with disability referred to the support they receive from their family in rather strong ways, either perceiving it as a very positive thing, or perceiving themselves as a burden and wishing they could reduce their dependence.

Either way, the issues of dependence and interdependence and reliability

seemed to play a key role in the extent to which an individual actively asked for support from family. This also heavily depended on practicality issues and if access to such support was available. Support received from family could both in regards to day to day physical activities and could also be psychological and moral support.

RECOMMENDATIONS

Promote accessibility and inclusivity as an element of corporate social responsibility, offering an improved brand image

Consider running an ‘inclusivity/accessibility’ accreditation scheme for hotels, flights and a range of other relevant services which have a strong link with transport services

Consider a Motability crowd sourcing platform to facilitate stakeholders’ continued contributions to the development of future priorities for research and development

FINANCE

EQUIPMENT COSTS



“ Brad loves outdoor life, off road life. We can't afford an off road wheelchair. We now live on his pension and I think I get £60 a week for caring for him, so there is nothing surplus for all the lovely stuff out there. ”

- Maria, 38
Family Carer

FINANCIAL SUPPORT

“ He's got a manual wheelchair, we fund raised for that. So what wheelchair services provide is good but actually when you see a lot of the equipment here and you have got a young son who wants stuff, it's like 'well, how you going to get that?' so again time scale is a big factor. So putting my organisational hat on, I tell parents that if they are looking at fund raising then you really need to look at that twelve months ahead. ”

- John, 36
Mobility Equipment provider & family carer



GOVERNMENT SUPPORT



“ Government cuts are going to make a big difference, because I can walk 20 meters with a stick I will probably lose my car. And I'm very frightened and I'm not the only one. So I think that is going to make -it's already making - a lot of people more isolated and it is such a shame. Because I will probably get middle rate mobility hit, that will pay for a couple of taxi rides. So it will change my life a great deal and I'm scared. ”

- Emma, 32
Driver of adapted car

SERVICE SUPPORT

“ I think the average Motability customer has an income of less than £20,000 a year. So if you're going to start changing £20,000 for a wheelchair they're just not going to be able to afford it and what we should be doing is getting this technology down in price and we should price it properly so that people can afford it. ”

- Geoff, 64
Motability Governor



SERVICE COSTS



“ For me, I'd like to see kind of a better quality wheelchair that is cheap, because I think one of the problems is wheelchairs are getting really nice but they're still very expensive. ”

- Pat, 53
Driver of adapted car

EXTRA COSTS

“ No it's really the cost. The majority of the transaction is in terms of the additional cost. The person's allowance tends to be up to £1,000 whereas that particular adaptation could be significantly more. A lot of the work that I get involved in in terms of the modifications to the car is that it's an additional cost, I mean it's not built into the cost of the car. So some people feel like they're being penalised and I think that's a constant challenge because in reality, if you have a disability that dictates that, it is a little bit unfair that you should have to pay a premium. ”

- Tim, 39
Automotive Company



FINANCE

Key Insights & Recommendations

EQUIPMENT COSTS

Many participants identified cost as the single most influential factor in choosing equipment to support their mobility needs. Many were not able to afford the equipment they wanted to purchase. One participant indicated that her former ‘action man’ husband wished to continue numerous outdoor activities; she felt this could have been possible had he been able to afford the necessary equipment needed to access the outdoor terrain.

FINANCIAL SUPPORT

Some parents found equipment so prohibitive expensive that they had turned to fundraising or applying for charitable grants. It was generally acknowledged that individuals’ financial circumstances were the key determinant as to whether they could access the equipment they required.

GOVERNMENT SUPPORT

Despite many participants being severely disabled and currently eligible for the mobility component under their Disabled Living Allowance, implicit in their narratives was a lack of faith in the assessment process for Personal Independent Payments. It was evident that participants felt that they may lose their benefits and were deeply fearful of that happening. Some participants were attempting to make financial provision for the future so that they could continue to own a car.

SERVICE SUPPORT

For many participants, Motability was seen as an affordable way of gaining independence and they wished they had joined the scheme earlier. The narratives of some participants indicated that there was some lack of awareness with regard to eligibility to the scheme. This is illustrated by a representative of an automotive company who had informed a mother that she could apply to the mobility scheme on behalf of her child with disabilities even though he child was under 16. The mother had not been aware she was eligible. Others had hoped to be eligible but because of they had become disabled after they retired, they did not think they were able to use the Motability Scheme.

Some participants felt that their ability to chose a car through the scheme was limited because they had to pay to adapt the vehicle before they could test drive it, or alternatively they had to be a passenger while someone else test drove the car. They felt this arrangement constrained the ability to make an informed choice.

Others felt the choice of vehicles was too limited. For example a family carer with a disabled child felt that her choices were constrained by the limited range of WAV vehicles. This family needed a vehicle of a specific size; to meet the everyday mobility needs of the whole family, as well as those of the disabled child. Others wished there was a wider range of automatic cars from which to choose. Those who wished to have a more expensive car than those offered by Motability did not want to have to change it every three years. They sometimes looked to buy a second hand sports car or top of the range car in preference and to have that adapted for the longer term.

SERVICE COSTS AND EXTRA COSTS

Some of the reasons for not using the Motability Scheme were the costs related to mileage or the costs of adaptations to the vehicle. For individuals requiring an adapted vehicle, the large deposits required on WAV vehicles or vehicles with automatic transmission, represented a significant financial barrier. Participants highlighted the high cost of having to adapt vehicles. Key adaptations highlighted in participant narratives, included the cost of replacing hoists and hand controls every few years. They felt penalised by the system for having to fund the cost related to their disability needs. One family carer had previously been a Motability customer, but had been fearful of using the vehicle because she was financially responsible for any damage. This fear of causing damage meant that she was unable to use the car in the way she would have chosen, such as taking the family dogs out in the car.

RECOMMENDATIONS

Increase awareness of eligibility of the Motability scheme e.g. parents of young children with disabilities

Consider funding car adaptations as part of the Motability package

Consider funding more expensive cars for longer lease periods

METHOD

In the Delphi survey solutions (n=22) related to future research priorities were presented to participants who had indicated an interest in taking part in online questionnaires in the form of a Delphi survey²⁴. The survey was administered by Cardiff University under its confidential and anonymous Bristol Online Survey System. A Delphi is usually conducted via at least three rounds of survey iterations in which participants firstly rate a statement on a Likert scale²⁵ and are then invited to comment on their rating. The purpose of a Delphi survey is to encourage consensus in a group of experts.

Its first iteration is normally an open ended discussion or questionnaire completed by those who are deemed to be expert in the topic. In the case of this project, the first iteration, used data analysed from interviews; it was carried out with participants who could be regarded as experts in the field of mobility and disability. The 22 items were identified and transformed into clear statements of research intent and then three questionnaires were issued for rating of the topics to 55 participants who had previously agreed to be contacted by email after they had been initially interviewed. A four point Likert scale was used as the rating scale in order to avoid a mid-point and encourage consensus on the items being rated. In addition, participants were encouraged to comment on their rating of the research priority. These anonymous comments were added to the percentage rating for each rating on the Likert scale when each subsequent Delphi round was returned for future rating.

²⁴ Hsu CC and Sandford B.A. 2007 *The Delphi Technique: Making Sense of Consensus. Practical Research and Assessment Online journal* available at <http://pareonline.net/pdf/v12n10.pdf> accessed on 12/10/15
NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012.

²⁵ Hayes BE 2008. *Measuring customer satisfaction + Loyalty: Survey design, use + statistical analysis methods.* ASQ Quality Press, Milwaukee, Wisconsin, USA

DELPHI RESEARCH PRIORITY STATEMENTS

Create an App that will tell you where the nearest available and empty disabled parking space is.
Advance the availability of driverless cars for disabled people
Develop an audio announcement system for public transport to say which bus or train is arriving (e.g. bus number/train destination)
Develop a modular system for prosthetics to enable them to be easily altered to suit different environments by the user
Develop a sensor to alert people when they park too close to disabled vehicles
Develop an automated system for guiding wheelchairs into and out of vehicles (e.g. up ramps)
Develop hover technology for wheelchairs
Create an automatic bike rack that lifts bikes onto the vehicle like the ones available for wheelchairs
Create a folding walker to attach to a mobility scooter
Create better designed and finished wheelchairs that make the disability less noticeable
Create a lift capable of taking wheelchair and the person into a vehicle
Create lighter more easily transportable mobility equipment (e.g. for taking on holiday)
Create one wheelchair that can be controlled manually or electrically to avoid having two wheelchairs
Create a wheelchair that enable the individual to change position easily
Create a new mechanism for controlling wheelchairs (e.g. using the body similar to Segway or programmable to self-steer)
Develop improved mechanisms for opening car doors easily
Develop an in car hoist for lifting things in and out of vehicle (i.e. luggage and shopping)
Develop an in car mobile changing station for personal care for both adults and children
Enable the placing of more grab handles located in vehicles to ease access
Develop a moulded body positioning system for the car seat
Develop vehicle adaptations that are easy to operate and user friendly
Encourage better facilities for personal care on flights

THE DELPHI SURVEY: RESULTS & DISCUSSION

55 participants had expressed an interest in participating in the Delphi survey and had provided email addresses. However, on sending out the invitation to participate in the survey, 12 were unusable email addresses and 4 participants asked to be removed from the list, due to unforeseen alternative commitments. Thus 37 participants remained within the survey population. The responses for all three rounds of the survey were:

Round one: 18 responses (49%)

Round two: 13 responses (35%)

Round three: 17 responses (46%)

This constitutes an above average response²⁶ to an online survey per population eligible. Each participant rated each statement in terms of agreement.

The results will be reported based on the final survey (survey three) which was the culmination of the previous Delphi iterations. Throughout the survey there were sometimes conflicting views and by survey three some of those remained, but on the whole the level of agreement as to the usefulness or otherwise of the research priorities were consensual. Nine solutions were identified as top priority.

For details of these additional lists of those statements with low or no agreement (see Appendix N).

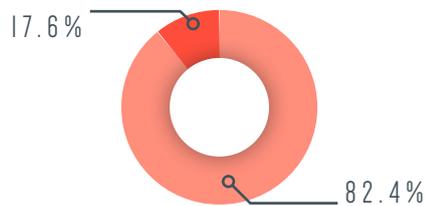
Research priorities which were highly popular with respondents:

²⁶ Dalkey N 1969 *The Delphi Method: An Experimental Study of Group Opinion*. Santa Monica Rand Fluid surveys 2015 available at: <http://fluidsurveys.com/university/response-rate-statistics-online-surveys-aiming/> accessed on 12.10.15

RESEARCH PRIORITY RATING SCALE USED IN THE DELPHI SURVEY

Rating scale #1	Rating scale #2	Rating scale #3	Rating scale #4
Definitely Agree	Mostly Agree	Mostly Disagree	Definitely Disagree
●	●	●	●

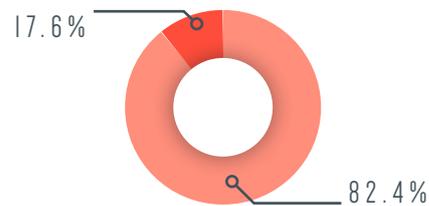
CREATE A WHEELCHAIR THAT ENABLES THE INDIVIDUAL TO CHANGE POSITION EASILY



“Some people need to shift to enable to be more comfy”

“More comfortable less pressure sores”

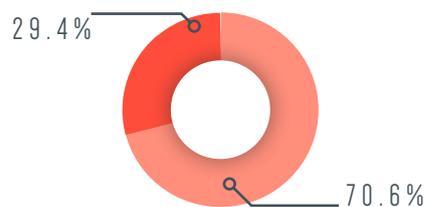
CREATE LIGHTER MORE EASILY TRANSPORTABLE MOBILITY Equipment (eg. FOR TAKING ON HOLIDAY)



“As long as the equipment was with strong & sturdy”

“Good idea”

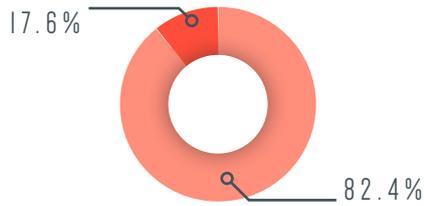
DEVELOP A MODULAR SYSTEM FOR PROSTHETICS TO ENABLE THEM TO BE EASILY ALTERED TO SUIT DIFFERENT ENVIRONMENTS BY THE USER



Easier to replace bits”

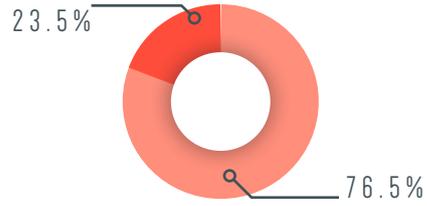
What a wonderful idea

DEVELOP WHEELCHAIR ADAPTATIONS THAT ARE EASY TO OPERATE & USER FRIENDLY



“ More disabled would be able to drive ”

DEVELOP IMPROVED MECHANISMS FOR OPENING CAR DOORS EASILY



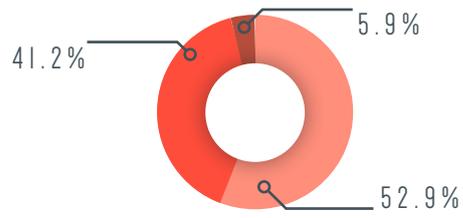
“ Good idea as it would help more so for closing as it would help not to reach for a handle ”

ENABLE THE PLACING OF MORE GRAB HANDLES IN VEHICLES TO EASE ACCESS



Always welcome make me feel safer

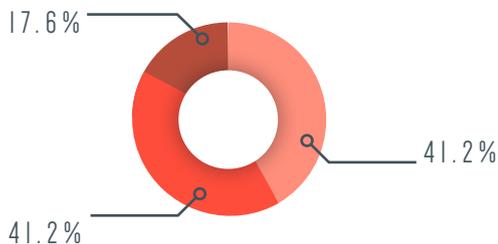
DEVELOP AN AUDIO ANNOUNCEMENT SYSTEM FOR PUBLIC TRANSPORT TO SAY WHICH BUS OR TRAIN IS ARRIVING (eg BUS NUMBER/ TRAIN DESTINATION)



“ Needs to be visual as well for deaf ”

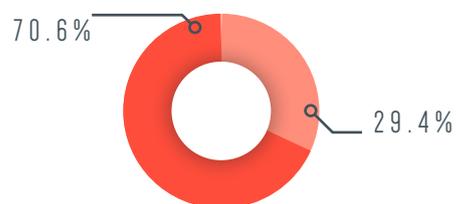
“ This would be helpful for people with poor sight ”

CREATE AN APP THAT WILL TELL YOU WHERE THE NEAREST AVAILABLE & EMPTY DISABLED PARKING SPACE IS



“ Being able to find disabled parking in a strange place would be a great help ”

DEVELOP AN IN CAR HOIST FOR LIFTING THINGS IN AND OUT OF VEHICLE (I.E. luggage and shopping)



“ Anything that helps prevent back injuries are welcome ”

PRIORITISED WISH LIST

The potential solutions to mobility challenges which emerged from the interview data analysis were prioritised by 37 of the original participants via an online Delphi survey.

The top nine priorities that emerged from the survey were:

- 01 Create a wheelchair that enables the individual to change position easily
- 02 Create lighter more easily transportable mobility equipment (e.g. for taking on holiday)
- 03 Develop vehicle adaptations that are easy to operate and user friendly
- 04 Develop improved mechanisms for opening car doors easily
- 05 Develop a modular system for prosthetics to enable them to be easily altered to suit different environments by the user
- 06 Place more grab handles in vehicles to ease access
- 07 Develop an audio announcement system for public transport to say which bus or train is arriving (e.g. bus number/train destination)
- 08 Create an App that will tell you where to find the nearest available and empty disabled parking space
- 09 Develop an in car hoist for lifting things in and out of vehicle (i.e. luggage and shopping)

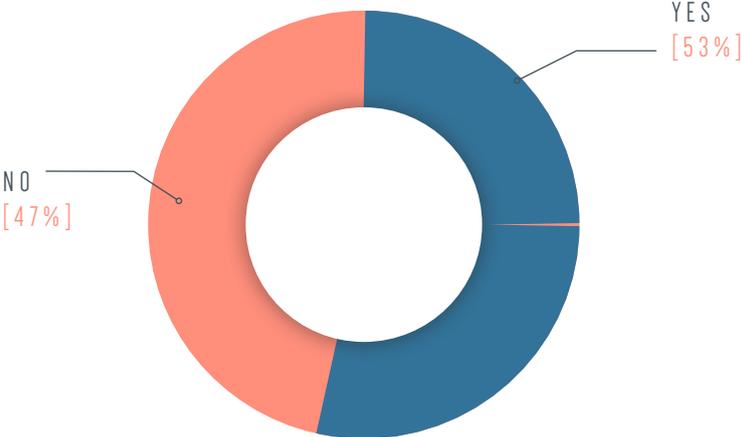
CAR CLUB CONCLUSIONS

COMMENCEMENT OF A MOBILITY CAR CLUB SCHEME

We interviewed 34 stakeholders and asked three questions :

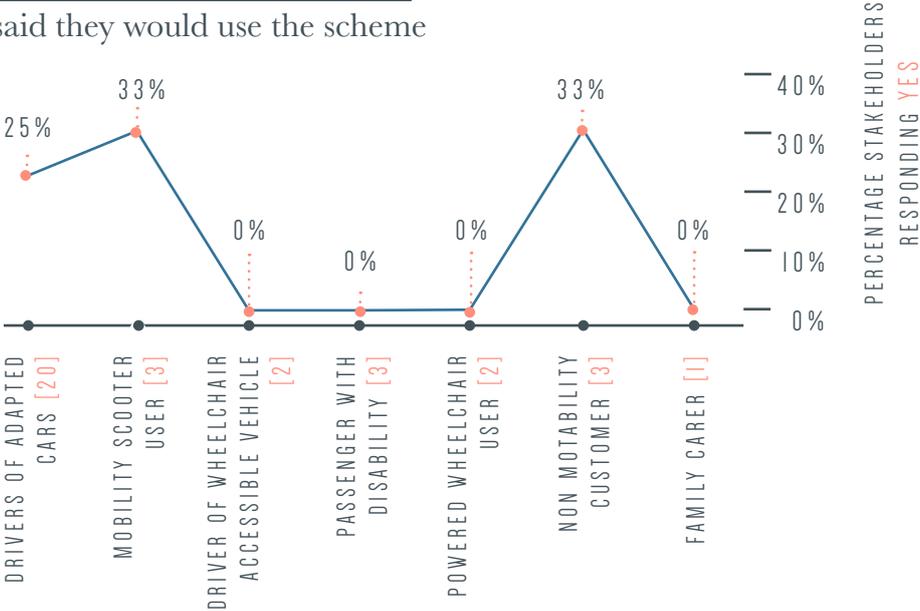
01 DO YOU THINK A CAR CLUB SCHEME IS A GOOD IDEA?

53% said they thought the scheme was a good idea.



02 WOULD YOU USE THE SCHEME?

24% said they would use the scheme



03 WHAT ARE THE ADVANTAGES/DISADVANTAGES OF SUCH A SCHEME?



“ I could spend the money I save on other mobility services ”

“ Useful if I don't qualify for a full vehicle ”



“ I doubt the shared car would have personalised hand controls ”

“ I like to know the car is there even if I don't use it. It is a symbol of my independence ”

“ I may need a car in an emergency ”

“ I use the car too often ”

QUERIES RAISED BY STAKEHOLDERS

- How would I access the car if I live in a remote area?
- Could it be brought to the house?
- Would it have the adaptations I need?
- Would the number of rentals be unlimited?
- Can I have money back on days when not needed?

SUMMARY

53% of participants interviewed were in favour of Motability providing a car club scheme. The main advantages were seen as being the possibility of saving money, thereby allowing them to pay for other means of transport. Participants were particularly in favour of the scheme if they did not use their own car that often. However some participants, who were in favour of a car club scheme currently felt they used their own car too often and therefore would not use the scheme personally. Consequently, only 24% of participants said the car club scheme is something they would use personally. It would be more valuable for this question to be posed to those who are not currently using the Motability Scheme as they may be more likely to be keen to take up this lower cost, flexible service. Some queries raised by stakeholders would be important to consider before a larger survey is conducted.

05 GUIDANCE REGARDING THE USE OF THE INFORMATION PROVIDED IN THIS REPORT

The findings summarised in this report are the result of a substantial multi-month research activity involving a relatively large number of disciplines, investigators and interested participants. As such, both the qualitative and quantitative characteristics of the data set are complex and deployable in several different manners depending on the aims and objectives of the reader. This section wishes to provide a brief exposition of the anticipated uses which can be made of the data.

STRATEGY, POLICY AND DISRUPTIVE INNOVATION

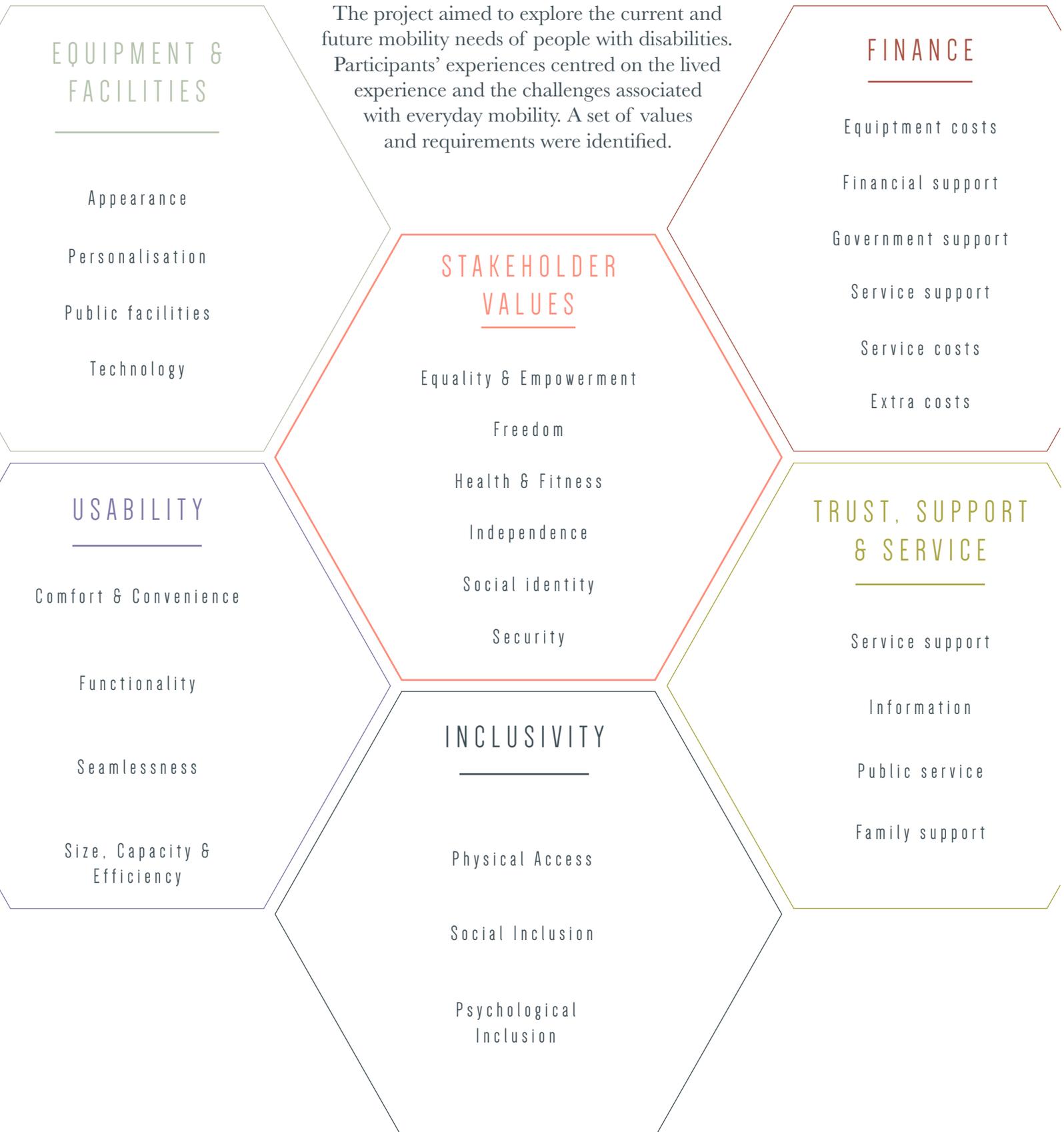
The principle result of the research investigation is a framework of values, and requirements practical recommendations which provides a strategic framework for describing the human desires and the human needs associated with mobility. The values at the centre of the framework can be considered to be the higher order social, ethical and spiritual aspects which are sought from the mobility support provision, regardless of its nature or source. The five requirements which are placed around the inner values in the framework can be considered the detailed manifestations and required of any product, system or service which will achieve the desired values.

It is recommended that the framework be considered a self-contained and relatively complete system for analysing mobility solutions, and thus a basis for strategy, policy or disruptive innovation decision making. Such frameworks of values and thematic characteristics are in common use in many business settings and are considered to be a relatively standard design tool. Traditional uses of such frameworks include:

- as a checklist against which to judge the compliance and completeness of proposed new initiatives (in this role the logic is additive, i.e. the more thematic characteristics which a new product, system or service achieves the more likely will be its commercial success)
- as a property discriminator which can be used to achieve design proposals which address individual, or a small number, of thematic characteristics (in this role the logic is subtractive, i.e. specific designs or business proposals are tendered with the objective of optimising a single or a small number of thematic characteristics)
- as a rating scale which can be used to compare and contrast opportunities

(in this role the logic is spectral, i.e. the placement of any new product, system or service is quantified in terms of the number and type of individual thematic characteristic which it is anticipated to achieve.

VALUES & REQUIREMENTS FRAMEWORK



ISSUES, OPPORTUNITIES AND INCREMENTAL INNOVATION

A secondary but valuable result of this research investigation is the relatively large number of short-to-medium term opportunities which have been summarised by means of the Prioritised Wish List. The list of opportunities was collated by means of the systematic reduction of the large mass of participant statements via a selection process based on the following logical criteria:

- is the explicitly or implicitly suggested innovation representative of the identified and tested thematic characteristic?
- is the explicitly or implicitly suggested innovation currently uncatered for or only partially catered for by the service provision?
- is there an obvious novelty or innovation involved?

The innovations which have been collated in this report thus represent a realistic “wish list” of possibilities provided by the stakeholders at the current point in time. The innovations cover a wide range of possibilities, with the statistical centre of gravity of the distribution being in the shorter term rather than the longer term. It is suggested that each recommendation be judged by Motability based on the Motability Board’s existing development plan and/or list of priorities.

PRIORITISED WISH LIST

The potential solutions to mobility challenges which emerged from the interview data analysis were prioritised by 37 of the original participants via an online Delphi survey.

The top nine priorities that emerged from the survey were:

- 0 1 Create a wheelchair that enables the individual to change position easily
- 0 2 Create lighter more easily transportable mobility equipment (e.g. for taking on holiday)
- 0 3 Develop vehicle adaptations that are easy to operate and user friendly
- 0 4 Develop improved mechanisms for opening car doors easily
- 0 5 Develop a modular system for prosthetics to enable them to be easily altered to suit different environments by the user
- 0 6 Place more grab handles in vehicles to ease access
- 0 7 Develop an audio announcement system for public transport to say which bus or train is arriving (e.g. bus number/train destination)
- 0 8 Create an App that will tell you where to find the nearest available and empty disabled parking space
- 0 9 Develop an in car hoist for lifting things in and out of vehicle (i.e. luggage and shopping)

APPENDIX A INFORMANTS' CRITERIA

SAMPLE: IDENTIFICATION OF KEY INFORMANTS²⁷

To obtain effectively wide range of insights from in-depth interviews in a relatively short period of time the following criteria were used to select participants.

01 WILLINGNESS

Key interpreters are willing to share their knowledge to the interviewer and cooperate as fully as possible.

02 KNOWLEDGE

Key interpreters conduct research on 'how people could give meaning to things in the same life context that a firm is targeting'.

03 SEDUCTIVE POWER

Key interpreters have seductive power to influence the emergence of new meanings as products, services or technology, which they create influence people's meanings, aspirations, and desires.

04 FORWARD-LOOKING AND PIONEERING PROJECTS

Key interpreters are exploring in-depth with specific vision involving in pioneering projects.

05 HYBRIDISING THE SMALL LOCAL AND BIG GLOBAL COMPANIES

Key interpreters are from a range of backgrounds with a variety of perspectives.

²⁷Verganti, R. (2009) *Design-Driven Innovation: changing the rules of competition by radically innovating what things mean*. Boston, MA: Harvard Business School Press.

APPENDIX B

TELEPHONE SCRIPT

Initial call to Motability customers from the Brunel University London research team:

Hello, Please may I speak to [Insert participant name]

Yes: Hello [Participant Name] my name is [Researcher Name] and I am working on behalf of Motability. I am calling to ask if you would be interested taking part in some research Motability has funded.

No: OK that's fine thank you for your time. Goodbye.

Yes: Great, so I will tell you a little more about the project so you can decide if you would like to take part.

We are calling Motability customers for their views on what could be helpful to them in the future and find out a bit about how people get around, what the current challenges are and what solutions could make getting about much easier. The findings of the research will go towards future ideas to help make the experience of getting around more accessible for everybody. Our project team are based at Brunel University London and overall, we are interviewing, on behalf of Motability, around 100 Motability customers across the UK.

Just to assure you, taking part is entirely voluntary. If you want taking part or not, it will in no way affect your access to your Motability services.

If you would like to take part we will be recorded the interview but your answers won't be linked to you personally- so no one will be able to identify that these were your individual views. You can also stop taking part in the interview at any point and you don't have to give any reason why.

So, would you like to know any more to help you decide if you would like to take part in this study or would you like to ask any questions?

Yes: [To researcher] Go through any additions from the Participant information sheet that you think need adding

All this information I have read out to you, including the consent form, participant information and questions is also available on our website at www.mapsproject.com
We can also post the information out to you if you'd prefer this? (If yes) What address would you like this to be sent to?

No more info wanted: So would you like to take part in the study?

No: OK that's no problem at all, thank you for your time. Goodbye

Yes: Great so we can do the survey over the phone now, which should take around 30 minutes. Or we

can call back at another time if you would like to have more of a think about taking part or if another time suits you better.

Can offer Skype...

If you would prefer we can also arrange a time to come out and visit you at a place of your choice (don't offer unless you can go!).

If agreed to telephone interview at the time:

Thank you [Participant Name] that's great. OK so I am going to start recording now Ok? **[TURN on recording device]** So first I just need you to confirm you are happy to take part by answering a few questions on the recording?

Informed Consent:

1. So you are a motability customer ...yes/ Carer of a motability customer....yes
2. Do you understand that you are free to withdraw from the research at any time without having to give a reason for withdrawing? YES/NO
3. Do you agree to you interview being audio recorded.... YES/NO
4. Can you confirm you have been given some information about the research and had a chance to ask asked any questions?... YES/NO
5. You know you are speaking to (say your own name)?... YES/NO
6. Do you understand that your answers won't be linked to you individually but we may put some anonymised quotes in the report we write up?... YES/NO
7. Some people have said they would like to named in the report as contributing to this project- would you like us to give your name? YES/NO
8. At the end of the 100 interviews we can share all the ideas people have come up with – would you like to see that? Would you like to be invited to help prioritise the ideas in the final stage of the project...yes....this is being done by email...can I take your email address please?

If yes – write it down and add to database on shared drive.

If agreed to a telephone interview at a later time/date:

Thank you XXX that's great. All the information about the research project including the consent form, participant information and questions are available on our website at www.mapsproject.com We can also post the information out to you if you'd prefer this? (If yes) What address would you like this to be sent to?

(Arrange time and date to contact with preferred telephone number)

If agreed to face-to-face interview:

Thank you XXX that's great. All the information about the research project including the consent form, participant information and questions are available on our website at www.mapsproject.com We would also post out to you information about the study before meeting with you along with details about the research team members and who would be coming to interview you. Our pictures are available on our website and we would also visit you wearing our Brunel photo ID badges.

(Arrange time and place that suits participant to meet)

If you have any calls or queries in the meantime please feel free to call us on XXX or you can email myself at XXX.

If No I don't want to take part: That's no problem at all and thank you for taking the time to talk to me today.

Complaint Management

If the person asks how we have their number/states they didn't give permission for their number to be used/or is unhappy with the use of their contact details for this research project.

Motability have provided us with your contact details but we are under a contractual agreement with Motability not to share this information with anyone else. We only have people's contact details if they have ticked a box in the original Motability documents to allow the use of their contact details for Motability's purposes.

If you are unhappy with this we can request for Motability to take your contact details off this mailing list which is no problem at all.

(If the person wants their details removed from the mailing list, this information should be added to the spread sheet by the interviewer and returned back to Motability)

Mobility Adaptation Priorities Study (MAPS)

The mobility needs of people with disabilities

“Scoping our future research priorities”

Harries, Giacomini, Nickpour, Unsworth, Boniface & Young

Thank you for your interest in taking part in our research.

We are working to establish the lived experiences of people with disabilities and those who support people with their mobility to understand mobility challenges and identify the research priorities that need to be investigated in the future. We are inviting people to take part in an interview. About 100 interviews with people with disabilities, people who support them and with key stakeholders will be carried out in the UK.

This project came about as it was recognised that the mobility needs of people with disabilities will change against a background of significant social, economic and technological change.

If you decide to take part, your participation will be kept confidential; the research team are the only people to know who has taken part. If you would like your name added to those thanked for taking part in the project, we can put you in the acknowledgements. However, your own views will remain confidential to the project team and will only be reported in the overall findings.

The project is carried out by Departments of Occupational Therapy and Design at Brunel University London and has Research Ethics approval from the Brunel University Research Ethics Committee.

Before you decide whether to take part in this study or not it is important that you understand the reasons for this research and what this involves. Please take time to read the following information and do ask any questions you may have. Take your time to decide whether you would like to take part.

What is the purpose of the study?

To establish the lived experiences of people with disabilities when managing their mobility challenges today and identify their views of their future needs and those of key stakeholders' who support people with disability to remain mobile.

Who has been invited to participate?

People who have been invited to participate are individuals with disabilities that impact on their mobility, people who support them with their mobility and key stakeholders in this area.

Do I have to take part?

As participation is entirely voluntary, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect your status professionally or personally.

What will happen to me if I take part and what do I have to do?

A researcher will interview you on one occasion during the study period of 6 months. You can choose to have the interview conducted by phone/face to face/ Skype. These will be audio recorded and you will be asked to sign a consent form to say that you agree that you are okay with this. We will contact you to arrange a time and place for the interview.

The interview will last about 30-45 minutes, depending on how much you want to share and say. We will ask you about your mobility needs, your thoughts, feelings and experiences of various mobility services and products to better support people's mobility in the future.

What are the benefits and/or risks of taking part?

The benefit of taking part is that you will be helping to improve awareness and understanding of various and diverse mobility experiences within the society and help inform future investments in research in order to meet the needs and desires of people using mobility services. Some people may find talking about difficult experiences distressing, but others may find it helpful to speak to someone who is interested in their experiences. The researcher will be experienced in talking to people about the impact of disability on mobility.

What if something goes wrong?

If you would like to complain about your experiences during any aspect of this study, you can do so by contacting the Department of Clinical Sciences Research Ethics Committee chaired by Dr John Barker. They can be contacted by e-mailing: john.barker@brunel.ac.uk

Will my taking part in this study be kept confidential?

All information you share with me is strictly confidential. The only time that strict confidentiality could not be guaranteed is if you tell me something that would result in harm to yourself or anyone else or if whistleblowing needs to be implemented. If this were to happen, I would tell you of what I intend to do. If you do want to be named as a contributor to the project and acknowledged in the findings brochure or to have a photo or video clip of yourself included in the findings brochure you can give us written consent to do so.

What will happen to the results of the research study?

Findings of the study will be written up and a final report will be produced summarising the research priorities of people who have (or support people who have) disabilities. The study findings will be shared at conferences and printed in journals, which in turn may influence further research activities.

You won't be individually identifiable in any of the reported findings. Should you wish, the final report and other reports from the study will be shared with you. If you request a face to face interview, should you be willing, photos or video footage (that would reveal your identity) will be collected.

This information will be kept strictly confidential unless you provide written consent that would allow researchers to include video/photographic information relating to your interview in reports from the project.

What is the Delphi process?

The Delphi process is a way of obtaining a consensus between groups of people through a series of structured questionnaires. When we have collected responses from all the interviews we will contact you (if you have consented to this) to ask you to help us prioritise our findings. These responses will then be collated and summarised and you will then be given an opportunity to further respond to the data. The Delphi is therefore an iterative multi-stage process designed to combine opinions into a group consensus.

Who is organising and funding the research?

The study will be conducted by a team of specialists from different backgrounds, including clinical, driving assessment/rehabilitation, human-centred design. Brunel University, Cardiff University and CQ University (Australia) will be involved in the study.

For further details please contact Dr Priscilla Harries, at Brunel University London, Department of Clinical Sciences, Mary Seacole Building, Kingston Lane, Uxbridge, Middlesex UB8 3PH, email: priscilla.harries@brunel.ac.uk.

What are the indemnity arrangements?

Brunel University London covers the conduct of the study through their insurance policy.

Who has reviewed the study?

The study has been reviewed and approved by the Brunel University London Clinical Sciences ethics committee. In case of query or complaint, please contact the Chair of the Committee, via john.barker@brunel.ac.uk.

Contact for further information:

If you would like further information please contact

Dr Priscilla Harries

at priscilla.harries@brunel.ac.uk

or at

Brunel University London

Department of Clinical Sciences

Mary Seacole Building

Kingston Lane

Uxbridge

Middlesex

UB8 3PH

You can also visit our website at www.mapsproject.com



THANK YOU FOR YOUR TIME AND FOR READING THIS. PLEASE KEEP THIS SHEET FOR INFORMATION SHOULD YOU CONSENT TO BEING IN THE STUDY.

This study has been reviewed and approved by the Brunel University Clinical Sciences Research Ethics Committee.

Mobility Adaptation Priorities Study (MAPS)

The mobility needs of people with disabilities

“Scoping our future research priorities”

Harries, Giacomini, Nickpour, Unsworth, Boniface & Young

Please circle as appropriate

Participant Demographical Information

I am a:	Person with reduced mobility	Carer/ Personal assistant	Partner / Relative / Friend of person with reduced mobility	Professional / Researcher	Other
Gender:	Male	Female			
Age Band:	18-30	31-45	46-60	61-75	over 75
Ethnicity	White	Asian	Black	Mixed	Other

Participant Consent Form

Please tick the appropriate box:

The participant should complete the whole of this form

Have you read the Participant Information?

Have you had an opportunity to ask questions and discuss this study?

Have you received satisfactory answers to all your questions?

Who have you spoken to?

Do you understand that you will not be referred to by name in any report concerning the study?(Unless you would like to be acknowledged in the final report brochure we can add you name to the listing)

Would you like to be acknowledged by name in the listings of the final report brochure?

Do you understand that you are free to withdraw from the study at any time without having to give a reason for withdrawing?

I agree to my interview being audio recorded.

I agree to the use of anonymised direct quotes when the study is written up or published.

I give permission for my responses to be used during the Delphi process.

I agree to being observed. (optional)

I agree to photos and the video recording of demonstration of mobility transfers. (optional)

I give permission for my photos / video footage to be included in the project findings. (optional)

I am interested in participating in the Delphi process to identify future research

priorities.(optional)

Email:

Do you agree to take part in this study?

Signature of Research Participant:

Date:

Name in Capitals:

Witness Statement: I am satisfied that the above-named has given informed consent.

Signature of Witness:

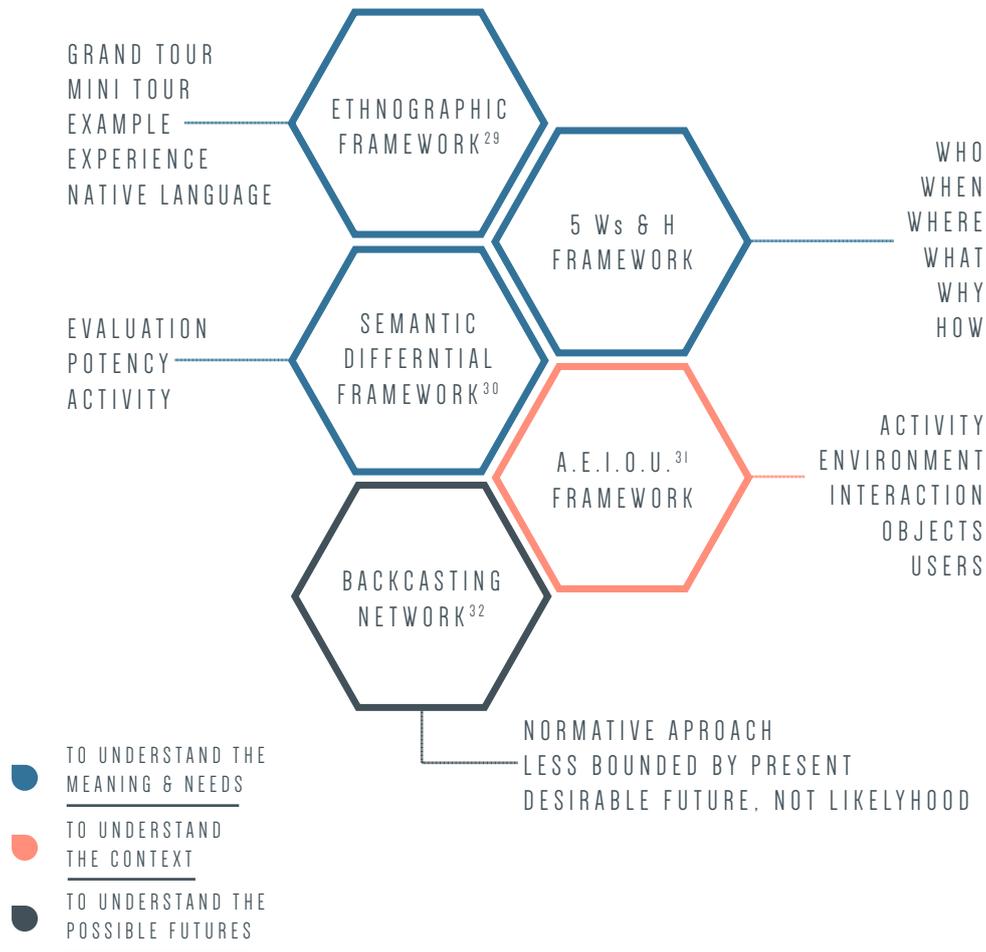
Date: Name in capitals:

Researcher Name:

Researcher Signature:

APPENDIX D
 DESIGN OF THE INTERVIEW QUESTIONS

All questions were structured based on *the mix of principal tools* which allow maximum possibility of responses²⁸.



²⁸ Coleman, C. (1996) *Perverse Fascination*. *Perspective* 3:37-39.

Hafner, K. (1999) *Coming of age in palo alto: Anthropologists find a niche studying consumers for companies in Silicon Valley*. *New York Times*, June 10: D1, D8.

Heath, R.P (1997) *Seeing is believing: Ethnography gets consumers where they live-and work, and play, and shop*. *Marketing tools* 3: 4-9.

Nussbaum, B. (1997) *Annual design awards: Winners the Best project designs of the year*. *Business week*, June 2: 92-95.

Robinson, R.E. (1993) *What to do with a human factorLA manifesto of sorts*. *American Center for Design Journal*. 7:63-73

²⁹ Robinson, J.B. (1988) *Unlearning and backcasting: Rethinking some of the questions we ask about the future*. *Technological Forecasting and Social Change* 33(4), pp. 325-338.

³⁰ Osgood, C.E., Suci, G.J., & Tannenbaum, P.H. (1957) *The measurement of meaning*. Urbana, USA: University of Illinois Press.

³¹ E-Lab LLC (1997) *Publicity Materials*. Author's files. / Wasson, C. (2000) *Ethnography in the field of design*. *Human Organization*, 59(4), p. 377

³² Robinson, J.B. (1988) *Unlearning and backcasting: Rethinking some of the questions we ask about the future*. *Technological Forecasting and Social Change* 33(4), pp. 325-338.

Main Interview:

Great, thank you for confirming those details, so lets make a start:

Section 1

Q1

Can I ask your ethnicity please?

Q2

Can you tell me a bit about yourself?

Prompts:

- Working/Volunteering
 - Routine
 - Weekly activities
-

Q3

Can you tell me a bit about how you manage to get around in your home?

Prompts:

- Equipment/Technology (pull cords/things to open the front door)

How did you find out about that? (Mobility centre/mobility scheme)

What is working well for you? (Attractiveness/function/ psycho/social)

(Prompt for a specific example – a time you remember)

What are the challenges? (Attractiveness/function/pet hates)

(Prompt for a specific example – a time you remember)

Do you have any ideas about what sort of equipment could help you to enhance the experience/ overcome these challenges?

- Support (Partner/Families/Personal Assistant/Environment)

What is working well for you? (If needed)

(Prompt for a specific example – a time you remember)

What are the challenges? (Attractiveness/function/pet hates)

(Prompt for a specific example – a time you remember)

Do you have any ideas about what sort of support could help you to enhance the experience/ overcome these challenges?

Q4

Please could you describe the area you live in and the areas you may visit (Wales/England/Scotland/Northern Ireland and countryside/town/city/etc.)?

Can you tell me a bit about how you manage to get out and about?

Prompts:

- Public transport (trains/buses/taxis/Dial-A-Ride/planes)
Equipment/Technology (WAV/ wheelchair/Powered wheelchair/passenger/adapted car)
How did you find out about that? (Mobility centre/mobility scheme – current/ex/non)
What is working well for you? (Attractiveness/function/ psycho/social)
(Prompt for a specific example – a time you remember)
What are the challenges? (Attractiveness/function/pet hates)
(Prompt for a specific example – a time you remember)
Do you have any ideas about what sort of equipment could help you to enhance the experience /overcome these challenges?

- Support (Partner/Families/Personal Assistant/Environment)
What is working well for you? (If needed)
(Prompt for a specific example – a time you remember)
What are the challenges? (Attractiveness/function/pet hates)
(Prompt for a specific example – a time you remember)
Do you have any ideas about what sort of support could help you to enhance the experience /overcome these challenges?

We have talked about some really interesting examples of what you enjoy or find challenging in going out and about. Have you ever been unable to do something that you wanted to do? What do you think could be done to change or improve this?
(Prompt for specific examples – a time you remember)

Q5

Can you tell me a bit about how you might manage if you were going away?

(Example)

Prompts:

- Public transport (trains/buses/taxis/Dial-A-Ride/planes/ferries/tram) - preference
Equipment/Technology (WAV/wheelchair/Powered wheelchair/passenger/adapted car)
How did you find out about that? (Mobility centre/mobility scheme)
What is working well for you? (Attractiveness/function/psycho/social)
(Prompt for a specific example – a time you remember)
What are the challenges? (Attractiveness/function/pet hates)
(Prompt for a specific example – a time you remember)
Do you have any ideas about what sort of equipment could help you to enhance the experience /overcome these challenges?

- Support (Partner/Families/Personal Assistant/Environment)

What is working well for you? (If needed)

(Prompt for a specific example – a time you remember)

What are the challenges? (Attractiveness/function/pet hates)

(Prompt for a specific example – a time you remember)

Do you have any ideas about what sort of support could help you to enhance the experience /overcome these challenges?

We have talked about some really interesting examples of what you enjoy or find challenging in going away. Have you ever been unable to go somewhere that you wanted to go? What do you think could be done to change or improve this?

(Prompt for specific examples – a time you remember)

Consent form in Welsh:

Astudiaeth Blaenoriaethau Addasiad Symudedd (MAPS)

Anghenion symudedd pobl ag anableddau

“Cwmpasu ein blaenoriaethau ymchwil ar gyfer y dyfodol”

Harries, Giacomini, Nickpour, Unsworth, Boniface a Young

Diolch am eich diddordeb mewn cymryd rhan yn ein gwaith ymchwil.

Rydym yn gweithio i sefydlu profiadau byw pobl ag anableddau a'r rhai sy'n cefnogi pobl gyda'u symudedd i ddeall heriau symudedd a nodi'r blaenoriaethau ymchwil y mae angen eu hymchwilio yn y dyfodol. Rydym yn gwahodd pobl i gymryd rhan mewn cyfweiliad. Bydd tua 100 o gyfweiliadau gyda phobl ag anableddau, pobl sy'n eu cefnogi a chyda deiliad diddordeb allweddol yn cael eu cynnal yn y DU.

Daeth y prosiect hwn i fodolaeth gan ei fod yn cael ei gydnabod y bydd anghenion symudedd pobl ag anableddau yn newid yn erbyn cefndir o newid cymdeithasol, economaidd a thechnolegol arwyddocaol.

Os byddwch yn penderfynu cymryd rhan, bydd eich cyfranogiad yn cael ei gadw'n gyfrinachol; y tîm ymchwil yw'r unig bobl sy'n gwybod pwy fydd wedi cymryd rhan. Os hoffech chi ychwanegu eich enw at y rhai hynny y diolchir iddynt am gymryd rhan yn y prosiect, gallwn eich rhoi yn y rhestr cydnabyddiaeth. Fodd bynnag, bydd eich barn eich hun yn parhau'n gyfrinachol i'r tîm prosiect ac adroddir amdano'n unig yn y canfyddiadau cyffredinol.

Ymgymerir â'r prosiect gan yr Adrannau Therapi Galwedigaethol a Chynllunio ym Mhrifysgol Brunel Llundain ac mae wedi cael cymeradwyaeth Moeseg Ymchwil gan Bwyllgor Moeseg Ymchwil Prifysgol Brunel.

Cyn i chi benderfynu a ydych am gymryd rhan yn yr astudiaeth hon ai peidio, mae'n bwysig eich bod yn deall y rhesymau dros y gwaith ymchwil hwn, a beth mae hyn yn ei olygu. Cymerwch amser i ddarllen y wybodaeth ganlynol a gofynnwch unrhyw gwestiynau sydd gennych. Cymerwch eich amser i benderfynu a hoffech chi gymryd rhan.

Beth yw pwrpas yr astudiaeth?

I sefydlu profiadau byw pobl ag anableddau wrth reoli eu heriau symudedd heddiw a nodi eu barn am eu hanghenion yn y dyfodol a barn deiliaid diddordeb allweddol sy'n cefnogi pobl ag anableddau i aros yn symudol.

Pwy sydd wedi cael gwahoddiad i gymryd rhan?

Mae pobl sydd wedi cael eu gwahodd i gymryd rhan yn unigolion gydag anableddau sy'n effeithio ar

eu symudedd, pobl sy'n eu cefnogi gyda'u symudedd a deiliaid diddordeb allweddol yn y maes hwn.

A oes rhaid i mi gymryd rhan?

Gan fod cyfranogiad yn hollol wirfoddol, mater i chi yw penderfynu p'un ai i gymryd rhan. Os byddwch yn penderfynu cymryd rhan, byddwch yn cael y daflen wybodaeth hon i'w chadw a gofynnir i chi lofnodi ffurflen ganiatâd. Os byddwch yn penderfynu cymryd rhan rydych yn dal yn rhydd i dynnu'n ôl ar unrhyw adeg a heb roi rheswm. Ni fydd hyn yn effeithio ar eich statws proffesiynol neu bersonol.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan a beth sy'n rhaid i mi ei wneud?

Bydd ymchwilydd yn eich cyfweld ar un achlysur yn ystod cyfnod yr astudiaeth o 6 mis. Gallwch ddewis cael y cyfweiliad dros y ffôn/wyneb yn wyneb/Skype. Bydd y rhain yn cael eu recordio ar ffurf sain, a gofynnir i chi lofnodi ffurflen ganiatâd i ddweud eich bod yn cytuno i hyn. Byddwn yn cysylltu â chi i drefnu amser a lleoliad ar gyfer y cyfweiliad.

Bydd y cyfweiliad yn para tua 30-45 munud, yn dibynnu ar faint yr ydych am ei rannu a'i ddweud. Byddwn yn gofyn i chi am eich anghenion symudedd, eich meddyliau, teimladau a phrofiadau o amrywiol wasanaethau a chynhyrchion symudedd i gefnogi yn well symudedd pobl yn y dyfodol.

Beth yw manteision a/neu risgiau o ran cymryd rhan?

Y budd o gymryd rhan yw y byddwch yn helpu i wella ymwybyddiaeth a dealltwriaeth o brofiadau symudedd gwahanol ac amrywiol o fewn y gymdeithas a'n helpu i lywio buddsoddiadau mewn ymchwil yn y dyfodol er mwyn cwrdd ag anghenion a dymuniadau pobl sy'n defnyddio gwasanaethau symudedd. Efallai y bydd siarad am brofiadau anodd yn boenus i rai, ond efallai y bydd eraill yn ei chael yn ddefnyddiol siarad â rhywun sydd â diddordeb yn eu profiadau. Bydd gan yr ymchwilydd brofiad o siarad â phobl am effaith anabledd ar symudedd.

Beth os aiff rhywbeth o'i le?

Os hoffech gwyno am eich profiadau yn ystod unrhyw agwedd o'r astudiaeth hon, gallwch wneud hynny trwy gysylltu â'r Pwyllgor Moeseg Ymchwil yn yr Adran Gwyddorau Clinigol sydd dan gadeiryddiaeth Dr John Barker. Gellir cysylltu â hwy drwy e-bostio: john.barker@brunel.ac.uk

A fydd cymryd rhan yn yr astudiaeth hon yn cael ei gadw'n gyfrinachol?

Mae'r holl wybodaeth y byddwch yn ei rhannu gyda mi yn gwbl gyfrinachol. Yr unig adeg na allai cyfrinachedd llym gael ei warantu yw os byddwch yn dweud rhywbeth a fyddai'n arwain at niwed i chi eich hun neu unrhyw un arall, neu os oes angen chwythu'r chwiban. Pe bai hyn yn digwydd, byddwn yn rhoi gwybod i chi am yr hyn yr wyf yn bwriadu ei wneud.

Os ydych am gael eich enwi fel cyfrannwr i'r prosiect a'ch cydnabod yn y llyfryn canfyddiadau neu gael llun neu glip fideo ohonoch eich hun wedi ei gynnwys yn y llyfryn canfyddiadau gallwch roi caniatâd ysgrifenedig i ni wneud hynny.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Bydd canfyddiadau'r astudiaeth yn cael eu hysgrifennu i fyny a bydd adroddiad terfynol yn cael ei gynhyrchu yn crynhoi blaenoriaethau ymchwil pobl sydd ag (neu sy'n cynorthwyo pobl sydd ag) anabledau. Bydd canfyddiadau'r astudiaeth yn cael eu rhannu mewn cynadleddau a'u hargraffu mewn cyfnodolion, a all yn ei dro ddylanwadu ar weithgareddau ymchwil pellach.

Ni fyddwch yn unigol yn cael eich adnabod yn unrhyw un o'r canfyddiadau yr adroddir amdanynt. Pe dymunwch, bydd yr adroddiad terfynol ac adroddiadau eraill o'r astudiaeth yn cael ei rannu gyda chi. Os byddwch yn gofyn am gyfweiliad wyneb yn wyneb, os byddwch yn fodlon gwneud hynny, bydd lluniau neu fideo (a fyddai'n datgelu pwy ydych chi) yn cael ei gasglu.

Bydd y wybodaeth hon yn cael ei chadw'n hollol gyfrinachol oni bai eich bod yn darparu caniatâd ysgrifenedig a fyddai'n caniatáu i ymchwilwyr i gynnwys fideo/gwybodaeth ffotograffig yn ymwneud â'ch cyfweiliad mewn adroddiadau ysgrifenedig o'r prosiect.

Beth yw'r broses Delphi?

Mae'r broses Delphi yn ffordd o gael consensws rhwng grwpiau o bobl trwy gyfres o holiaduron strwythuredig. Pan fyddwn wedi casglu ymatebion o'r holl gyfweiliadau byddwn yn cysylltu â chi (os ydych wedi cydsynio i hyn) i ofyn i chi ein helpu i flaenoriaethu ein canfyddiadau. Yna bydd yr ymatebion hyn yn cael eu casglu a'u crynhoi ac yna byddwch yn cael cyfle i ymateb ymhellach i'r data. Felly mae'r Delphi yn broses aml-gam ailadroddol a gynlluniwyd i gyfuno barn i mewn i gonsensws grŵp.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Bydd yr astudiaeth yn cael ei gynnal gan dîm o arbenigwyr o wahanol gefndiroedd, gan gynnwys clinigol, asesiad gyrru/adsefydlu, dylunio dynol-ganolog. Bydd Prifysgol Brunel, Prifysgol Caerdydd a Phrifysgol CQ (Awstralia) yn cymryd rhan yn yr astudiaeth.

Am ragor o fanylion, cysylltwch â Dr Priscilla Harries, ym Mhrifysgol Brunel Llundain, Adran Gwyddorau Clinigol, Mary Seacole Building, Kingston Lane, Uxbridge, Middlesex UB8 3PH, e-bost: priscilla.harries@brunel.ac.uk

Beth yw'r trefniadau indemniad?

Mae Prifysgol Brunel Llundain yn cwmpasu ymddygiad yr astudiaeth trwy eu polisi yswiriant.

Pwy sydd wedi adolygu'r astudiaeth?

Mae'r astudiaeth wedi cael ei adolygu a'i gymeradwyo gan bwyllgor moeseg Gwyddorau Clinigol Prifysgol Brunel Llundain. Mewn achos o ymholiad neu gŵyn, cysylltwch â Chadeirydd y Pwyllgor, trwy john.barker@brunel.ac.uk

Cyswllt am fwy o wybodaeth:

Os hoffech ragor o wybodaeth, cysylltwch â

Dr Priscilla Harries

priscilla.harries@brunel.ac.uk

neu yn

Prifysgol Brunel Llundain

Adran Gwyddorau Clinigol

Mary Seacole Building

Kingston Lane

Uxbridge

Middlesex

UB8 3PH

Gallwch hefyd ymweld â'n gwefan yn: www.mapsproject.com



DIOLCH I CHI AM EICH AMSER AC AM DDARLLEN HWN. CADWCH Y DAFLEN HON ER GWYBODAETH OS GWELWCH YN DDA OS BYDDWCH YN CYDSYNIO I FOD YN RHAN O'R ASTUDIAETH.

Mae'r astudiaeth hon wedi cael ei hadolygu a'i chymeradwyo gan Bwyllgor Moeseg Ymchwil Gwyddorau Clinigol Prifysgol Brunel.

Astudiaeth Blaenoriaethau Addasiad Symudedd (MAPS)

Anghenion symudedd pobl ag anabledau

“Cwmpasu ein blaenoriaethau ymchwil ar gyfer y dyfodol”

Harries, Giacomini, Nickpour, Unsworth, Boniface a Young

Rhowch gylch o'i amgylch fel y bo'n briodol:

Gwybodaeth Ddemograffig am y Cyfranogwr

Yr wyf yn:	Person gyda symudedd cyfyngedig	Gofalwr / Cynorthwydd Personol	Partner / Perthynas / Ffrind i berson gyda symudedd cyfyngedig	Person Proffesiynol / Ymchwilydd	Arall
Rhyw:	Gwryw	Benyw			
Band Oedran:	18-30	31-45	46-60	61-75	dros 75
Ethnigrwydd:	Gwryw	Asiaidd	Du	Cymysg	Arall

Ffurflen Caniatâd Cyfranogwr

Ticiwch y blwch priodol os gwelwch yn dda:

Dylai'r cyfranogwr gwblhau'r cyfan o'r ffurflen hon

Ydych chi wedi darllen y Wybodaeth i'r Cyfranogwr?

Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?
Ydych chi wedi cael atebion boddhaol i'ch holl gwestiynau?

Gyda phwy rydych chi wedi siarad

.....?

Ydych chi'n deall na chyfeirir atoch chi wrth eich enw mewn unrhyw adroddiad sy'n ymwneud â'r astudiaeth? (*Oni hoffech gael eich cydnabod yn y llyfryn adroddiad terfynol yna gallwn ychwanegu eich enw at y rhestr*)

A fyddech chi'n hoffi cael eich cydnabod wrth eich enw yn y rhestrau o'r llyfryn adroddiad terfynol?

Ydych chi'n deall eich bod yn rhydd i dynnu'n ôl o'r astudiaeth ar unrhyw adeg heb orfod rhoi rheswm dros dynnu'n ôl?

Rwy'n cytuno i'm cyfweiliad gael ei recordio ar ffurf sain.

Rwy'n cytuno i'r defnydd o ddyfyniadau uniongyrchol dienw pan gaiff yr astudiaeth ei hysgrifennu neu ei chyhoeddi.

Rwy'n cytuno i'm hymatebion gael eu defnyddio yn ystod y broses Delphi.

Rwy'n cytuno i gael fy arsylwi. (dewisol)

Rwy'n cytuno i'r lluniau a'r recordiad fideo a fydd yn arddangos trosglwyddiadau symudedd. (dewisol)

Rwy'n cytuno i'm lluniau/fideo a dynnwyd i gael eu cynnwys yng nghanfyddiadau'r prosiect. (dewisol)

Mae gen i ddiddordeb mewn cymryd rhan yn y broses Delphi i nodi ymchwil yn y dyfodol. (dewisol)
E-bost:

Ydych chi'n cytuno i gymryd rhan yn yr astudiaeth hon?

Llofnod y Cyfranogwr Ymchwil:

Dyddiad:

Enw mewn Priflythrennau:

Datganiad Tyst: Rwy'n fodlon bod yr uchod wedi rhoi caniatâd gwybodus.

Llofnod y Tyst:

Dyddiad: Enw mewn Priflythrennau:

Enw'r Ymchwilydd: Llofnod yr Ymchwilydd

Interview questions in Welsh:

Astudiaeth Blaenoriaethau Addasiad Symudedd (MAPS)

Anghenion symudedd pobl ag anabledau

“Cwmpasu ein blaenoriaethau ymchwil ar gyfer y dyfodol”

Harries, Giacomini, Nickpour, Unsworth, Boniface a Young

Diolch i chi am gytuno i gymryd rhan yn yr astudiaeth hon ac am fod yn barod i rannu eich profiadau yn ymwneud â naill ai:

- eich heriau symudedd (**Adran A**)
- neu heriau symudedd y bobl rydych yn eu helpu (**Adran B**).

Yr wyf yn gwerthfawrogi eich amser a gallaf eich sicrhau bod eich cyfraniad yn werthfawr gan y bydd eich barn yn ein helpu i nodi meysydd penodol o gefnogaeth symudedd sydd angen ymchwil a datblygu pellach.

Drwy gynnal y cyfweiliad hwn, yr wyf yn awyddus i gael gwybod beth y mae'r syniad o 'symudedd' yn ei olygu i chi. Hoffwn hefyd ichi ddweud wrthyf amrywiaeth o fanylion am sut rydych yn (neu'r person/pobl sydd yn eich helpu) symud o gwmpas eich/eu cartref, ac allan yn y gymuned.

Drwy gydol y cyfweiliad hwn, cofiwch y gallwch ddewis i dynnu'n ôl o'r astudiaeth hon ar unrhyw adeg heb orfod rhoi unrhyw reswm.

Adran 1 –

C1 *A allwch chi ddweud wrthyf ychydig am eich hun?*

C2 *A allwch chi ddweud wrthyf ychydig am sut yr ydych yn llwyddo i symud o gwmpas yn eich cartref?*

C3 *A fydddech cystal â disgrifio'r ardal yr ydych yn byw ynddi a'r ardaloedd efallai y bydddech yn ymweld â nhw (Cymru/Lloegr/Yr Alban/Gogledd Iwerddon a chefn gwlad/tref/dinas/ac yn y blaen)?*

A allwch chi ddweud wrthyf ychydig am sut yr ydych yn llwyddo i fynd allan?

C4 *A allwch chi ddweud wrthyf ychydig am sut y bydddech yn ymdopi pe baech yn mynd i ffwrdd?*

C5 *Gan feddwol ymlaen at y dyfodol, mewn tua 10 mlynedd, beth hoffech chi ei weld yn cael ei gynllunio?*

C6 *Rydych chi wedi rhoi i ni lawer o syniadau diddorol iawn, pe baech yn gallu dewis y prif un i gael ei gynllunio, pa un fydddech chi'n ei ddewis?*

C7 *O'n sgwrs, gallaf weld bod gyda chi lawer o brofiad. Fel cwestiwn olaf, os gwelwch yn dda allech chi roi eich awgrym neu'ch cyngor gorau i rywun arall sy'n dechrau wynebu'r heriau rydych chi wedi siarad amdanynt?*

**A oes unrhyw beth yr hoffech fy mod wedi ei ofyn i chi na ddaeth i fyny yn y cyfweiliad?
Diolch yn fawr iawn!**

Adran 2 –

C1 *A allwch chi ddweud wrthyf ychydig am eich hun?*

C2 *A allwch chi ddweud wrthyf ychydig am sut rydych chi'n helpu pobl i symud o gwmpas yn eu cartrefi?*

C3 *A fydddech cystal â disgrifio'r ardal yr ydych yn byw ac yn gweithio ynddi (Cymru/Lloegr/Yr Alban/Gogledd Iwerddon a chefn gwlad/tref/dinas/ac yn y blaen)?*

A allwch ddweud wrthyf ychydig am sut yr ydych yn cynorthwyo rhywun sydd ag anawsterau symudedd i fynd allan?

C4 A allwch chi ddweud wrthyf ychydig am sut y gallech gynorthwyo rhywun sydd gydag anawsterau symudedd pe baent yn mynd i ffwrdd?

C5 Gan feddwl ymlaen at y dyfodol, mewn tua 10 mlynedd, beth hoffech chi ei weld yn cael ei gynllunio?

C6 Rydych chi wedi rhoi i ni lawer o syniadau diddorol iawn, pe baech yn gallu dewis y prif un i gael ei gynllunio, pa un fydddech chi'n ei ddewis?

C7 O'n sgwrs, gallaf weld bod gyda chi lawer o brofiad. Fel cwestiwn olaf, os gwelwch yn dda allech chi roi eich awgrym neu'ch cyngor gorau i rywun arall sy'n dechrau wynebu heriau symudedd?

**A oes unrhyw beth yr hoffech fy mod wedi ei ofyn i chi na ddaeth i fyny yn y cyfweiliad?
Diolch yn fawr iawn!**

1. Bias and subjectivity reduction

- transcription checking by multiple individuals
- establishment of agreed coding criteria
- coding, theme generation and theme reduction by multiple individuals

2. A checklist of criteria for good thematic analysis Process No. Criteria Transcription

1 The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.

Coding

2 Each data item has been given equal attention in the coding process.

3 Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.

4 All relevant extracts for all each theme have been collated.

5 Themes have been checked against each other and back to the original data set.

6 Themes are internally coherent, consistent, and distinctive.

Analysis

7 Data have been analysed / interpreted, made sense of / rather than just paraphrased or described.

8 Analysis and data match each other / the extracts illustrate the analytic claims.

9 Analysis tells a convincing and well-organized story about the data and topic.

10 A good balance between analytic narrative and illustrative extracts is provided.

11 Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.

Data analysis implementation:

Stage One:

Familiarisation with the interview

²²Braun, V and Clarke, V.(2006) *Using thematic analysis in psychology. Qualitative Research in Psychology* 2006;3: 77-101pp.

- Gain an overview of the data through the careful selection of data. Data will be selected based on a review of the proposal with particular attention paid to the stated objectives and key deliverables as outlined within the proposal.
- The familiarisation process will continue until the diversity of the circumstances and characteristics of the data are understood. The aim is to identify recurrent themes/attitudes/behaviours and motivations of stakeholders.

Stage two:

Coding

- Line by line coding and indexing of the data using a case and theme based approach. Key phrases /themes will be summarised in-vivo codes. Categories/themes will later be developed from these in-vivo codes.
- Notes and memos will record analytical notes and impressions of the data and will be linked to the relevant transcripts.

Stage Three:

Developing a working analytical framework

- Data will be sorted by similar codes and themes to allow a review of the material
- From these, the conceptual framework will be developed. This framework will incorporate the recurrent themes and issues identified in the interviews with stakeholders. These will be reviewed by two researchers to ensure rigour.
- Classifications will be developed within Nvivo which will enable the analysis to explore across different stakeholder groups/gender /age/ethnicity and UK country.

Stage Four:

Applying the analytical framework

- Using framework matrices in Nvivo 10, the conceptual framework will then be applied across the raw data. The framework will be applied by indexing segments of transcripts using the existing categories and codes identified in the interviews with stakeholders.

Stage Five:

Charting data into the framework matrix

- Charting data into the framework matrix will involve summarizing the data by category from each transcript.
- Each code will be highlighted and linked back to the original quote in the transcript for easy identification and retrieval. This process will enable the data to be reduced, while retaining the original meanings and feel of the interviewees' words. The chart will include references to interesting or illustrative quotations.
- Thematic charts will contain both the main themes and the associated sub themes. Each case/participant is allocated a row with themes and subthemes displayed in separate columns.
- Key terms and expression used by participants will be retained
- Data that does not fit identified themes will be retained and reviewed.

SUBTHEME: EMPOWERMENT & EQUALITY

31-45

Family Carers (P1FFC0)

“My second son has got technology at school, laptop and stuff to help him access stuff and that. So yes, and also they have ... well often at school we have interactive white boards, did you used to use those, yes? Then they have a screen linked up to that so whatever is written on the interactive white board comes up on a screen in front of them so they can see - and they can access it the same as anybody else in the class.”

46-60

*M**Driver of adapted car (22DACFN)*

“Ever since I’ve been able to drive I just love it. And it’s one of those few times when I feel I’m on a level playing field with everybody else because if I’m sat in my car on the road, on the motorway or wherever, there’s no external indication that I have a disability or anything. I’m just another road user. [...] Well it’s this need or want to fit in.”

46-60

*M**Driver of adapted car (P4DACLV)*

“I like things as normal as possible, so I try and have the bits of kit in my life to make life nearly normal. That’s the aim. In a way I don’t even consider myself disabled, I suppose, I think of myself as normal that just happens to be sat down, that sort of thing, so I like life to be as normal as possible.”

31-45

*F**Driver of adapted car (88DACWY)*

“When I first had my accident they got a (inaudible 0:11:41) the house if you like, or to make our bathroom into a wet room and my mum said that she didn’t want it to look really like a disabled person lived there, she wanted it sleeker or refined and so that was very important. [...] But in terms of our house we’re always very conscious that it looks like a normal house because if you want to sell it again people who are coming are going to be concerned over the attractiveness of your house. So in terms of the house that is really important.”

61-75

*M**Driver of adapted car (65DACJR)*

“I have done in the past and the very subtle thing that I say to people is look, you’re alive, you’re alive. You’re alive, you’re not dead, so enjoy the life that you have”

18-30

F

Family carer (16FCSW)

“Yeah so this gets her to the same height as standing and it allows her to jump up and down and feel like she’s participating really. So I think that things that allow you to be part of everyday life work a lot better than other things. Sometimes some of the things that she has her chair goes up and down which is quite good, again she can be at a certain level but this also allows her in normal groups to come up the table and do things that other children can do as well.”

31-45

F

Family carer (63FCLVI)

“We could have gone down the wheelchair assisted route sooner but I wanted to hold off as long as possible so I had a sense of normality in my life.”

31-45

F

Driver of adapted car (88DACWY)

“It’s empowering because through my chair I can do anything the exact same as anybody else. So it’s my game changer, it makes me equal”

61-75

M

Driver of adapted car (65DACJR)

“I have done in the past and the very subtle thing that I say to people is look, you’re alive, you’re alive. You’re alive, you’re not dead, so enjoy the life that you have”

SUBTHEME: FREEDOM

Megan, 33

Driver of adapted car

“Your car is your freedom, your car is your legs. I use a lot of taxis and access to work and I keep on encouraging people to drive because not only can you get to work then you can visit your family, you’re not isolated, you can do lots of social activities. I’d be lost without my car. When I got out of hospital my dad had a car sitting there and I learnt how to drive and that was my freedom”

61-75

F

Driver of adapted car (78PDCLV)

“[My car] ...gives me good freedom, I can get around again because I was always driving, but I couldn’t use my foot on the accelerator or the brake, not with any strength.”

31-45

F

Driver of adapted car (80DACPH)

“Obviously there would be if we did lose it, there would be an extraordinary cost and obviously we’d have to look into it, but having Motability it helps so much because it does give me the freedom to go out and about, and obviously to maintain it, put petrol in it, you don’t mind because at the end of the day it’s your car.”

61-75

F (78PDCLV)

“It’s brilliant because it gets me out and about. If I didn’t have a Motability car I would be stuck at home at all the time or dependent on friends and family to get me out and about. Without Motability I would be stuck”

31-45

F

Driver of adapted car (88DACWY)

“anyone young, anyone who’s newly had a spine injury like me is to get a car. Your car is your freedom, your car is your legs. I use a lot of taxis and access to work and I keep on encouraging people to drive because not only can you get to work then you can visit your family, you’re not isolated, you can do lots of social activities. I’d be lost without my car. When I got out of hospital my dad had a car sitting there and I learnt how to drive and that was my freedom,”

SUBTHEME: HEALTH & FITNESS

31-45

F

Driver of adapted car (88DACWY)

“[...] shoulder injuries are our problem in general when you’re a wheelchair user so that’s why it’s a bit of a prevention of getting long term kind of injury if you like. We knew we had to do something so it was a bit of an investment for our health down the road.”

46-60

M (12PDCFN)

“this is a manual chair so that I can wheel it when I want, so I can keep reasonably fit, but then if I’m carrying shopping I flick the lever and it’s then motorised so I’ve got the best of both worlds.”

46-60

M

Driver of adapted car (P4DACLV)

“You’ve got to find what floats your boat, what makes you want to get up in the morning otherwise you won’t and you’ll just let things deteriorate. So mine was health and fitness and then when I read into it, I started realising...because I was swimming, I was an ex-diver as well, so it was obvious to do...my coping strategy was pretty obvious it was going to be physical.”

46-60

F

Occupational Therapist (P13PTPCO)

“The other thing is I’m about to change my chair and I want a hybrid one, in between electric run and manual when I need it, people don’t realise even though you’re in a wheelchair you do need to exercise and wheeling yourself around is a large part of the exercise that you do.”

SUBTHEME: INDEPENDENCE

46-60

F

Family Carer (14FCWY)

“You just improvise life. I mean I’ve made him cook a little bit, but I’m very concerned at 60, I’ve smoked most of my life, I might not live forever but he needs to be independent and I make him do all sorts of crazy things just to make sure he can do it. In the kitchen, we’ve got the table legs on four corners but they’re actually on a frame so we had them moved backwards so now he can get in on the end with his wheelchair and that’s his work surface. He didn’t need everything lowered, I’ve made him cope with life.”

46-60

M (12PDCFN)

“The reason we went down that route is it means that we can be totally independent, we can go shopping, we can go out. We’re going to Cornwall for a fortnight so we’ll pack up the car, it’s an estate car so we can chuck the luggage in the boot quite easily and we’ll just go off and please ourselves.”

31-45

F

Driver of adapted car (77DACLV)

“Yeah, it gets me out and about, it gives me independence, if I didn’t have that I wouldn’t be independent or anything. I would be stuck. I would be housebound and stuck using public transport and that’s expensive.”

46-60

F (9PDCU)

“For me, it is coming to terms with losing my independence and having to rely on others to get me from A to B, because I can’t go anywhere without help. I want to get my independence back by driving so fingers crossed, I will be able to do it.”

31-45

F

Driver of adapted car (80DACPH)

“Independence. Freedom because you’re out and about and obviously mobile.”

61-75

F/M

Driver of adapted car (62DACLV)

“Yeah, because you’re independent with a car. You don’t have to go by the clock; you go when you want and you come back when you want.”

Unknown

F

Researcher (P12REB)

“Every time we do surveys or research, you know, mobility and the ability to, you know, to get around independently or as independently as possible is really important to people’s lives.”

46-60

F

Driver of adapted car (54DACLV)

“I have got a Motability car that doesn’t get used much. It is handy, if I do need it, it is handy. If my daughter can’t take me to the doctors and I will say, “It is okay it is just up the road, I will go myself”. But then I do think what have I got a car for if I need anything I can just phone my daughter but it is putting pressure on her all the time. So I need a bit of independence myself, do you know what I mean?”

46-60

M

Driver of adapted car (P4DACLV)

“I’m a very fiercely independent person so... In fact after my injury, friends and family wanted me in the local area and that’s not what I wanted so I went completely... somewhere where I was completely away... from everybody to make sure that I did everything for myself. It goes back to what I said about the independence side of things. I built everything into my life; a) to be as healthy and fit as I can, and b) to be as normal as I can and to achieve those things I’ve bought the various bits of kit to fulfill those two criteria.”

18-30

M

Leisure/sports activity provider (20MFMG)

“I mean there’s a few of our members who have various different disabilities, are able to drive, who are by far the most sort of free to attend events, to do what they want, or there’re wheelchair users who have their own cars and can drive and get around, really do have the best kind of quality of life in terms of taking part in activities and leading life, like a functional diverse sort of lifestyle so I know we have ... one of our dancers has quite bad cerebral palsy and she flinches quite a lot and she’s got quite a lot of issues with movement but I remember when she goes to her car and she gets her keys out people are always offering to open the passenger door for her but she can drive perfectly well, she’s a really good driver and, you know, she comes to everything, she’s always out and about it doesn’t seem to inhibit her lifestyle at all. So I see the most positives are just generally people who are able to take control of their own transport and their own mobility if ... without that when people rely on the carer or someone it’s a bit more of a struggle.”

18-30

F

Family Carers (16FCSW)

“At the moment we’re looking at trying to have a powered wheelchair; it depends whether she has the ability to be able to use it, just to give her a little bit of independence and not be so reliant on us.”

46-60

M

Professional carer (10PCDM)

“What we do is we set out goal programmes so that staff follow a rigid routine and once that person, he or she, can get used to that routine we’ve made a start; we had residents who wanted to make their own cup of tea so you set that programme and now they can make their own cup of tea.”

31-45

F

Professional carer (11PCGB)

“We have a few that are able to go out, they’ve had travel training and we live right by a train station, they’re able to get onto the train, go to a nearby town, buy a cup of tea or a magazine and come back, but the majority of our residents they do go out with a carer. They either go on the train or we’ve got quite a few vehicles.”

SUBTHEME: SOCIAL IDENTITY

31-45

M

Equipment provider (37MEPEB)

“They [family] came along, wandered round the show, talked to the manufacturers face to face and found the suitable powered chair for their son, purchased it from the show and now he’s gone on to have greater independence out of school, in school. As a teenager it’s very important to engage with his peers and also gone on to play power chair football as well, so it’s kind of opened up a whole new social life .”

46-60

F

Family carer (P2FCCOI)

“I suppose one thing I could say is when he used to go to scouts, the way we integrated him with the other scouts was we got them involved in using his wheelchair so we used to take him out and mix him in with all the others and so forth so we used to take him to (inaudible 0:03:06.6) across fields and so forth and we were out on hikes and when the going got tough, because we just used a manual chair for that, when the going actually got tough, we used to have ropes that we would attach to the chair and we would have a couple of scouts on one end and a couple of scouts on the other end and we would literally carry on regardless. Absolutely. It all counted when he was in the cubs and of course having a wheelchair has meant that he can access that which other children at the time could.”

61-75

F

Mobility scooter Customer (87MSCWY)

“I’m very happy in the church I’m in and I have been involved in that (s.l 30 years 00.02.46). (Multiple speakers 00.02.48) I’m able to do voluntary things but things like this baking and so on that I’m doing, today it’s not for anything special it’s just for home but things like that I really enjoy and I enjoy pottering about in my garden too. But that gets very hard as you can imagine with the limitations.”

46-60

F

Passenger with disability (82PDWY)

“I would be able to go to the old age pensioners’ hall and do bingo and that. I don’t really like bingo but I would go, it would get me out for a couple of hours and my daughter just lives right by the old age pensioners’ hall, that’s my daughter that’s got the car. So yeah, I would feel a bit more, how to explain it, independent.”

61-75

M

Driver of adapted car (65DACJR)

“I have done in the past and the very subtle thing that I say to people is look, you’re alive, you’re alive. You’re alive, you’re not dead, so enjoy the life that you have”

SUBTHEME: SECURITY

Sarah, 57

Driver of adapted car

“I’d probably be a lot happier because it [the adapted car] would have a few things in it that I’ve got now, so I would feel a lot happier. Again, I’d feel secure and confident, that’s what it’s all about.”

61-75

M

Driver of adapted car (55DACLV)

“I: [...] I’m going to ask you about how you feel about using your car at the moment. So when you’re on your own how do you feel when you’re using your car in three words?”

R: Right, I feel very secure in this particular car.”

APPENDIX I

EQUIPMENT & FACILITIES: LONG LIST OF EXAMPLE QUOTATIONS

SUBTHEME: APPEARANCE

31-45

M

Equipment Provider (37MEPEB)

“I’ve seen in the last five years the stigma of having a mobility product is changing massively through design and design, especially across settings as well, products look cool. They’re not mechanical things to be embarrassed about anymore. Style and innovation has taken over with that, that’s a big thing.”

M

Motability Governor (P5MGPH)

“I guess most young people wouldn’t want to be, you know, turning their car or their house into what looks like a hospital if they can avoid it. But on mobility, you know, a lot of the reason why many people use scooters is they don’t want to be seen dead in a wheelchair.”

31-45

F (57PDCLV)

“in an ideal world there’d be something a little bit more stylish than the walking frame I’ve got, let’s put it that way.”

46-60

F

Public transport preference (P13PTPCO)

“There is this KENGURU car, and that’s sort of like a smart car and you go in, in your wheelchair. I don’t know whether it’s taken off – I don’t know why people don’t manufacture things like that. Well you know there’s a company who are trying to produce a sort of the Segway version of a wheelchair and that would be of interest to people who are not disabled but still want to maybe get around; I think it looks really trendy and smart and everything. The thing is they have to look trendy and smart, if you saw this scooter by Honda, you’d want to ride it as well, it’s not something that would be just for somebody who is disabled.”

Unknown (middle aged)

F

Researcher (P8R7R)

“So the main things are around making things slim line, lightweight... colour is important and making it look ... making the technologies and equipment look unobtrusive.....”

46-60

F

Public transport preference (P13PTPCO)

“When I look at the shower chair I think, “This looks hideous in my beautiful bathroom.” When I look at the standing frame I just think, “There’s got to be something better than this to help me stand.” And there is something called another standing frame, but it is huge, it doesn’t fold up and I would never use it, because it’s just even more hideous than the one I’ve got at the moment.”

31-45

F

Professional carers (42PCEB)

“they don’t like to go out at all, normally, the clients, they’re just at home and they don’t really want to be seeing others because they’re disabled and have a NHS shitty chair; they are ashamed of it”

31-45

M

Driver of adapted car (66DACJR)

“I’d like to be able to see a nice affordable off-road scooter that doesn’t look like a shopper, a sort of mounted quad bike that that would allow you to get into the countryside.”

Unknown (put middle aged)

F

Researcher (P12REB)

“I think people just like stuff that looks, you know, doesn’t look too sort of special.

It looks kind of like yeah, looks like stuff that everybody else has got. Some of the car adaptations look really clunky and they look mechanical and they look like they’ve scared a bad engineer, you know, in a garage and some of them look good. Just like, you know, like something you might find in a racing car or something that just looks yeah, mainstream and cool. So people like, you know, they like things that are designed that look good and, you know, that’s why a lot of people I think like, come to that later on I think say something about inclusive design. They like mainstream products that, you know, that are easy to use because partly they look good”

31-45

F

Family carers (63FCLV)

“Wheelchair assisted vehicles are what they are, they’re big and ugly.”

46-60

F

Public transport preference (P13PTPCO)

“And I think what people don’t realise is if you have mobility issues or you’re disabled in any way, you know, the one thing that’s around you all the time is usually equipment and sometimes you’re very much housebound and you’re looking at the equipment, and hideous equipment just makes your self-esteem feel even worse because okay you’ve lost the use of your legs or arms or whatever, but then you still want to be able to have a nice time in your home and you want to look how you want to look; you don’t want to look like a hideous deformed person riding around in something that’s designed in the 50s, in my opinion.

Most mobility things are rubbish just to keep the costs low, but what people want is they want accessible cars, you know you can get these ones you can get in with your wheelchair and start driving but they’re using really boring makes of car and having a sports car or a go faster car I’m sure is what they want. This is about mobility scooters but someone from Stoke Mandeville rang me because what we talk about on the website is a lot about disabled aids, and it’s all about disability with style. And she rang up and said, “I’ve got a newly young disabled guy who has been here for 6 weeks who won’t go out with

his scooter, because he doesn't want to look like his grandmother. Are there any scooters that look like Vespas?" I said, "No, no such thing; there are no trendy scooters, they all look like mobility scooters."

31-45

F

Family carer (P1FCCO)

"My first son has got a wheelchair and it's one of these horrible black things and it's all about money, it's all about funding and keep it cheap. I don't know, but then there probably is something out there but it probably costs a lot of money. So yes, something cheap but cheerful. Yes, and it's like, "Are you going to town?" "Yes." "Are you going to take your wheelchair?" "No," because he doesn't want to be seen in this horrible black old person's wheelchair whereas ..."

Unknown (put middle aged)

Insurance company representative (44ICPH)

"I think it will happen because it is such a busy marketplace with a lot of scooters in there that people are going to have to start finding ways of making scooters more attractive, you know? Because they all are reliable, they have all got decent battery life, they are all easy to...you know? So they have done the basics. So it is a bit like the car market was 20 years ago, lots of cars were made but some of them were more desirable than others. And I think we will start seeing scooters being more desirable. And desirable could be cheap, desirable could be fantastically good looking or whatever, you know?"

SUBTHEME: PERSONALISATION

46-60

F

Family carers (14FCWY)

"He loves outdoor life, off road life. We can't afford an off road wheelchair. We now live on his pension and I think I get £60 a week for caring for him, so there is nothing surplus for all the lovely stuff out there. Every time you change your shoes for whatever occasion, so you're going to pub, you look lovely like that, you're going to a wedding, you put on some sort of smart lacings perhaps, you go out for a run, you put on your trainers, you go into the countryside you put on your wellington boots. I don't know. Think about how many pairs of shoes you've got in your closet, really and truthfully [name] needs to change his wheelchair for every one of those events because one doesn't cover all."

46-60

M

Occupational Therapist (P110TDALV)

"It's the same with any product really; the perceptions and the presentation is really important for people, not just young people, middle-aged and older people as well, they want to present in the manner which they're comfortable with, and that will change from person to person and generation to generation. Young people in universities often have front-wheel drive chairs because that's the image which is kind of cool at the moment and the chair obviously is very functional and the technology is very good. Whereas someone over the age of 60 for instance doesn't really want a wheelchair because they don't want to look disabled; they'd be happy with a mobility scooter. Whereas the young person will say, "Well the mobility scooter is for old people, I don't want to look old, I want a powered

wheelchair.” So you can see actually generations have different perceptions of what’s cool and the image they want to project really. Older people don’t want to look less able than they actually are, which is why a wheelchair might not be what they think is going to work and younger people say, “Mobility scooters are for older people, and the technology isn’t as good as a wheelchair so I’ll go for a wheelchair.” So again it’s different generations”

31-45

F

Driver of adapted car (88DACWY)

“So that is really important, that my chair is attractive, but it doesn’t take away from the person that I am. You see chairs that all you see is the chair rather than the person and the fact that it is... the way it’s made, it looks quite sporty and the casters are quite big and I need them to get around my environment really easy. “

46-60

F

Public transport preference (P13PTPCO)

“If you think about it, someone who is housebound they don’t want something put in their house that doesn’t suit their décor. Whatever their décor may be; I might love chintz, in which case I want a chintz wheelchair, or I want something that fits in with it, I don’t want an industrial looking piece of equipment, which is what most things are like. And it defeats the object of having the equipment because it then becomes not fit for purpose, because you’ve got a blanket over it, which you’ve got to take off and whatever.”

46-60

F

Passenger with disability (9PDCU)

“I have got a scooter but it is uncomfortable. It is finding the one which would suit me and I am still looking for that scooter. Because some of them, yes, some of them are just geared to the elderly, yes. And yes they are not modern. And they make me feel even older getting in the scooters. Because I am not being rude but the elderly have got a bad name for being in scooters, you know?”

SUBTHEME: PUBLIC FACILITIES

61-75

M

Driver of adapted car (55DACLV)

“changing facilities are not what you will call hygienic. You will find dirty and smelly nappies, the room stinks of the smell of them.”

M

Professional carer (11PCGB)

“Yes toilets...I had a guy in an electric wheelchair, we would struggle to get him in and out of the toilets and then you’ve got to try and turn it round. He was 19 stone, he could weight-bear slightly with help and I would find myself physically helping him up out of the wheelchair, holding onto

him, spinning him round to get him in a position where he can use the toilet. That is my real bug-bear, toilets. They need to be more thought into them. It's not appropriate when you've got someone stood there waiting, or sitting there waiting to go to toilet and you've got to take out bins, sanitary bins, put up baby changing mats and things. By that time they've had an accident, which isn't nice for them. So yeah toilets need addressing."

31-45

F

Family Carers (63FCLV)

"I think there's a lot of parents that are like me who get very, very frustrated that they can't change a child who's doubly incontinent anywhere and you have to take towels and this that and the other to put on the floor and to change them anywhere, that is frustrating."

SUBTHEME: TECHNOLOGY

Sarah, 42

Family carer

"He'll say: "I need to go to so and so: I'll just get it up on Google maps and it will tell me the best way to get there on a bus," or the best way to get there on a train and how long it's going to take and what to change and things like that. He just uses technology for whatever he needs to do really."

Unknown

F

Researchers (48RSW)

"There are issues in terms of how mobility is actually addressed in clinical practice when people come into contact with services in that often options aren't necessarily explored so people don't hear about technology that might be available to support them."

61-75

M

Powered Wheelchair user (72PWULV)

I: (powered wheelchair) what sort of features does it have that make it different?

R: Well it's three wheels, it's got two big wheels on the sides and it has a rear wheel, similar to some of the child buggies you see, so there's no front wheels so there's no castor wheels to get stuck anywhere. The rear wheel is on a hydraulic damper so the whole thing is built in suspension. You can change the camber on the side wheels just by twisting a rod so if you wanted to use it indoors you can straighten the wheels so they take up less room.

I: Right, so you could use it indoors and outdoors?

R: Oh yes. If you want to use it outdoors then you splay the wheels out to give you a better camber.

I: And can that be done automatically?

R: Yeah you just twist a rod underneath. It's quick release wheels, the motors are in the wheels."

61-75

M

Powered Wheelchair user (72PWULV)

R: the only thing it could probably have is a longer battery life. But as I haven't taken it out all day yet etc. etc. I'll see how long the battery lasts. It only takes a couple of hours to charge it up.

I: Right, but that's a consideration though for you?

R: That would be a consideration yeah. It may be a situation later on to buy a second battery as a backup.

I: Because then you've always got the option to change it?

R: That's right, if one battery goes you can put the second one in.

I: Is there anything that you think could be done to make that battery life last longer?

R: Yes you could put a different type of battery in which would give it a longer range but you're talking expensive technology."

31-45

F

Driver of adapted car (88DACWT)

"My fiancé buys and sells cars, actually we got solar panels last year and a man put a car charger point at our house so when I was doing a lot more miles, I needed to get some kind of battery related car; that's how my fiancé, came up with Toyota and we sourced it. A car dealership got it over from England for me and I got it."

61-75

M

Powered Wheelchair user (68PWULV)

"when I'm going along in the winter your hand freezes, because it's on the controller, it just freezes, even if you've got a glove on. If you could programme it then you could just go."

SUBTHEME: COMFORT & CONVENIENCE

31-45

F

Family carers (63FCLV)

“Comfortable, practical, lifeline, that’s the three words I’d use about my car.”

46-60

F

Passenger with disability (9PDCU)

“I did see one which folded up really small because a lot of them they do fold up but they are still big and bulky and heavy, because I can’t lift them on my own and that is another thing. I would like them to be lighter. So even though I am disabled I can pick them up if I needed to.”

61-75

M

Driver of adapted car (55DACLV)

“The other thing is they’re cutting so many routes on the public transport front. I have a lot of friends who live in Cornwall and they don’t even have a bus route now. They have to get someone with a car to come and pick them up to take them to go and do their shopping and things, or they utilise their mobility allowances on taxis to do it. Which I suppose that’s what the mobility allowance is there for but it’s inconvenient, you’ve got wait and, or else, you know.”

61-75

F

People with disability as passenger and car driver (57PDCLV)

“What makes it comfortable for me is that the seats are at the right height. Leather seats I find much more easy to move in and out and move around on rather than fabric seats.”

61-75

M

Driver of adapted car (59DACLV)

“Yeah, porter then, if I ask for where I park the car up they will meet me there with some sort of transport and take me there, like a little buggy thing and they’ll take me straight in and I go to customs and what have you. And when it’s time for the plane to fly they take me down to the gate and then it is helped onto the plane and everything is fine.”

61-75

M

Driver of adapted car (59DACLV)

“at the moment he can manage quite well providing he’s got an automatic gearbox and something called cruise control, I don’t know if you’ve come across that, you maintain a speed without having to keep your foot on the accelerator all the time, so that you’re pretty much sat back not using your feet, only covering the brake as necessary.”

61-75

M

Driver of adapted car (55DACLV)

“they talk about driving position memory. Well, that’s fine when you get into the seat, what you should be doing is having a switch somewhere that says your initial, you know, in our case it would be ANT, so if A gets in she would be in this position, if T get in the seat should be in that position. Jaguar, actually, are the closest, funny enough, my wife had a Jaguar one time, on loan because her car was in for service believe it or not.”

61-75

M

Powered Wheelchair user (68PWULV)

“It’s not too bad, I just wish we had a zebra crossing at the top of the road, because you’ve got the shops and you’ve got to cross the main road”

46-60

Unknown

Equipment provider (40MEPJR)

“I think from our point of view is the... All our products always come down to the weight. Everybody wants a nice long ramp that will fold as small as it possibly can and weigh next to nothing.”

M

Motability Governor (1MGPH)

“if the adaptations that are provided could be simpler to operate, you know, some of the hand controls...I’ve got pretty light ones but they can vary in the amount of strength that is needed to operate them, just a general improvement in user friendliness.”

SUBTHEME: FUNCTIONALITY

61-75

M

Powered Wheelchair user (68PWULV)

“I’ve actually put one of them bike alarms on mine, so it’s almost like a mini siren, and also because the horn on the wheelchairs are rubbish.”

61-75

M

Driver of adapted car (55DACLV)

“If cars had a simple touch button means of raise, lower, forward, reverse, it would be helpful to disabled people”

61-75

F

Driver of adapted car (69DACLV)

“Yeah much more, yeah. I mean with my husband changing gear means constantly putting his foot on the clutch which would absolutely cripple him. And I know you’ve got a lot of people that have

got problems with their arms so the last thing they want to do is keep changing gear. So for them to be standard most of them... I mean all cars come with automatic gearboxes if you want them”

45-60

F

Occupational Therapist Driving assessor (86OTDALV)

“I think hospital wheelchairs they have the bar at the back like a shopping trolley, it’s so much easier to push.”

46-60

M

Driver of adapted car (58DACLV)

“how would you like to feel when you are with them in the car? / R: Safe.”

18-30

M

Mobility Facilitator (20MFMG)

“I think it completely depends. It depends how much they get in benefits or whether they’re able to work or how much money you have. So I think the vast majority, vast majority of dancers at our classes have NHS provided wheelchairs, they can’t afford to buy their own, and in general they’re kind of like old tatty, struggle with cobbles, and not at all really designed for, well not capable that much of going out and about and, or certainly not going off road or like on grass or anything like that. You know, they’re only really capable of going on paved roads. So yeah (laughter) I don’t know, it’s ... in my experience it’s most wheelchair users can just afford the NHS chairs they get given and they don’t really have the budget to go for anything more expensive or anything more high end. In terms of what’s affordable, I don’t know, there’s, you know, we have wheelchair users at both ends of the sort of spectrum when it comes to income.”

SUBTHEME: SEAMLESSNESS

31-45

F

Driver of adapted car (88DACWY)

“only thing I would need to do about changing my chair is getting a more updated one maybe, they last like seven/eight years. So my chair actually is really economical so the health board rather than getting a cheaper one that used to change more often.”

46-60

F

Driver of adapted car (79DACLV)

“I think I’d tell them to look at a few cars, try a few cars, have some adaptations as well, because you have the car for three years and things do change as the years go by, you need to make sure really that that car is going to be suitable for you for the next three years. So I’d tell somebody to look at the car and see how that feels, drive the car and look at it from the point of view is it going to be alright for me in two years, three years time? Is it going to have everything I want then if my condition or whatever it is deteriorates.”

46-60

F

Driver of adapted car (54DACLV)

“The Motability scheme I found that out off my brother in law. He was actually on it. And I have been on there, the Motability, now about 18 years I think.”

SUBTHEME: SIZE, CAPACITY & EFFICIENCY

61-75

M

Driver of adapted car (55DACLV)

“With my wife and I both being disabled, and both using walking frames now, we also need a boot that’s big enough to carry two of them without needing the car lift.”

Unknown

Unknown

Motability Customers (1MGPH)

“Likewise with the personal side of mobility, well, one of the problems why I haven’t gone onto a powered wheelchair is because they take up more space than the one that I’ve got and the turning circle, and this is very important, that you’re in somewhere that’s got a relatively narrow hallway or corridor, getting access, so enhancements on that side, really as small and compact as it’s possible to be.”

46-60

M

Driver of adapted car (58DACLV)

“Well big enough to take any equipment I have got to take with me like the wheelchair and the (inaudible 00:18:26).”

61-75

F (78PDCLV)

“I think we’ll manage because it’s got quite a big boot and at the moment we can get both the walkers in the back and some luggage and I think some luggage will have to go on the back seat. But as long as there’s only the two of us we’ll be okay, taking luggage and stuff, yeah.”

APPENDIX K

INCLUSIVITY: LONG LIST OF EXAMPLE QUOTATIONS

SUBTHEME: PHYSICAL ACCESS

61-75

M

Powered Wheelchair user (68PWULV)

“the bathroom’s still upstairs, so it defeats the object”

31-45

F

Family Carers (63FCLV)

“disabled parking spots are very very limited wherever you go and you need the additional space to get a disabled person in and out of a car and also to get a wheelchair in and out of the vehicle. A lot of car parks have very very tight parking spots because they try and get as many people in as they want”

61-75

M

Driver of adapted car (56DACLV)

“Yes, yes, because that’s one of the ideas we went to the show for is to look at the different type of vehicles like that and for her to pick out the one that she finds easiest to get into –

I: Fantastic!

R: - which makes a lot of difference.”

Unknown

M

Mobility Equipment providers (29MEPSW)

“I find most access needs are about space at the end of the day and like all disabled people I am the least disabled when I am at home yes because that is the environment that I control and it is as near as possible it is ideal for me.”

31-45

F

Passenger with disability (85PDJR)

“Because the one [WAV vehicle] we have got currently, we are having to terminate our contract early. The one thing I hadn’t realised was where we are, and I can fully understand why the council do it, they’ve got height restrictive barriers on car parks, especially car parks that are next to beaches, because they don’t want travellers and holiday homes parking over night or for days, so it would be nice if Motability could have more vehicles that are – I think they’ve got to be under 2 metres high.”

46-60

M

People with disability as passenger and car driver (12PDCFN)

“Getting round the home is mainly now we’re finding the doors and having storage where we can reach, I would say that’s the main thing, because we know we’ve got room in the hall but then it’s actually being able to have storage that we can reach and having the units at a height where we

can reach them. We've stopped using an oven because most of the ones that are built in they're this height so we thought it was dangerous lifting food out at this height. So there was a danger that it could tip and spill on you, so we use a combination oven on the work surfaces which we've had one of them lowered so that's better but we still feel we could do with eventually changing it so you can get nearer"

18-30

F

Equipment provider (4MEPCO)

"Access to buildings I guess maybe generally small things like if shops have a ramp that they can... If it's not level access, yeah so people can just get in because I think that's one of the main things that people struggle [...] Access. Basically just getting into the building itself."

46-60

F

Family carer (14FCWY)

"There is no wheelchair accessible coaches."

46-60

F

People with Public transport preference (P13PTPCO)

"Yes, we've got a disabled loo, you can get a wheelchair in there." I said, "Have you got grab rails in there?" "No, but you can get a wheelchair in." [...] There are standards but if it's an old building you don't necessarily have to put them in, plus they get misinterpreted the wrong way, which I will show you. That looks like a reasonable disabled loo, but please note, when you get into the loo, right you grab with your right hand; when you're getting off the loo where are you going to grab? This is meant to be on that side or that's meant to be ... yes, that's meant to be on that side but because they put such a big toilet roll dispenser in the builders saw they couldn't fit the bar in so they thought, "Well where are we going to put it?" So we've got 2 bars on that side. Now how ridiculous is that? "

SUBTHEME: SOCIAL INCLUSION

Unknown

F

Occupational therapist - Local Authority (P30TLAMG)

"No, I just wanted to mention it because it is a pet hate because you see it happening a lot and because my view is that it's not...I think in some of the bigger supermarkets, it's like, well, you know, it's not our responsibility to ensure that those spaces are kept free for people, so my view is that they need to take more responsibility for ensuring that those spaces are free for people who really need them and who should be using them, not others. So although it's there, it is something that is a pet hate because you see that, the misuse of those spaces, a lot. So on that one I'm thinking of more policing of it, more responsibility."

31-45

M

Driver of adapted car (66DACJR)

"Well for example if you want to sit in an (inaudible: 00.13.09) exit seat on a commercial flight you

can't be a passenger who requires assistance. No you can't, you're not allowed to, because I check that out. And what you can't either do is you can't book a seat for your companion, you can book one for yourself but you can't book one for your companion. So we have faced the possibility where we were on a long-haul flight with the kids where I am away from the rest of the family because they couldn't book their seats"

31-45

F

Driver of adapted car (88DACWY)

"We live in a world where everybody is different"

M

Motability Governor (P5MGPH)

"But there is a whole range of issues where disabled people don't have a choice, other people do so if you think about with buses where people are using, putting prams in the wheelchair space and that means a wheelchair user can't use the bus."

61-75

M

Driver of adapted car (55DACLV)

"I've had that experience out as well at restaurants and stuff. You know, people will place you in places away from the normal people you know, and sometimes it these things just aren't thought about at all. As I said, I've become quite a portly person since I became disabled, and they put in a booth where the table is pushing against you, and there's no comfort to eat the meal, and it's things like that. The spacing in restaurants, I think should be looked at, and in fairness the whole countries becoming more obese than ever. Now, maybe restaurants having bigger spaces isn't very ... obesity, but I think, in general, they should be thinking of that extra inch. "

31-45

F

Driver of adapted car (88DACWY)

"Yes. I suppose my view of my chair is really positive because without it my participation wouldn't happen, I would have no social outlet and I couldn't get anywhere and that would happen equally if I had a badly fitting chair."

31-45

F

Passenger with disability (85PDJR)

"Some people who are disabled seem to think that if the driver can walk and your do it in a wheelchair, that you can park anywhere whereas somebody else may not be able to. They forget that you need the length or width of a disabled car parking space to safely use it."

M

Motability Governor (P5MGPH)

"You know because there is some research, if people get (inaudible 27:24) they don't park there again, so I've heard, you know. It is frustrating when people park in blue badge spaces, I mean some blue badges are, of course, given out far too easily."

31-45

F

Family carer (63FCLV)

“I also come across a large prejudice as well because it’s my daughter that’s disabled and not me, so if I put the badge up and get out of the car and then people challenge you and you say, “Well hang on a minute yes I’m not disabled but the person in the car is”.[...] Very angry but you keep your cool and you just say, “Look the person in the car is disabled” and then when you get them out they eat their own words. But yeah you do get some funny looks sometimes. It’s because I get out of the car and there’s nothing wrong with me, I have no physical disability or anything else and I look absolutely fine and when you get out of the car and you put the Blue Badge up it’s like what are you doing parking in one of these spaces? I might not be disabled but my daughter is.”

31-45

M

Equipment provider (37MEPEB)

“Well if we talk about these folding scooters, the one challenge I suppose is that you wouldn’t think but there’s still an issue with batteries, taking scooter batteries on planes because pilots will only allow a certain... I don’t know the technicalities but they will only allow a certain type of battery on a plane and I don’t know whether it’s going to explode... It’s like some kind of safety risk but I have come across that and it has been an issue where people have tried to go abroad and it gets sorted but I think there probably needs to be more, again, education with the airline side of things about what is acceptable and what isn’t so people don’t have hassle.”

31-45

M

Driver of adapted car (80DACPH)

“Awareness really. Awareness because they need to know what we need.”

SUBTHEME: PSYCHOLOGICAL INCLUSION

31-45

F

Driver of adapted car (67DACJR)

“I live near a train station and there is quite a good train station in that it links all the way to Southampton, Brighton and London without having to change trains and if I plan my journey they’re very helpful. But if I wanted to go on the spur of the moment it varies as to whether I get enough help. I was once at East Croydon Station stuck on the train waiting for the ramp and the train nearly pulled away with me still on it.”

31-45

M

Driver of adapted car (66DACJR)

“I think one of my biggest fears if I was to be re-assessed that they said, “I’m sorry but you’re not bad enough for all PIP” because I’d have to look at other ways of getting around.”

61-75

F

People with disability as passenger and car driver (57PDCLV)

“consequently I rely on the car very, very heavily to get anywhere that I need to go and days are just spent coping with ... that I can manage, so I like to shop a little bit, go out to visit friends, we have a lot to do with our local church.”

61-75

F

Driver of adapted car (69DACLV)

“As I'm getting older I'm finding that I'm not quite such a confident driver anymore.”

61-75

F

Driver of adapted car (69DACLV)

“but I know a lot of people do have a lot of assistance with their cars, they have a lot of different special controls and that, but that's for people that are more disabled than my husband.”

31-45

M

Driver of adapted car (66DACJR)

“we've had more than our fair share of disasters where you expect one thing when you arrive somewhere and you suddenly find well actually the disabled parking is not close to the venue and there isn't the (inaudible: 00.09.37) service available that you were told. And before you get there you're knackered (laughter).”

M

Motability Governor (1MGPH)

“Here's a problem then. If I am some distance from where I can normally self-propel myself in terms of range, I mean I always have the precaution of having these hotels' phone number in the vehicle and I ring and I simply ask them for someone.”

31-45

M

Passenger with disability (43PDEB)

“Yeah, yeah, so lots of disabled people are driving and that's also not good to go in from the side because like you need to take two or three parking spaces (laughter) you know and when you get blocked then you're really stuck because the (sl PA 00.09.05) cannot drive, not allowed to drive things like that, how are we going to move that vehicle? So it's just a nightmare when it's blocked and we cannot approach the car.”

31-45

F

Passenger with disability (85PDJR)

“We could if, well, we've got kneeling buses in the area. It's okay if you want to get on at town and go anywhere along really, [...] but coming back it would be hit and miss. They have only got one wheelchair spot and if somebody else is in the queue in front of you that needs it, you have to wait for the next bus and hope that somebody else hasn't got on at the previous bus stop.”

18-30

F

Family Carer (16FCSW)

“We don’t tend to use the buses just because I’m always a little bit worried that there was recently because on the buses, one of our friends, basically there is a park for a wheelchair but if somebody’s already there with a buggy you won’t be able to use it and therefore because we’re just in a normal buggy and [NAME] has no sitting balance, I’d then have to take her out, take that one out, so I’m always reluctant because I just don’t want to get into that situation (laughter). Also it’s not as easy when you can’t take her out of the buggy to collapse the buggy because she’ll be lying on the floor somewhere.”

18-30

M

Mobility Facilitator (20MFMG)

“in general our members or what I’ve experienced with my members just verbally talking to them is that they’ll avoid public transport and they’ll avoid flights as well, just because it’s too much hassle and there’s limits to the number of wheelchair users you can take on flights. So you can’t have ... if there’s a group of eight they’d all have to take four separate flights or whatever because you can only have two wheelchair users on each flight. So yeah, there’s definitely a lot of issues in trying to get a group of wheelchair users from one side of the country to the other.”

46-60

M

Driver of adapted car (45DACJR)

“So what’s funny is, is my wife and I, we used to go away a lot but we’ve lessened the amount that we fly now because one, you’ve got the security stuff that is a real drain, I mean I keep getting my wheelchair now taken off me and it has to be x-rayed and then it has to be stripped and it’s like you know, thanks guys. And I always take tools with me whenever I go abroad in case the chair breaks, that always causes problems. So yeah it can be a bit troublesome, but I suppose I do alright. I’ve worked with people that have much higher levels of impairment than I do and you know, when you see them have their wheelchair dismantled and put in plastic and all this kind of stuff and then be manhandled on and off airplanes, because there’s no real understanding of how you assist someone”

46-60

F

People with Public transport preference (P13PTPCO)

“I have used the train. I will use public transport but I won’t do it on my own, I have to make sure someone’s with me, it’s too frightening on my own. Cabs I will do on my own because I’ve got someone with me – the cab driver, but trains and buses I won’t because I’m too worried about not being able to get off at the other end, or at the front end.”

Unknown

M

Mobility Equipment providers (29MEPSW)

“You have got things like catheters and things like that but I am not saying you will want to do it but needs must. If you are on a long journey you can either dehydrate yourself or use the other methods, you know?”

61-75

F

Driver of adapted car (78DCLV)

“It’s a struggle sometimes but most of the time, if I’ve got a trolley going round the supermarket it’s not too bad all but going round the district, unless I took my walker and I don’t like to do that where people know me, I know it sounds a bit silly”

31-45

M

Driver of adapted car (66DACJR)

“I think sometimes because, well I’m too heavier than I should be and I think there is a natural tendency for people to look at you and pass judgment perhaps if you’re too big or you’re young and you’re in a chair or a scooter they think there’s nothing wrong with you, you’re taking the mickey”

31-45

M

Driver of adapted car (66DACJR)

“I suppose you could be embarrassed about having to use equipment, (inaudible: 00.19.07) descriptive words, embarrassed, conscious, you try to normalise its use and what would (inaudible: 00.19.19) you’d want it to be a bit more discreet, less obvious, less obtrusive”

SUBTHEME: SERVICE SUPPORT

46-60

*M**Driver of adapted car (58DACLV)*

“the car for a reasonable amount over a couple of years and you get quite a good service from them. So (inaudible 00:27:29) a little bit but it is also very handy having the mobility scheme because everything is under one roof and you just have to speak to one person and (inaudible 00:27:37) from there. So (inaudible 00:27:42) a bonus really (multiple speakers 00:27:44) having it all like a one stop shop baspavically”

31-45

*F**Family Carers (63FCLV)*

“from the point of view of practicality and mobility, I like the fact that I know if there’s any problems with the car I can phone up the mobility assistance and they will get to you as soon as they possibly can and they will prioritise you because you have got a disable person in the car, so that takes one worry away, that I know that whatever happens, if we have an issue with the vehicle they will take care of that and take care of us,”

61-75

*M**Driver of adapted car (65DACJR)*

“Motability is a really wonderful thing, but it’s a company and needs to be paid. If you are on an allowance, that is gone, you don’t see it, it goes straight to Motability.”

61-75

*F**People with disability as passenger and car driver (78PDCLV)*

“I did see the Motability people and they were very very helpful at the show, in fact everybody was, I was really impressed with the show. And I was able to see what was available, what was going on”

46-60

*F**Driver of adapted car (79DACLV)*

“It’s an excellent thing; it gives you peace of mind, you have no worries. You’ve got enough worries with your illnesses and just day to day living, but to have a car on the drive, it’s just giving freedom. You’re not restricted, but you don’t have to worry about that car either. Everything is included. You don’t have to worry about paying for the road tax, paying for the insurance, oh my God, it needs new tyres. Those sorts of things are gone. So it really does take pressure away from you”

31-45

M

Mobility Equipment providers (21MEPFN)

“Of course there are holes and you read about people, or meet people, and they have a really tough time of it and I think one of the frustrations is you get different services in different areas so you meet some families that will be getting on very nicely and perhaps because of their own volition they will have found out what they need as a family and actually other families aren’t perhaps as in a position to pick up on the services that are around them.”

18-30

F

Family Carer (16FCSW)

“I think people are coming up with loads of things every day really, like coming to this I’ve already seen a few things that people have already come up with which is amazing. I’m a physio myself and I think you only know what’s out there when you go to see it for yourself because even as a professional you only know what you’ve seen already.”

31-45

M

Mobility Equipment providers (37MEPEB)

“From my experience... Gosh, unfortunately there are still a lot of challenges that people... As I touched on, the major challenge is finding credible information. Unfortunately there aren’t many people like me who work in media and generate content about products in this sector. The major marketing and design agencies tend to work out of the sector, so there’s very few consultants like me putting information out there. So you know, however hard we work, it’s still quite limited out there to find information but in terms of day to day living, accessibility in the outside world is still not there.”

46-60

M

Driver of adapted car (58DACLV)

“we would check websites and make phone calls and explain to people what my situation was and how could they accommodate me? Things like that.”

31-45

F

Driver of adapted car (67DACJR)

“if it was made available do you think personally it’s something you’d use, or you’d need more information?”

R: More information.”

Unknown

F

Researchers (48RSW)

“There are issues in terms of the sort of how questions of mobility are actually addressed in clinical practice when people come into contact with services in that often options aren’t necessarily explored so people don’t hear about technology that might be available to support them.”

SUBTHEME: PUBLIC SERVICE

46-60

M

WAV driver (53WAVLV)

“when my wife is in work I get carers come in 3 days a week round about lunchtime, just to make sure I’m okay, fed in the middle of the day and that’s it”

61-75

M

Driver of adapted car (56DACLV)

“They don’t get charged any extra, they still get charged the normal rate like you do with an ordinary customer, but they always take about fifteen minutes extra to deal with those type of customers”

18-30

F

Mobility Equipment providers (4MEPCO)

“I think if places just do their best to make it as accessible as possible and also, promote the fact that it’s accessible, so maybe publish information on the website, pay for staff training, that kind of thing so basically they know about”

SUBTHEME:FAMILY SUPPORT

46-60

F

Driver of adapted car (54DACLV)

“I rely on my daughter for a lot of things. Say like if I need to go to the shops or anywhere she will take us”

61-75

F

Mobility scooter Customer (60MSCLV)

“I rely on my daughter for a lot of things. Say like if I need to go to the shops or anywhere she will take us”

46-60

M

WAV driver (53WAVLV)

“[...] if you’re in hotels and that then you’ve got the support of the hotel staff (inaudible: 00.23.54). Yeah, I don’t think we’ve encountered any problems in that way yet.”

31-45

F

Driver of adapted car (64DACLV)

“airports are fantastic because obviously they’ve got assistant people to help NAME, because he can’t wheel me (inaudible: 00.10.05) airport”

61-75

M

Driver of adapted car (55DACLV)

“R: [...] My wife and daughter, as I say, are really fantastic in driving on with me.

I: Ah, it sounds like you’ve got a very good close knit family.

R: We actually have four generations living in the one house, which is a fantastic thing. Our grandson’s ten years of age, and my father in law is 92. So we fill that spectrum. I think a lot of people in disabled circumstances should find family support before they get council and government type support. I think families can offer so much more in encouragement and making things that you’re able to do.”

APPENDIX M

FINANCE: LONG LIST OF EXAMPLE QUOTATIONS

SUBTHEME: EQUIPMENT COSTS

46-60

M

WAV driver (53WAVLV)

“getting around and moving around depends on the financial side of things”

SUBTHEME: FINANCIAL SUPPORT

John, 36

Mobility Equipment provider & family carer

“He’s got a Panthera manual wheelchair, fund raised, so we fund raised for that, so what wheelchair services provide is good but actually when you see a lot of the equipment here and you have got a young son who wants stuff, it’s like ‘well, how you going to get that?’ so again time scale is a big factor. So in terms of like putting my [organisational] hat on I tell parents that if it is applicable and they are looking at fund raising then you really need to look at that twelve months ahead.”

SUBTHEME: GOVERNMENT SUPPORT

46-60

M

(12PDCFN)

“We don’t earn a fortune, I know for a fact the government are on about cutting back on benefits, so it might realistically be that because I’ve got (sl a fitter 00.14.36) if I lose my mobility allowance I would lose my car, even though it’s my car, I wouldn’t be able to replace it, so there are going to be financial constraints on anybody.”

31-45

F

Driver of adapted car (80DACPH)

“Well obviously it’s a bit worrying that the government are making cut-backs on the DLA and the Motability grant, so that’s a bit of a worrying thing, because if they took that away we’ve lost our independence. So obviously that’s worrying.

I: Yes, because that’s the key way of funding your car?

Yeah, funding my car and funding me to get out because if I had no car I can’t get out. Very important to all of us, not just me.”

31-45

F

Driver of adapted car (67DACJR)

“Unless it changes and it’s going to make a big difference, because I can walk 20 metres with a stick I will probably lose my car. And I’m very frightened and I’m not the only one. So I think that is going to make, it’s already making a lot of people more isolated and it is such a shame. Because I will probably get middle rate mobility hit, that will pay for a couple of taxi rides. So it will change my life a great deal and I’m scared. I’ve got an indefinite award and my care is three years so I’ve got until 2018 so I

think I'll be done in 2018 and I'm trying to save towards buying my own car but it's the adaptations. I use quite a lot, I use (inaudible: 00.17.12) hand controls and a steering ball and they're £800 on their own. A car it's not like you can just rent a car like anyone else, I have very bad credit because I'm on benefits and I've got to have these controls and that's difficult to... and those kind of barriers you don't know until you're in it."

SUBTHEME: SERVICE SUPPORT

46-60

M

Driver of adapted car (P4DACLV)

"Although as far as I'm concerned money is not everything, if you take the extreme case where you have none, what quality of life can that lead to? And all the things that I bought, that I've been able to buy and I've been very lucky with supportive family and helping, I mean, these chairs don't come cheap. This is about £4500. My stand-up chair that I bought ten years ago was £3500, the car conversion that I bought last time was nearly £2500, so this is extra to whatever you need. As you're asking here, these are bits to give me this freedom to have the health and fitness benefits associated with these bits of equipment. But if I didn't have that money, I wouldn't have these devices. "

61-75

F

Driver of adapted car (84DACWY)

"[...] to be honest there's mobility options out there and I believe they're very good for people of all walks of life. But me personally I just think it's a great service."

31-45

F

Driver of adapted car (80DACPH)

"Obviously there would be if we did lose it, there would be an extraordinary cost and obviously we'd have to look into it, but having Motability it helps so much because it does give me the freedom to go out and about, and obviously to maintain it, put petrol in it, you don't mind because at the end of the day it's your car."

M

Motability Governor (P5MGPH)

"[...] "that is the sort of technology you need and then I'd come to the other thing is how would you pay for it, that immediately cuts out a whole range of people who have got no money. Most disabled people are quite poor; I think the average Motability customer has an income of less than £20,000 a year. So if you're going to start changing £20,000 for a wheelchair they're just not going to be able to afford it and what we should be doing is getting this technology down in price and we should be price it properly so that people can afford it"

SUBTHEME: SERVICE COSTS

46-60

M (12PDCFN)

"With regard to the car, I mean I know they've got the Motability scheme but I still think for what it is it is still very expensive [...] Because it's so expensive. I mean for my hoist it costs about £5,000

to buy and it's £1,000 to put it on your car, so if you've got to change that every three years with the Motability scheme it starts to get a bit expensive. I mean they have improved that. Yeah I could get a wheelchair accessible vehicle but then you're looking at a lot of money. I mean a deposit on I think what they would call a wheelchair accessible vehicle, to buy it outright could be in the range £50,000 / £60,000 to get it on the scheme you'd still need somewhere in the range of £16,000 / £17,000 deposit. So for a lot of ordinary folk the deposit and the money that's involved is out of the question. I tend to have my vehicles and keep them for about six or seven years so I get the value out of them."

46-60

M

Driver of adapted car (45DACJR)

"for me, I'd like to see kind of a better quality wheelchair that is cheap, because I think one of the problems is wheelchairs are getting really nice but they're still very expensive. I mean you know, kind of there's a chair out now, the carbon black, that's £25,000. I think that's ridiculous, it's criminal and I think that that creates a kind of two tier system where you have people that have got the most expensive chairs that do everything and are perfect for them and then you've got people that get sort of saddled with the really cheap wheelchairs"

46-60

F

Driver of adapted car (79DACLV)

"The only thing we found that was we have an automatic just now, so we wouldn't want to go back to a car with gears, so we'd need an automatic, but they don't do that many automatics. There's very few cars that come in automatic. But you have to put a certain amount there, up front, to have an automatic and it can be quite expensive. That's the only thing we found. Last time we put down about £1300, which is sort of dead money. You don't get it back, but at least we could have the car we wanted with the automatic."

M

Motability Governor (P5MGPH)

"And then there is my vehicle which of course is so damned expensive, it doesn't actually pay me to use Motability."

Unknown

M

Mobility Equipment providers (29MEPSW)

(WAV) "You can get them on Motability, they are horrendously expensive. You are talking about, I think it is on a five year lease, then the upfront payment is something like £34,000/£35,000. And that is just for a five year lease so that is money down the drain at the end of the five years. So I bought mine second hand. They are on the market. And they are quite common, there is quite a few of them here."

Pat, 53

Driver of adapted car

"For me, I'd like to see kind of a better quality wheelchair that is cheap, because I think one of the problems is wheelchairs are getting really nice but they're still very expensive."

SUBTHEME: EXTRA COSTS

Tim, 39
(34ACPH)

“No it’s really the cost. The majority of the transaction is in terms of the additional cost. The person’s allowance tends to be up to £1,000 whereas that particular adaptation could be significantly more. I think one of the challenges is that a lot of the work that I get involved in terms of the modifications to the car is that it’s an additional cost, I mean it’s not built into the cost of the car. So some people feel like they’re being penalised and I think that’s a constant challenge because in reality, if you have a disability that dictates that, it is a little bit unfair that you should have to pay a premium.”

Research priorities which respondents felt were already in existence but required improvement or were too expensive

Encourage better facilities for personal care on flights

82.4% definitely agree, 11.8% mostly agree and 5.9% mostly disagree

Comments associated with these responses were: “I have not been on a plane so do not know any problems they face”

Develop a sensor to alert people when they park too close to disabled vehicles

58.8% definitely agree, 11.8% mostly agree, 23.5% mostly disagree and 5.9% definitely disagree.

Comments associated with these responses were: “It is a good idea because disabled drivers need a good space to get out of the car” but no comments were offered to explain the mostly disagree responses.

Create better designed and finished wheelchairs that make the disability less noticeable

52.9% definitely agree, 35.3% mostly agree and 11.8% mostly disagree

Comments associated with these responses were: “people see chairs first and person second, if chairs were designed to look nicer then people would not stare so much in despair or disgust” “wheelchairs need to be seen”

Develop an in car mobile changing station for personal care for both adults and children

47.1% definitely agree, 35.3% mostly agree and 17.6% mostly disagree

Comments associated with these responses were: “not sure how it would work would need big car”

Develop a moulded body positioning system for the car seat

47.1% definitely agree, 47.1% mostly agree and 5.8% mostly disagree

Comments associated with these responses were: “holding me safe” no comments were offered for the mostly disagree response.

Advance the availability of driverless cars for disabled people

11.8% definitely agree, 41.2% mostly agree, and 47% mostly disagree.

Comments associated with these responses were: “I can't see that happening” “I believe this opens up too much scope for accidents with technology going wrong”

Develop hover technology for wheelchairs

23.5% definitely agree, 29.4% mostly agree, 35.3% mostly disagree and 11.8% definitely disagree

Comments associated with these responses were: “wow no more bumps” “hovering would take a lot of resource energy, and if energy ran out while out then it would cause problems”

Create a lift capable of taking wheelchair and the person into a vehicle

29.4% definitely agree 64.7% mostly agree and 5.9% definitely disagree

Comments associated with these responses were: “This is nothing new”. “The only safe method is to use a ramp like a WAV car”

Create an automatic bike rack that lifts bikes onto the vehicle like the ones available for wheelchairs

11.8% definitely agree, 64.7% mostly agree, 17.6% mostly disagree and 5.9% definitely disagree

This means that despite being identified in the data analysis of the interview transcripts, as areas for research, 9 research areas (listed below) were not regarded as having a high priority by the respondents in the Delphi.

- 1 Encourage better facilities for personal care on flights
- 2 Develop a sensor to alert people when they park too close to disabled vehicles
- 3 Create better designed and finished wheelchairs that make the disability less noticeable
- 4 Develop an in car mobile changing station for personal care for both adults and children
- 5 Develop a moulded body positioning system for the car seat
- 6 Advance the availability of driverless cars for disabled people
- 7 Develop hover technology for wheelchairs
- 8 Create a lift capable of taking wheelchair and the person into a vehicle
- 9 Create an automatic bike rack that lifts bikes onto the vehicle like the ones available for wheelchairs

Whilst numbers 6 and 7 above would appear to be future possibilities, they did not chime with the respondents as being current priorities. The research priority area related to personal care on flights was very important to some respondents and totally irrelevant to others who never flew. It is also an area of interest which whilst potentially important, lies outside the remit of this project or the power of any organisation other than the aviation authority or individual flight providers to alter. The remaining priorities would seem to be reasonable but were not important to the respondents. Finally as respondents were unable to come to agreement on these remaining areas for research priority, although initially identified in the interviews, they would not appear to merit a research priority at this point.

APPENDIX 0

CAR CLUB QUOTATIONS

Yes I would say it would. (Multiple speakers 00:20:32) I use my car which is now and again (inaudible 00:20:36). My daughter she takes me to all my hospital appointments and everything through the city. And the odd now and again my son he will have to go back and drop them off somewhere, his friends or something. And apart from that I don't use my car.

I think it certainly would. I am fortunate that I have got my car through Motability and I've got it for a few years now, it's great. If Motability or a similar company said look, there's a car there that is necessarily adapted, then it could be hired for a day or half a day or whatever period of time it might be needed. I think the important thing is there that it would need to consider adaptations for each of these vehicles.

I guess it depends on the outcome of PIP. If you don't hit the threshold for mobility under the personal independence payment for both the mobility and the DLA then the answer's yes. I think one of my biggest fears if I was to be re-assessed that they said, "I'm sorry but you're not bad enough for all PIP" because I'd have to look at other ways of getting around. I don't know if that's something that's a common theme or not but the change-over is one of the issues in the back of my head that is a nag, what happens if you are re-assessed and you do not hit the new criteria? Now people around me tell me not to worry about it, they say, "You will", but because there's a degree of uncertainty it is not really conducive to allow me to get on with my life in an independent way and I'm sure there are people who have had a mobility vehicle and have had it taken away who are having all sorts of issues as a result. I think if it was taken away I would probably become ill quite quickly. Because I would have to do more physical exertion which would put more stress on the condition, it would just mean that I'd become unwell.

I'm not sure how it would work but in theory it's a great idea.

Well that sounds like a good idea because what might be a good round the town car or popping to the supermarket that sort of thing would not be very good for a trip up to the North East for instance or to France. Well I can see the attraction of it, but on the other hand it is quite nice to have your car that is yours as well, but I can see there's a lot of sense to that argument because I don't use my car every day. So yeah I think that's quite a good idea. And then if you wanted a car to go for a local trip that would be fine and if you wanted a different car for a longer journey that again would be a feasibility with a car club idea.

Well yeah I would be interested but the thing I would like to know is the cost. Well yeah I would be interested but the thing I would like to know is the cost.

That would be great wouldn't it? So at the moment, I don't know a huge amount about it, but they're making it now easier to get a Motability car but you can only get a Motability car if you've got the higher rate of disability living allowance can't you? So if they didn't have to spend all their money on a Motability car that would mean that they could... I don't know what else it would mean they could do instead, but they wouldn't have the upkeep of the car would they? It sounds like a good idea I'm just trying to think what would be the purpose of having to rent a car rather than having the car? - yeah I think it's a good idea. Also if somebody's thinking about getting a mobility car I suppose it would give

them a chance to see what one's like.

Right, okay. I didn't know that they did one. Well I think that's a fantastic idea. [something you'd look at in the future] Most definitely

Quite possibly. Yes. (Inaudible 00:27:14) the car for a reasonable amount over a couple of years and you get quite a good service from them. So (inaudible 00:27:29) a little bit but it is also very handy having the mobility scheme because everything is under one roof and you just have to speak to one person and (inaudible 00:27:37) from there. So (inaudible 00:27:42) a bonus really (multiple speakers 00:27:44) having it all like a one stop shop basically. [so would car scheme work for you] I think at the moment I am probably happier with the way we are.

Oh right yeah I see what you mean. Well that might suit some people. If you don't use the car very much, is that what you mean? Just hire a car as and when you needed it? Rather than have one sitting on the drive all the time doing nothing? And keep some of your mobility allowance? Yeah that might be something that some people would like. I wouldn't say everybody. If they did that would they do that just for some people but not everyone? Yeah, I can actually see that there probably is [an appetite for it], because especially for older people that don't go out very often, they might prefer that because they only perhaps use the car once a week to go shopping or something like that and then that might suit them better.

Oh yeah that's good. [about saving money] Yeah I know because it takes a big chunk doesn't it? No I don't want things like that. I feel more safe knowing that it's going to be serviced every year by them and yeah, I'm a bit sort of... It's the security of if something goes wrong, it can go straight to the garage without costing me anything because obviously I've done from a damn good wage working at the hospital of nearly £2,000 a month and now I'm just living on benefits now.

Yes that would be a good idea. That is interesting but for down here in Cornwall we need a car. And that wouldn't work down here. It might work in other parts of the country but it wouldn't work down here in Cornwall necessarily.

No, I think that might be ideal for people in a different situation from myself, I'm in a country village where there isn't easy public transport really, no, I wouldn't say it would work very well. Me, personally it definitely wouldn't work because if I say there's no local supermarket or anything, you have to drive there, you can't even get a bus there. I: So even if it was a case that you knew that you wanted to go to the shops the next day, or on a Monday, for example, that you knew you could book a car for that time ...

I definitely wouldn't be interested because my lifestyle ... I need my car all the time, you know, I get to work at eight o'clock and I leave at five. And then I go other places so I wouldn't want to be obligated to anyone else to drop the car back, it would just be inconvenient plus I live in the middle of nowhere. (Inaudible 0:53:00.7) on alternatives, you know, public transport. So I wouldn't, that's not to say it's a bad idea for someone, like I said, originally I couldn't afford to give up a portion of my (inaudible 0:53:14.5) for a car even though I see the advantage of having that scheme. So I think there may be some people who would be in that position who couldn't afford to give up their DLA but that could benefit some accessing a job by renting a car or having a car certain parts of the week. So as an incentive for people to get back into social inclusion, living in the community, also work, I think that could be a really positive thing. But only if it's a free scheme.

Well that may work for some people but for myself no, I like to be ... I like to have a car at the moment. because I think if you ... if you were dependent on the other scheme you might be restricted in what you could ... in what would be available. Well I think you would be restricted to less expensive models maybe which might not be exactly to your wishes.

Yes, yes I do probably. I don't think it would probably be right for me, but I do think it's a really good idea actually. No it's okay, I was going to say because I don't drive, and somebody who can drive probably would find it more beneficial than I would.

that would be good for them, yes it would, because they'd be able to get about. Because not everybody has learned to drive have they? And not everybody who becomes disabled would have the confidence to learn to drive afterwards. - having the ability, even if their partner could drive it for them and get them out.

Not for me, it may be for some people that don't use the car too often. I mean some people still go out on buses fine, and I suppose if they were going to go away on holiday and then they want to hire a car that would be fine, yeah. Or if they had like an emergency (inaudible: 00.21.51) or something. But I'm quite happy the way mine is at the moment.

Yes no I wouldn't...it is because the wife uses the car for work as well so I couldn't do that. But I can see a lot of people if they don't work that would work well. If the wife didn't need the car for work yes that would be a reasonable idea. But I think people still like their own car because you never know when you are going to need it. You know what I mean? So if something happened, an emergency or something, if you were in a car club, how long would it take you to get the car delivered for you? You couldn't have it within...you might need it within half an hour. So I can understand it working in certain ways but it wouldn't be my idea. It wouldn't give you the feeling of you can do anything, any way, go anywhere anytime basically. Yes I think it would for some people definitely. Yes I was going to say if you were going to hire it for the weekend yes. But I was just thinking you could just get taxis I suppose but then again it is not always feasible. [about emergencies] Yes exactly at your disposal. It gives you like peace of mind that you know you can get anywhere I suppose. I am trying to think, (inaudible 00:31:19).

That wouldn't really interest me. No, I don't think I'd like that. Even though we might not use the car every day, knowing it's there, you know you've got that freedom if you need it. You're not restricted. I would feel restricted if I went to something like that. And you wouldn't always know, would you, when you'd need the car? I suppose you could plan ahead but you couldn't put, like if my daughter rang me up this morning and said mum, can you do so and so, I wouldn't be able to do it because I wouldn't have a car.

I would feel restricted with that sort of scheme.

Although financially it would be better, no I'd feel restricted.

Not really no. Yeah what we'd do is if we had to do it we'd just go down to one car and share it. [would you use a car club on top] no

Oh no, I would rather have the car there so if I needed to go to hospital or that, the car's there right away for me. It takes me to the doctor's, I'm going to the doctor's on Thursday and the car will be there waiting and my daughter will come down with me to the doctor's and the car's there waiting for

me to come out the doctor's to get me home.

It wouldn't be anything I'd be interested in because I use the car every day.

No at all, no.

Well I don't see how that is going to work, I mean the car I've got is with me 24/7, whereas if you've got to go to a motor pool to pick a car up you have got to get there which is, I mean if your car, motor pool could be in the city which is twelve miles away, how do I get there? I can't walk very far, it means I would have to try to walk down the road, get on a public service bus, go down the railway station, get on a train, go down to the city and then get from the station to wherever the motor pool is and then use the car and then take it back there and then I've got the reverse journey which is painful, to say the least. So I don't think having a motor pool would be of any, to be personally it wouldn't be any use at all. No, I mean I am talking about me personally, I can't speak for anybody else but I can't see people who are finding it awkward to walk, I don't think that would be any help to them either be honest with you. Because it's like hiring a car, you've got to go to the depot, wherever the depot is to pick it up which is the only thing that may work for the motor pool is if the car is brought to you and then picked up from your home, that might be acceptable. But again, it wouldn't work for me because at the moment, I mean if I wanted to go out I could just walk over the garage, get my car out and go, whereas if I've got to phone up for a car, it could be there in half an hour, it could be there in five hours. So really, truly it's not sure if they haven't got one that they can give you straight away then I'm waiting for them which might be very awkward for me; I couldn't do what I wanted to do on the spare of the moment. So I'm quite happy with the way things are, it suits me exactly how it's being operated at the moment.

I have to say for us no. I don't think that quite fits in with what you're talking about.

I wouldn't personally because obviously I've got to have a car with hand controls, and I find with the hand controls I set my seat up to where I need it to be, so if I had to give that car to someone else then get it back a day later or an hour later it again mucks me up (sl as the driver yet 00.23.45) again. And also if I had to borrow someone's car they might not have hand controls because obviously everyone's got different abilities with MS, so it doesn't affect some people's legs so they wouldn't have hand controls. So for me personally I don't think it would work, but I obviously know there's lots of people that it doesn't affect their legs and it could be a good idea to swap the cars and they could try out a different vehicle really.

To rent a car would be no good at all. I mean the nearest rental place is about 20 miles away and they wouldn't have adapted vehicles anyway. I doubt it. They wouldn't have a hand control vehicle that I could drive. To rent a car would be no good at all. I mean the nearest rental place is about 20 miles away and they wouldn't have adapted vehicles anyway. I doubt it. They wouldn't have a hand control vehicle that I could drive. I've never tried to hire one. I don't think you'd be able to get vehicles (inaudible 0:33:03.7) my license which I could use. It's great if you live in Birmingham. It's no good down here at all. Because you've got to go 20, 30, 40, 50 miles to get it. I mean if I go to hospital, the nearest hospital is about 45 miles away. You've got to get there. All right, I could pack up my Motability car tomorrow and endeavour to use taxis. But I would be struggling then to find taxis in which I could put my wheelchair. I couldn't find them. Not around here.

Not particularly, I just think that sometime... and my mobility car is in brilliant order and it's well looked after and several people have said to me, "When that one goes back we would like to consider buying it, how do we go about it?" now that's one area of which we have no, or I have no knowledge at all and that would be very useful if I could find out.

Not for me no. I need to have a vehicle here all the time just in case. As I say my daughter gets ill and she can get ill at a moment's notice, she can come home from school absolutely fine and three hours later she's got a temperature so to be able to know that I can just put her in the vehicle and go to the hospital or go and see the doctor or whatever I would prefer to have a vehicle with me full time. For some people that would probably be very practical, people that don't use their vehicles very often, it would be a very good idea and perhaps for somebody of the older persuasion that only perhaps uses it once or twice a week, I think it's a very very good idea, but in a family situation I think we would need to have a vehicle all the time.

Well I don't know. As I say I want to try and get a car off of Motability so I don't think I'd really want to rent.

I wouldn't like that I don't think. I: So I suppose one of the reasons why they think people might be interested is because of the saving? R: I'm sure that's correct. But then you've got to think of... well I just feel it's a way of life and everything and I just think it's (inaudible: 00.36.18).

It wouldn't be useful to us specifically because then we would be without the vehicle and enable us to have an adapted vehicle supplied to us... but I could certainly see it would be very useful for some people, but I guess if we get visitors, there is some friends that come down to visit us sometimes and it is uneconomical for them to bring their car down because their daughter is still quite small and she can be lifted in and out of the van... ..but when they get down here, if they wanted to use it as a base and go and visit other places, if they could hire a vehicle while they are down here for a day or maybe a couple of days, it would be useful for people like that, or I've got a friend in Holland who likes to come over to the UK and whenever they go, it's not just to us, but they go to other family and friends, and they find that because their son is large, either they've got to stay within walking distance or use taxis, if they can find a wheelchair taxi, or have two people to lift him in and out of a vehicle they can get hold of, so having wheelchair adapted vehicles for hire, that would be a very good thing I think.