Study Protocol

Full title:

Needs and experiences of children and young people in the UK with a disability and mobility difficulties, and their parents

Workstream 2 of 2 in *Numbers and needs of children and young people in the UK with a disability and mobility difficulties*

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1. Protocol version number and amendment history

Version	Author	Date		Approved
1.0	Stuart Jarvis	2024-09-19		**SJ**
Amendments				
Version	**Author**	**Date**	**Changes made**	**Approved**
1.1	Julia Hackett	2024-10-30	Refinement of WS2 description and readability edits	**SJ**

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2. Plain English summary

There are many children and young people in the UK with conditions that limit their mobility. This can have a large impact on their lives and those of their families, with difficulties in completing some daily tasks of living, additional costs and the potential for limitations on whole-family activities.

Currently, government support is available in the form of Disability Living Allowance (although the mobility component of this is not available before three years of age) and there are several charities offering support for specific conditions or with mobility aids. However, there is not good information on the numbers, characteristics, experiences and needs of children and young people with disabilities and mobility difficulties, nor those of their families. Estimates of numbers are often based on a 2010 study that is now outdated and lacks detail on conditions, locations and demographics. Most studies of needs have looked at specific conditions and so lack information on common issues across the population with mobility difficulties.

Motability, a provider of vehicles to young people and their families (and, through sister organisations Designability and Family Fund, providers of other mobility aids and funding) have funded the present research to better understand the numbers and needs of children and young people with mobility difficulties in the UK. The present research has been split into two parts, one aiming to estimate the numbers, geographical distribution and characteristics of children and young people with mobility difficulties and the other aiming to better understand their needs and experiences and those of their families. It is hoped that this research will inform improved provision of services and support by both showing who needs support and where and what kinds of support and services are most useful.

This document concerns the second part of the research, looking at experience and needs. It will involve researchers talking to children, young people and their families to understand their experiences of mobility difficulties and of existing services and support, gathering their views on things that work well and areas where there are limitations or obstacles to support.

The findings from this part of the research will be collated under common themes, to summarise the experiences and needs of children, young people and their families. These will be communicated in scientific research papers and conference presentations, but also in plain English summaries to participants and research briefings to charities and policy makers to aid in improvements in the services and support offered.

3. Scientific Abstract

Background

There are many children and young people with a disability and mobility problems in the UK, with a 2010 report concluding that 1.5% of 0-18 year olds had mobility difficulties. This figure is still widely quoted, but is likely to be outdated given changes in prevalence of many more complex conditions since then. It also lacks detail on the mix of conditions, the locations and demographics of those with mobility difficulties and, particularly, their experiences and needs. The present study is part of a wider study aiming to address these limitations.

Aim

To understand the needs and experiences of children and young people with a disability and mobility difficulties, and those of their families.

Methods

The study is a cross-sectional qualitative study involving semi-structured, in-depth interviews. The sample will include parents of children aged 0-18 years with mobility difficulties and also children and young people aged 10-18 years with mobility difficulties. The sampling strategy will reflect the diversity within the population of children and young people with mobility difficulties by considering diagnoses, age and ethnic group – all of which have been identified as potentially affecting access to care and services. We anticipate a sample of 10-15 children and young people and 20-25 parents will be required.

Proposed findings

The findings of this study should build up a picture of the experiences and challenges of living with a disability and mobility difficulties, identifying needs for service and support, and strengths and limitations of those currently offered, including any barriers to access.

The findings will be integrated with those from a quantitative workstream in the wider study to build up a national picture of numbers and needs of children and young people with mobility difficulties in the UK.

4. Background

There is a lack of information on disability, and particularly disability with mobility difficulties among children and young people in the UK. Many charities and researchers refer to a paper published in 2010[1], but this is limited in terms of age disaggregation and category of disability and is now outdated. A recent report prepared for Motability (see appendix) confirmed that there is no single readily-available source of better estimates. There is also little understood about the experiences, needs, and support requirements of children and young people with mobility difficulties and their families as far as this relates to mobility (there are many studies on other aspects of living with a disability[2-6]). Charities operating in this area, such as Motability, therefore have limited information on the size of the population in need of their services, the nature of their conditions, their geographical distribution and trends through time, making it difficult to plan and target current and future services. They also lack in-depth information on needs, experiences and barriers to support. While this information would directly help Motability to plan and target services, it would also be of wider use to: other charities serving this (or parts of this) population; national and local government; the NHS for service planning; those campaigning for better statutory support. Public and Patient Involvement during preparation of this application, with the research group's Family Advisory Board, has highlighted several areas of potentially unmet needs around mobility support for children with long-term conditions, including difficulties in accessing support for very young children, particularly before diagnosis, and the need for flexibility in support provided as needs develop and, potentially, change rapidly.

5. Study aim and research objectives

This study aims to explore children/young people's and their parents' perspectives on disability and mobility difficulties.

Objectives:

This study will explore the following objectives:

1. To explore children/young people's and their parents' experiences of living with a disability and mobility difficulties.

2. To explore children/young people's and their parents' perceptions of the barriers and facilitators to mobility and the subsequent impacts on their lives.

3. To describe children/young people's and their parents', needs, support requirements and experiences of accessing and using mobility aids, including those offered by Motability/other charities.

6. Study design

The overall study is mixed-methods. Workstream 1 is a quantitative secondary data analysis of survey data and routinely collected healthcare records and Workstream 2 is a primary qualitative study involving semi-structured, in-depth interviews with children and young people and their families.

This protocol is related to workstream 2, the qualitative component.

7. Patient and public involvement

The Research Group's PPI panel, the Family Advisory Board (FAB), has been formally consulted twice during the development of this research proposal. They have provided input on areas to study relating to changing needs and flexibility in provision, among other areas, that will inform topic guides for interviews in Workstream 2. They have also suggested a number of potential avenues for participant recruitment.

The FAB will continue to provide input to the study throughout its course, with consultations planned and the ability to schedule additional meetings if required. Martin House Children's Hospice also has a Young Person's PPI Panel, whom will also be consulted throughout the study. There are a number of aspects of the study on which input will be sought:

- Recruitment approaches – including organisations and review of advertising materials;
- Content and design of participant information sheets and letters for recruitment;
- Helping to refine and pilot the interview topic guide;
- Providing feedback on interviews;
- Development and review of themes identified during the analysis;
- Interpretation of study findings and development of recommendations for policy and practice;
- Co-production of study outputs, including plain English summaries and identification of routes for dissemination.

The FAB meets monthly and the research team will be able to consult the FAB as needed. As a minimum, they will be consulted three times each year. Members will also informally liaise with SJ/JH for interim updates on progress, and by email, post or telephone when needed between meetings or when reviewing documents, depending on individual parent preferences regarding mode of communication. The first consultation following study commencement (two consultations have already taken place while developing the study proposal) is scheduled for November 2024. Meetings are mostly via video conference, with one in-person meeting each year.

A PPI log, guided by the Public Involvement Impact Assessment Framework[7] will be completed to record planned and unplanned involvement, including details about who was involved and how and the ways in which the PPI activities impacted the study.

PPI participants will be formally informed of study findings at the end of the study via presentation to the FAB, a plain English summary to be provided to the FAB and any other participants and to be made publicly available on the study website. All will also be provided access to other outputs, including published research papers and research briefings/reports.

8. Study methods

Sample & sampling strategy

The sample will include both parents and children and young people.

Parent sample

The sample will include parents, or legal guardians, of a child or young person who meet the following criteria:

- Parent/legal guardian is ≥16 years old.
- Their child has/had mobility difficulties (example conditions: cerebral palsy, epilepsy, paralysis, acquired absence of limbs, congenital absence of limbs, or a neurological condition).
- If their child has died, this was ≥3 months ago and <5years ago.
- Their child is <19 years old (or died when <19 years old) (i.e. age range of children included is 0-18).

We will not include:

- Parents/legal guardians aged <16 years old.
- Those who lack capacity to participate, guided by the 2005 Mental Capacity Act.

All adults who provide regular parenting for a child or a child who has died are eligible to be invited to take part (e.g.: mothers, fathers, step-parents, adoptive parents, legal guardians). Referred to as 'parents' herein.

A stratified maximum variation purposive sampling strategy[8] will be undertaken to ensure the sample includes similar size sub-groups of parents, which reflects the diversity within this population both in terms of parents' own characteristics and their child's condition. These purposive sampling criteria include: diagnoses and age of the child; ethnic origin and socioeconomic status, all of which have been identified as potentially affecting access to care. This will enable diverse perspectives to be captured, and comparative analyses where appropriate[9]. To capture the diversity of perspectives, we anticipate a sample of ~20-25 parents will be required. We will monitor recruitment to ensure we are achieving a spread across these key characteristics.

Child and young person sample

The sample will include children and young people who meet the following criteria:

- Child/young person is >7 and <19 years old (i.e. age range of children included is 8-18).
- Child/young person has mobility difficulties (example conditions: cerebral palsy, epilepsy, paralysis, acquired absence of limbs, congenital absence of limbs, or a neurological condition).
- Child/young person able to communicate during a semi-structured interview.
- Child/young person capable of providing written or verbal assent or consent.

We will not include:

- Child/young person aged <8 years old.
- Child/young person aged >18 years old.
- Child/young person unable to communicate via a semi-structured interview.
- Child/young person under 16 years old who is unable to assent.
- Child/young person over 16 years old who is unable to consent.

Supporting diversity and inclusion is highly important, especially given the higher prevalence of mobility difficulties in children from deprived areas and some ethnic minority groups. We will ensure both samples include those from a range of ethnic origins and socioeconomic statuses.

Recruitment

Parents and children and young people will be recruited from: children's hospices; parent and child facing organisations in the UK, e.g.: Motability, The Family Fund, Designability, Scope; and via social media sources, e.g.: Twitter, Facebook, X (formally known as Twitter), and Instagram. Parent advisors are keen that we use these sources to avoid organisational gate-keeping.

Data collection

For parents, we will conduct face-to-face, telephone, or video-call (Zoom or Microsoft Teams), in-depth semi-structured interviews, depending on individual preference. For children and young people, we will conduct face-to-face or video-call (Zoom or Microsoft Teams), in-depth semi-structured interviews, depending on individual preference. Although face-to-face interviews are most often used in qualitative research, there are a growing number of studies, including our own, that successfully use telephone and video interviews. [10-14]

Interviews with parents and children and young people will explore their accounts of living with a disability and mobility difficulties; experiences of accessing and using mobility aids; perceptions of the barriers and facilitators to mobility; any impacts this has; and their expectations, support requirements and needs.

During interviews with children (8-15 years), parents can be present if the parent / child wishes. During interviews with young people (16-18), parents can be present if the young person wishes. Interviews with children and young people will be tailored according to age and cognitive ability and a range of participatory activities will be used build rapport in order to facilitate these interviews. For example:

- Using third person scenarios / vignettes depicted in pictures or simple stories
- Creating own painting / drawing on topic suggested by researcher
- Card sorting exercises (e.g.: a set of cards with a different picture / word / simple phrase relevant to a particular topic(s): worries / concerns, feelings, sources of support).

All tools/activities will be piloted and, recognising that children and young people vary in their interests and preferences, we will ensure at least two activities can be used to explore a topic.

Data analysis

All interviews will be analysed using thematic analysis. Audio-recordings of interviews will be transcribed. Two analysts will work together through the analytical steps. This will help to ensure rigour, authenticity and dependability of findings. Familiarisation will be enabled through an iterative process of reading, re-reading and comparing transcripts. A combination of inductive and deductive coding will be utilised to organise the data into meaningful codes. Codes will be classified into potential themes via identification of meaningful patterns across all codes. Themes will then be reviewed with the reading of all codes in each theme for pattern coherence, followed by reading of the entire data set in relation to each theme to confirm the validity of individual themes. Final themes will be agreed, refined and developed through discussion with the wider team, including the Family Advisory Board and the Martin House Young Person's PPI Panel. Findings from parent data will be used to examine/verify findings from children and young people and vice-versa. .

9. Study management and oversight

9.1 Study Team

Dr Stuart Jarvis (Study lead)

Dr Julia Hackett

Professor Lorna Fraser

Mrs Laura Barratt

Mrs Nicola O'Donnell

Mr Andrew Haynes

9.2 Sponsorship

University of York

9.3 Study management and oversight

Dr Jarvis and Dr Hackett will oversee day to day management of the research (for Workstream 1 and Workstream 2 respectively) with Dr Jarvis taking overall responsibility. Professor Fraser will provide advice and guidance.

Laura Barrett (LB) and Nicola O'Donnell (NOD), both experienced qualitative research associates, have been appointed to work on the study under the supervision of JH, to conduct the qualitative data collection and undertake the analysis. SJ will be responsible for the study's timely completion, the quality of the work, adherence to ethical standards, and effective dissemination and impact. SJ and JH will meet with LB and NOD bi-weekly throughout the study, and LF will join these meetings bi-monthly.

A Study Steering Committee/Advisory Board (SSC) will be established including other subject matter experts from the University and beyond, representatives of Motability and at least one Parent/Young person representative from the Family Advisory Board. This panel will meet approximately 6 monthly to assess progress of the study against the defined milestones and deliverables and provide advice and expertise to the Study Management Team.

The overall success of the study will be measured through delivery on the study objectives and on the specific deliverables set out below (see enclosed appendix for target timelines):

1. Interim presentations to Motability on findings (at SSC meetings as appropriate; Motability have their own six-monthly reporting procedures).

2. Combined report, in plain English, summarising and integrating the findings from both workstreams, providing Motability with a detailed picture of the size, location, demographics and needs of the population requiring support.

3. A research briefing for charities, commissioners, service leads and health professionals, setting out the key findings and implications for practice and training.

4. A Plain English Summary and recommendations/guidance for parents. This will be a short, text-based output developed in partnership with the Parent Advisory Group, highlighting key research findings, implications and next steps. This will be shared with all participants and via parent-facing organisations, e.g. charities, support groups.

5. A tool (nature to be agreed, but e.g. web based) to provide custom disaggregation of data from Workstream 1.

6. Scientific papers and conference abstracts (at least one of each from each workstream).

Ongoing success will be monitored with reference to the timelines in the enclosed document, with any delays with respect to these timelines addressed by the management team, either through simple mitigations or through discussion with the SSC, including representatives of Motability, for any more serious issues. We would inform Motability of any changes to proposed timelines or other plans.

10. Governance and ethical approval

The study will be conducted to protect the human rights and dignity of the participant as reflected in the 1996 version of the Helsinki Declaration. The explicit wishes of the participant will be respected including the right to withdraw from the study at any time, the interest of the participant will prevail over those of science and society, provision will be made for indemnity by the investigator and sponsor and a contact name for further information will be provided.

We will seek ethical approval from the University of York Department of Health Sciences Research Governance Committee, addressing issues concerning informed consent, participant burden and distress, participant confidentiality, data management and researcher safety and distress, as summarised below.

10.1Informed consent

Parents

Parents will be provided with a brief information sheet and a recruitment video (made by a parent) about the study either directly from a recruiting organisation, or by accessing a website from a social media post. They can express an interest in taking part by returning a paper or electronic "consent to be contacted form" to the research team, or by emailing or phoning the study team directly. The study team will then send them detailed information packs either by email or post. If posted, the information pack will contain a consent form and a stamped addressed envelope, marked 'confidential' for the participant to use. A researcher from the team will arrange a call with parents who are interested in taking part, or their child taking part, to explain and discuss the study, to provide an opportunity for them to ask questions, and to check that they understand what the study is about, what will happen to them if they take part, and how we will use their information.

If the parent is happy to continue, the formal process of documenting consent will be started, demographic information recorded, and an interview will be arranged. Both the researcher and the parent will sign and date a hard copy or electronic Consent Form to confirm that consent has been obtained prior to the start of an interview. The parent will receive a copy of this document and a copy will be securely filed by the study team at the University of York.

Consent will be monitored throughout the interviews of parents, e.g. looking for disengagement or withdrawal, checking that they are happy to continue, and parents will be reminded that they can choose not to answer questions that are too distressing or that they would prefer not to answer, and that they can stop the interview at any time.

Children and young people

Children aged 8-15 years old:

For children aged 8-15, parents will provide consent and the researcher will obtain assent from the child throughout each stage of the study. Where the child expresses an interest in taking part in the study, consent to be contacted by the researcher will be obtained. The subsequent consent process will be as above with all information communicated to both the parent and also the child in an accessible format for each individual. Care will be taken to ensure that the child and their parents fully understand what the research is about, what is expected of them, what the risks and benefits are, and that participating is voluntary. If a child doesn't assent to participate, this overrides consent from the parent.

It is important that children can make an informed decision about participating where possible and their assent is given, despite it being their parents who provide consent. We will be careful to make sure in all information shared, that the content of the interviews and their possible impact on children is clearly articulated. The information sheet is designed to be accessible to children and cognitively appropriate, using simple language and visual images. In the initial telephone call with parents providing consent for their child to participate in the study, they will be asked whether they have read the form to/with their child or summarised this information in an accessible format to support their understanding. Children will also be sent an accessible invitation letter along with the information sheet. All communications will make it clear that children can ask to have a break, stop the interview at any time, re-schedule it for any reason, or ask not to answer a specific question or speak about a particular issue. Children will be reminded of this at the start of the interview.

Young people aged 16-18 years old:

Young people will be provided with brief, age-appropriate information and a recruitment video (made by a young person) about the study from a recruiting organisation, a children's hospice, or via their parents. Where the young person expresses an interest in taking part in the study, consent to be contacted by the researcher will be obtained. After receiving a consent-to-contact form, the researcher will send out an invitation letter and a study information sheet to the eligible young person via email or post (dependent on participant preference), communicated in an accessible format for each individual.

The researcher will organise a telephone call (or other appropriate contact) with the young person at least three days after the information pack is sent giving time for them to review the documents and their participation in the study. The young person will have an opportunity to ask questions and discuss taking part in the study and the researcher will check their level of understanding and capacity, i.e.: Gillick competency. They will do this via considering the young person's understanding of what the research is about, what is expected of them, what the risks and benefits are, and that participating is voluntary.

Young people aged 16-18 years old will provide written or verbal consent or consent via use of communication aids. If the researcher thinks that the young person is being persuaded, pressured or influenced to participate by their parent or any organisation, their consent will not be valid and the researcher will stop the recruitment/data collection process, check whether the young person wishes to participate and discuss this with them. They will only continue if they are sure this is not the case.

All participants will be informed of their right to withdraw at any time and without giving a reason. This is covered in the participant information sheet and will be reiterated prior to starting the interview.

If a participant chooses to withdraw, they will be able to withdraw their information as long as it has not already been used in the study (i.e. for analysis). To ensure fairness and to allow for concurrent data collection and analysis we have specified that participants can withdraw any data they have provided up to 30 days after their interview. No further data will be collected from participants who withdraw and all data able to be withdrawn (from their contribution) will be destroyed unless consent is provided to include data collected up to the point of withdrawal in the study.

10.2 Participant burden and distress

It is possible that parents may feel pressurised to participate. They will be informed that the decision about whether to participate is voluntary and will not affect any services or benefits they or their children receive. It is also possible that children and young people may feel pressured to participate, they will be informed that the decision about whether to participate is voluntary and will not affect any services or benefits they receive. If the researcher thinks a child/young person

is being pressured they will sensitively pause and subsequently stop the recruitment/data collection process, check whether the young person wishes to participate and discuss this with them. They will only continue if they are sure this is not the case.

Taking part may lead to participants becoming distressed/upset. The fact that this may happen will be explicitly addressed in the participant information sheet and by the researcher at the start of the interview in order to put them at ease and also impart to them a sense of control. To help mitigate against this, an outline of areas that the interviews will cover will be provided in the participant information sheet. This will also help to make sure that participants are prepared for the interview.

If a participant becomes distressed during the interview, the interviewer will ask the participant if they want to continue or to take a break, and be guided by the participant, who may wish to continue despite experiencing some distress. In cases where distress is significant or sustained, the interviewer may suggest that the interview is stopped, although the decision will be made with the participant. In these cases, a second interview may be arranged to enable participants to participate fully if they wish. Where needed, assistance will be given to help the participant identify appropriate sources of support, or a recommendation made that they contact their GP or mental health professional. If appropriate, the interviewer may also ask the participant if they would like to be contacted by the trusted health professional that they were able nominate during the consent process. If this is the case, then the researcher will immediately contact the trusted professional via the telephone number supplied on the consent form. For children and young people, if appropriate the interviewer may also ask them if they would like them to speak with their parent.

At the end of the interview, the researcher will ask parents and young people (aged 16-18 years) whether they would like to receive a follow-up call (via the arranged method), two to three days after the interview (timeframe chosen by parent). This will be used: a) to check the parent is happy for their interview to be used for the study; b) as an opportunity for the parent to raise anything that they have reflected upon since the interview; c) and to signpost them to organisations, such as Together for Short Lives, if they require any further support. If parents still need support at the end of this call, the study team member conducting the call will ask the parent if they would like to be contacted by a trusted health professional that they will be asked to nominate during the consent process. If this is the case, then the researcher will immediately contact the trusted professional via the telephone number supplied on the consent form.

As a research centre we have a safeguarding procedure. If the researcher has serious concerns regarding the safety of a parent, child or young person, they should follow the research centre's safeguarding procedure and, if appropriate, the identifying centre's safeguarding protocol. They will advise the parent during the call of this process. At all times during an interview, there will be a senior researcher on call. The researcher will first telephone the senior researcher on call, who they will discuss their concerns with. As a team, a decision will be made as to whether it is necessary to escalate their concerns. In a case of immediate danger, the chief investigator will contact the police.

10.3 Participant confidentiality

Participants will be informed of their right to confidentiality, and what this means if they disclose information that suggests that they or others are at serious risk of harm. Participants will also be informed that they have the right to withdraw from the study at any time, and to exclude their data from the study if not already analysed as part of the research.

All personal data will be stored in password-protected files, using a participant identifier to link participants' details to their data (i.e. interview transcript). On entering the study all participants will be given a study identifier code. Codes and the corresponding names will be kept in a separate file location to the study data, in a password-protected file. This information and all data will be stored on the University of York secure servers and will not be accessed by anyone outside of the research team.

Qualitative data will comprise interview transcripts, researcher field notes, and any follow-up comments from participants. The interview transcripts, which will have all potentially identifiable data removed, will be the primary data source for the study. Audio-recordings, which will be password-protected and stored securely on the University of York server following participants' interviews, will be kept until the transcripts have been checked and anonymised. They will then be destroyed.

Quotations from participants may be used in research reports and other publications and presentations; however, care will be taken to protect the anonymity of participants so that others are not able to identify them. Any quotations that are used in the final report or any other publications will be anonymised through giving the participant a pseudonym. Additionally, the characteristics of participants and their children will be presented in a way that will ensure anonymity, e.g. condition categories rather than individual diagnoses will be reported.

10.4 Data management / Data protection

In line with the 2018 General Data Protection Act and the Research Governance Framework for Health and Social Care Research, data (anonymized interview transcripts and field notes) will be securely archived by the University of York for a minimum of 10 years. Paper consent-to-contact forms and consent forms will be stored in a locked filing cabinet in a locked office at the University of York. Electronic consent-to-contact and consent forms will be stored on a secure University of York server. These will be kept for 10 years in line with the University of York's requirements.

All information collected during the study will be kept strictly confidential. Information will be held securely in paper and/or electronic formats at the University of York. The University of York complies with all aspects of the 2018 General Data Protection Act and operationally this will include obtaining consent from patients and carers to record personal details including name, postal and email address, and contact telephone numbers; and appropriate storage, restricted access and disposal arrangements for patient and carer personal details.

Consent data from parents may be gathered via Qualtrics. All personal information will be held within the UK or European Economic Area in full compliance with data protection legislation.

All participants will be anonymised at the point of consent, by assignment of a study identifier code. Personal data and pseudonymised data will be stored separately in a restricted access folder on a secure university server and access will be password protected.

- All data will be stored in accordance with data protection requirements and will be kept either in a locked filing cabinet in a secure office or in the case of electronic data on a secure sever with a password-protected computer and files.
- Participants' names and contact details will be stored in a secure place (a locked office) and only accessed by the research team. Electronic data will be stored on password-protected secure computers in the research team members' locked offices.
- Audio recordings of the interviews will be downloaded onto a password-protected area of the University of York server and deleted from Zoom or the recording device. Audio recordings will only be used during analysis if needed, e.g. to check the meaning of a participant response. These will be destroyed when the transcripts have been analysed.
- No data will be stored on a home computer or laptop.
- All anonymised interview data will be stored for a minimum of 10 years, which will allow time for any academic challenge to be made. All data will be deleted after this time.
- Personal data and consent forms will be stored for up to 3 years after the end of the study. It will then be destroyed.

10.5 Researcher safety and distress

To ensure researcher safety, we will adhere to the University of York policy and procedure on lone working and employ a buddy system to monitor researchers' whereabouts and safety if visiting participants or conducting virtual interviews from University premises outside of normal office hours. We will also develop risk management protocols that are consistent with those used by the Trusts and hospices we will be working with. All research staff will be GCP (Good Clinical Practice) trained.

We will only use experienced qualitative researchers who have previously worked on sensitive topics to interview participants and analyse data. However, it is possible that the researchers may experience some emotional distress as a result of interviewing parents and children about their experiences or during the process of data analysis. To monitor and manage this, the researchers will meet weekly throughout the study to reflect on data collection and analysis. In preparing for data collection, the researchers will also have an opportunity to conduct one or two pilot interviews with our parent advisors. Additionally, debrief meetings will take place 1-3 days after the first few interviews (between the interviewer and JH), and then be organised as and when needed after this and throughout the data collection process. These strategies have been used successfully in similar studies.

11. Dissemination

The outputs from the work packages will be as follows:

1. Interim presentations to Motability on findings.

2. Combined report, in plain English, summarising and integrating the findings from both workstreams, providing Motability with a detailed picture of the size, location, demographics and needs of the population requiring support.

3. A research briefing for charities, commissioners, service leads and health professionals, setting out the key findings and implications for practice and training.

4. A Plain English Summary and recommendations/guidance for parents. This will be a short, text-based output developed in partnership with the Parent Advisory Group, highlighting key research findings, implications and next steps. This will be shared with all participants and via parent-facing organisations, e.g. charities, support groups.

5. A tool (nature to be agreed, but e.g. web based) to provide custom disaggregation of data from Workstream 1.

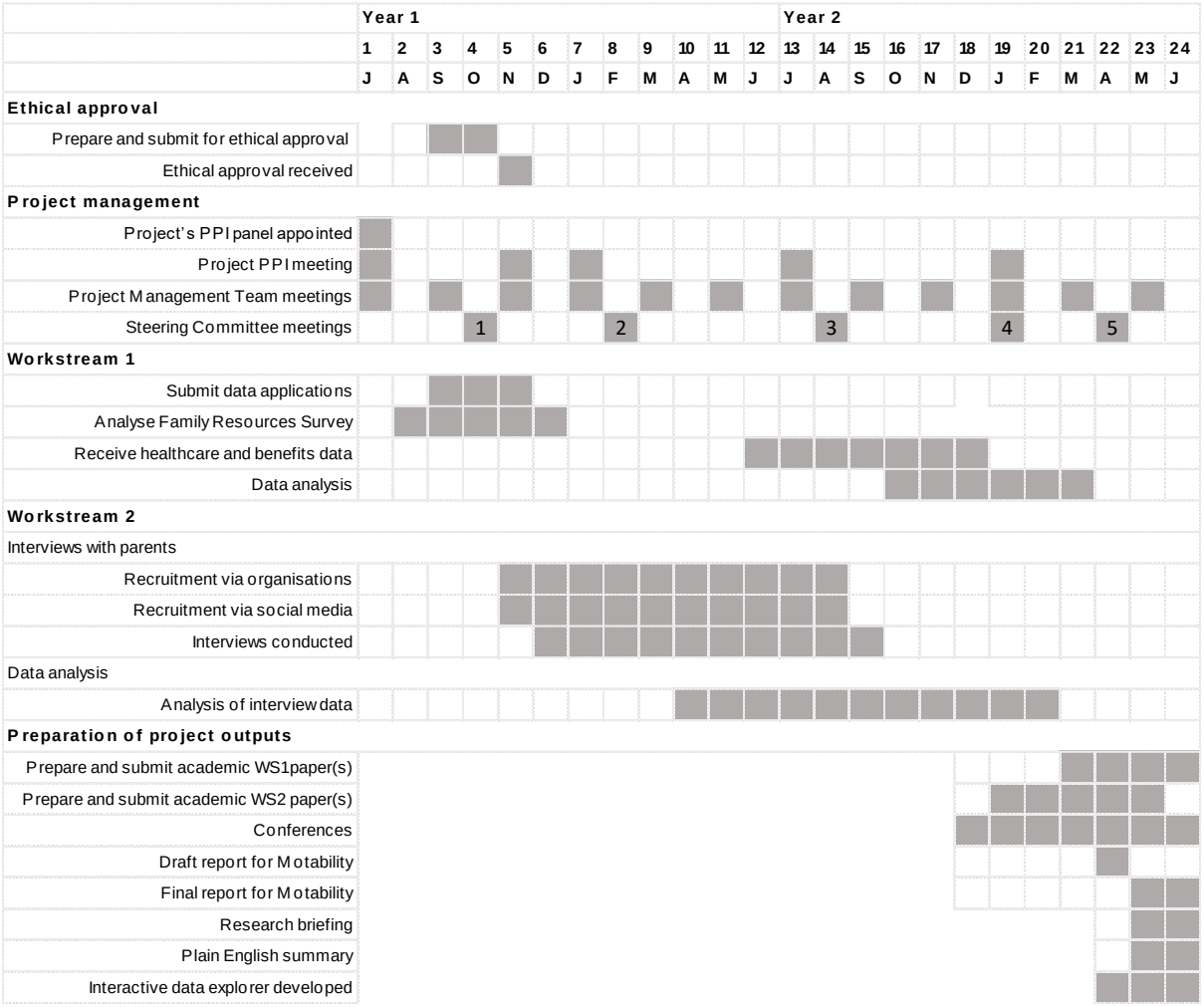
6. Scientific papers and conference abstracts (at least one of each from each work package).

The outputs of the research will provide a number of benefits:

- Motability and its sister charities will receive detailed information on the size and change in size over time of the population of children and young people with a disability and mobility difficulties helping with to plan and target support and, if necessary, offer new or expanded services to better meet the needs of this population.
- Other charities, commissioners, service leads and health professionals will be provided with a shorter Research Briefing which will highlight the size and needs of this population and may be used to influence commissioners and government to better support this population. The findings will also be useful to other charities operating in this area, including local charities, helping them to identify needs both in terms of numbers requiring support and the nature of support required.
- Families involved in the study will receive a Plain English Summary, highlighting what has been learned, the value of their input and any important insights of use to them in navigating support options for their children.

- The ground will be laid for future research and service changes through a knowledge exchange event at the end of the research bringing together all the above groups to discuss the key findings and next steps. This also provides an observable benefit to participant families, enabling them to see that the research findings to which they have contributed are communicated directly to relevant parties and to have the opportunity to have their say on the resultant actions.
- The findings will be directly communicated to MPs by sending the Research Briefing and Plain English Summary to relevant All Party Groups within the UK Parliament and devolved administrations – e.g. in the UK Parliament, the All Party Group on Equipment for Disabled Children.
- The work will inform other researchers and clinicians through academic outputs (e.g. papers, conference presentations) raising awareness of this population, helping to focus future research priorities and providing reproducible methodology and tools (e.g. the coding framework) for interested parties

12. Timeline


Year 1
Year 2
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24
J A S O N D J F M A M J J A S O N D J F M A M J
Ethical approval
Prepare and submit for ethical approval
Ethical approval received
Project management
Project's PPI panel appointed
Project PPI meeting
Project Management Team meetings
Steering Committee meetings
1
2
3
4
5
Workstream 1
Submit data applications
Analyse Family Resources Survey
Receive healthcare and benefits data
Data analysis
Workstream 2
Interviews with parents
Recruitment via organisations
Recruitment via social media
Interviews conducted
Data analysis
Analysis of interview data
Preparation of project outputs
Prepare and submit academic WS1paper(s)
Prepare and submit academic WS2 paper(s)
Conferences
Draft report for Motability
Final report for Motability
Research briefing
Plain English summary
Interactive data explorer developed

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