PAVING THE WAY FOR MORE INCLUSIVE RESEARCH

Better practice research with disabled people and people with long-term conditions

A report for Ofcom and Communications Consumer Panel by Magenta

July 2024

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MAGENTA FOREWORD

As researchers, it is our responsibility to ensure that we are capturing and reflecting views from across society. It is therefore imperative that research meaningfully engages disabled people, people with long-term conditions and people who do not identify as disabled but experience barriers to taking part in research.

As a team of researchers with a passion for inclusivity, we are grateful to have been entrusted by Ofcom and the Communications Consumer Panel (CCP) to undertake this research on their behalf. We would like to thank all the stakeholders who generously contributed their time to the research. Their expertise and insight have been collated into this research report.

This research has found that there is no ‘perfect’ approach to conducting research with disabled people and people with long-term conditions. As we progress our approach to inclusive research, we recognise that there may be frustration from some that the industry is not moving quickly enough, not going far enough, or still needs to be wedded to systems that do not feel as inclusive as they could be.

However, what we have been able to achieve through this research is a set of clear recommendations on how we, in the research sector, can all move forwards. Our hope is that these findings provide commissioners, agencies and others working with disabled people and people with long-term conditions with clear guidance on how to incorporate more inclusive research practices, and to take steps forward on what will be an ongoing journey. The recommendations within this report should not be considered an ‘endpoint’, but rather steps forward.

We know this report has the power to make change because as a research agency we have learnt much from this process, and whilst, prior to this research, we felt we were taking an inclusive approach, there is so much more we could have done, and are now doing.

As an additional benefit, whilst the recommendations within this report are framed for disabled people and people with long-term conditions, much of the guidance can be applied to research with other demographics or groups of people, as well as to contexts outside of the research industry. We hope that this supports the research industry to also take broader steps forward in inclusivity.

The Magenta research team would like to thank Ofcom and the CCP for entrusting us with such an important piece of work, and once again thank those that we spoke to, without their contributions this research would not have been possible.

Magenta
July 2024

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EXECUTIVE SUMMARY

Introduction

Ofcom and the Communications Consumer Panel (CCP) commissioned Magenta to undertake research to explore better practice when conducting and reporting on research with disabled people and people with long-term conditions. There were three stages to the research study: a literature review; 40 interviews with stakeholders across a range of sectors; and a workshop with 21 stakeholders from the interviews. This summary covers the key findings from the research across each stage of the research process. It also outlines recommendations based on the stakeholder insight and the practicalities and limitations of conducting social and market research studies.

The recommendations are grounded within the key themes that have emerged from the research; using these themes to guide research from design to delivery will support an approach inclusive of disabled people and people with long-term conditions:

- **Positive intent**: How are you thinking about the research and the participants? What are your intentions behind the research? Have these been communicated clearly to everyone involved in the research (researchers and participants)?
- **Rationale**: Have you considered and provided a reason for the choices you have made?
- **Transparency**: Have you been open and honest in your reporting about the decisions you have made and any limitations?

Guiding principles around language

Key stakeholder insight

Language can impact whether people feel included in research. Stakeholders had their own preferences and agreed it may not always be possible to have 'catch-all' terminology. It was recommended that, wherever possible, participants should be able to self-define and use the terms they wish to use. Stakeholders had differing views on the use of person-first vs. identity-first language[1], although in the UK, identity-first language tended to be used more often. It was also considered important that reports are written in an inclusive way, for example, by focussing language on barriers for disabled people and not using language which victimises or stigmatises individuals.

Recommendations

Researchers should be sensitive to individuals' language preferences at all stages of the research process from recruitment through to reporting. They should be aware there is no consensus on some terms and uncertainty around language and terminology should not present a barrier to conducting research with disabled people and/or people with long-term conditions. It is important for researchers to be sensitive, transparent and willing to adapt. More specifically:

- Reflect participants' personal preferences in how they choose to describe themselves as far as possible.
- Unless there is a reason not to, use 'disabled people' as the standard term (as opposed to 'people with disabilities').
- Use language which does not stigmatise disabled people or portray disability as negative.
- Be consistent in using inclusive language throughout reporting where possible.
- Be transparent about the justifications for choice in language in all research materials (such as screeners, surveys and topic guides) and reporting.

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[1] Person-first language emphasises the person before the disability, for example, 'person with a disability' whereas identity-first language emphasises the disability before the person, for example, 'disabled person'

Defining disability for research purposes

Key stakeholder insight

Stakeholders told us that it is important to explain why questions around disability need to be asked. It was common for regulators and government bodies to use the Government Statistical Service (GSS) harmonised definition so the data are in line with other sources of Official Statistics, allowing comparisons to be drawn and differences between different groups to be identified and understood. However, stakeholders highlighted that this approach could inadvertently exclude some disabled people, such as people who have overcome barriers, people who experience conditions which are not stable and people who do not identify as disabled. It was raised that only defining disability through self-identification, risks under-representing people who experience barriers, or have a condition, but do not identify as disabled. Stakeholders discussed a range of ways in which questions around disability can be asked if not needing to align with other sources of Official Statistics.

Recommendations

- Provide a reason for asking questions about disability so participants know why the information is needed.
- When defining disability, be guided by the aims of the research and what the research is wanting to understand or look at.
- If the GSS harmonised definition is used, consider also asking about barriers and how people identify.
- When doing quantitative research where you need to understand specific conditions, use the GSS harmonised definition. However, consider changing the answer options slightly.
- If there is no need to compare data to other sources of Official Statistics, consider other ways of asking questions about disability.
- If you do not need to categorise people, ask people how they choose to describe themselves.
- For research which does not focus on disability specifically, make sure questions focus on asking about support and access needs.

Sample design

Stakeholder insight

Stakeholders discussed the challenges in building a sample frame. Some did not believe disabled people should be categorised at all (i.e. they should not be categorised as 'disabled' or by disability type/condition) and others were aware of the drawbacks but felt it was needed for inclusive research. Stakeholders discussed the difficulties with using 'disability' as a marker for creating a nationally representative sample. At the same time, they spoke about the challenges with relying on Census data to create quotas. Stakeholders told us that certain disabled people are more likely to be left out of research samples and there can be risks of overburdening the same participants to take part in research studies.

Recommendations

- Clearly state who your target group includes. For example, if using the term 'disabled people' outline who is included in this term, and whether all people included should identify as disabled.
- When undertaking a nationally representative survey continue with standard data collection approaches but be open and clear about the drawbacks. For example, a quota on disability may not include the full spectrum of barriers faced by different disabled people.
- Consider a minimum disability quota of 18% for nationally representative samples.
- Agree on the different socio-demographic data to collect from participants at the sampling phase (such as age, gender, ethnicity and disabilities or conditions the participant may experience), allowing researchers to conduct intersectional analysis.

- In qualitative research, avoid overburdening the same people.

Recruitment

Stakeholder insight

Stakeholders agreed that more than one recruitment source should be used. Recruitment should also involve online and in-person engagement. Regardless of which recruitment method is used, stakeholders talked about providing enough information about the research upfront for participants. This allows them to make an informed decision about taking part and builds trust in the research process. Many examples were provided that could help make the recruitment process more accessible. This included the use of easy read materials, translating materials into BSL and providing different ways of contacting recruiters or researchers. In relations to qualitative research, stakeholders highlighted the importance of asking about additional support needs. There was strong agreement that disabled people should be compensated for their time when taking part in research, which does not always happen.

Recommendations

- Consider a specific budget to support accessibility in recruitment and fieldwork.
- Provide enough information about the research project upfront.
- Factor in more time to support participants.
- Consider the use of easy-read materials, translating materials into BSL and screen-reader accessible materials.
- For qualitative research in particular, focus on asking about access needs upfront.
- Provide different ways of getting in contact with recruiters or researchers.
- Consider the language used when a participant is informed that they have been screened out.
- When doing research with the general population, choose a recruitment method which is most appropriate for the research objectives. From there, put things in place to reduce people being excluded.
- For research which focusses on disability, use more than one source to recruit disabled people. Make sure there is more time for recruitment.

Research methods

Stakeholder insight

All stakeholders talked about how important it is to design an accessible research approach from the start. In qualitative studies, stakeholders discussed the importance of making accommodations and adjustments to improve accessibility and allow disabled people to contribute to research meaningfully. For quantitative and qualitative research studies focusing on disability, it was considered essential to involve disabled people within the research design and process. Views around what this should look like in practice varied.

Recommendations

- When designing research with the general population, accessibility should be considered at every stage.
- For qualitative research with disabled people, research should be designed with accessibility at its core.
- For qualitative and quantitative research focussing on disability, involve disabled people throughout the research process.
- When conducting research with the general population, consider a lived experience panel or an advisory board to ensure the research is accessible and meaningful to disabled people.
- For qualitative studies, build relationships through regular communication with participants.

Analysis and reporting

Key stakeholder insight

When reporting qualitative findings, many stakeholders spoke about how important it is to be clear with participants about how findings will be reported, and how quotes and case studies will be used. Many stakeholders considered it best practice to analyse and report by themes or similar experiences, such as barriers experienced. This is opposed to disability type or condition. There was widespread agreement that an intersectional approach to analysis should be taken. When reporting qualitative findings, stakeholders used and recommended different measures to bring disabled people's experiences to life such as case studies and personal stories. Some stakeholders also discussed the importance of making sure reports are in accessible formats. When it comes to qualitative research, it was considered important to share reports with stakeholders.

Recommendations

- Be clear with participants about how findings will be reported.
- If the sample size allows, consider conducting intersectional analysis and report on intersectional characteristics.
- In general population qualitative studies, do not make assumptions based on a person's disability, identity or condition.
- In qualitative research reflect participant's personal preferences in how they choose to describe themselves where possible.
- In disability specific research, consider reporting on barriers as opposed to disability type or condition.
- Reporting should be in accessible formats and, if practical and appropriate, shared with participants.
- When reporting qualitative findings, report in ways which bring disabled people's experiences to life.

1. INTRODUCTION & CONTEXT

Ofcom and the Communications Consumer Panel[2] (CCP) recognise the importance of conducting research that includes the experiences of all citizens and consumers. As part of its regulatory, policy, and enforcement duties, Ofcom undertakes and commissions numerous research studies involving disabled people and people with long-term conditions. The CCP has encouraged Ofcom to consider more expansive ways of conducting this research to be more inclusive and adopt an approach to research design and policy development more in line with the social model of disability.

In response to this challenge, and with the aim of becoming thought leaders in fostering inclusivity in research, Ofcom and the CCP jointly commissioned this research study. The purpose of this research is to explore and identify a more inclusive approach to designing and reporting on studies involving disabled people, people with long-term conditions, and/or people who may face barriers but do not identify as disabled.

In many research studies, there is a reliance on capturing disability through a list of medical conditions. This approach (known as the 'medical model') is often used because the categories used in questionnaires align with UK Census data, helping assess representativeness; it allows for benchmarking of findings; and the categories align with legal definitions of disability, for example, enabling the evidence to be used to assess compliance with legal obligations.

However, capturing a list of medical conditions does not always reflect individuals' experiences on a day-to-day basis. In its challenge, the CCP encouraged Ofcom to investigate how the social model of disability could be used to gain a deeper understanding of the experiences and challenges faced by disabled people and people with long-term conditions. The social model reflects that people are 'disabled' by the limitations placed on them by society. For example, a person who is unable to open a door to a building due to the handle of the door being difficult to grip is not disabled by challenges with their grip, but rather by the design of the door and/or the lack of an automatic way of opening the door.

In addition, Ofcom and the CCP recognise that some people who do not identify as disabled can require adjustments based on barriers, and that these experiences also need to be captured within research studies.

1.2 Research objectives

Ofcom and the CCP commissioned Magenta to undertake research to explore better practice in terms of conducting, reporting, and actioning research that is inclusive in its approach and provides accurate evidence of the experiences of disabled people and people with long-term conditions. When using the terms 'disabled people' and 'people with long-term conditions', we are referring to all types of disabilities and conditions, including physical disability, mental health and neurodiversity. The research also includes people who do not identify as being disabled or as having a long-term condition but may experience barriers to taking part in research.

The study aims to create an output that Ofcom and the CCP can use to:

- Understand how to better design research methodologies, including recruitment and survey questions and techniques, to ensure that they meet the purpose as described above.
- Ensure that reports and findings from the research provide clear and actionable evidence, and report findings in such a way that they do not risk alienating the potential audience.

Rather than a definitive set of guidelines, this research aims to act as a starting point for anyone commissioning or undertaking research and seeking to improve their practices.

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[2] The CCP has cross-membership with Ofcom's Advisory Committee for Older and Disabled People.

1.3 Approach summary

The research study comprised three stages:

Stage 1: Literature review and discourse analysis
A review of published literature to explore how research with disabled people and people with long-term conditions has been conducted and reported on. A detailed search protocol was developed, which allowed us to identify published reports which included disabled people in their sample. Reports published since 2019 from public sector organisations, government departments, and regulators were included. Following review of the reports, six were chosen on which to conduct discourse analysis. These reports covered different types of organisations and different models of disability. We used discourse analysis to explore the language being used in reports around disabled people and to understand how language can be used to represent a social or medical model of disability.

Stage 2: Stakeholder interviews
40 x 45-minute online in-depth interviews with a broad range of stakeholders across the following types of sectors: charity, government and public sector, market and social research, academia, and diversity, equity and inclusion. Some stakeholders specialised in disability and research, whilst others specialised in either research or disability. The interviews captured stakeholders' experiences and perspectives and built on findings from the literature review. As stakeholders had very different professional backgrounds, the interview discussion was guided by stakeholders' experiences. As such, not all stakeholders were asked the same questions.

Stage 2: Stakeholder workshop
A 2.5-hour workshop with 21 stakeholders from the interviews. This was conducted as a hybrid session, with stakeholders joining online and in-person. This allowed us to discuss interview findings, explore conflicting viewpoints, and align on the approach in some areas.

Fieldwork took place between 15th January and 13th March 2024. A full methodology with a sample breakdown can be found in the appendix of this report.

1.4 Limitations

As with all qualitative research, there are limitations to the research findings. Sample bias is inherent with any research, and findings are based upon the views of stakeholders willing to take part. Although there was a broad representation of stakeholder types and disabilities, the sample skewed towards stakeholders within the charity sector and those covering pan-disability.

The report is grounded in the practicalities in what is achievable for researchers to implement, and therefore we recognise not all research findings are directly translatable to recommendations or guidance. The guidance in this report is intended for making progress towards inclusive research, not as an endpoint.

The study does not fully represent the experiences and perspectives of disabled people; the stakeholders spoken to were selected for their experience and expertise in certain areas, and not all stakeholders had direct lived experience of disability.

Stakeholders sometimes held conflicting views on what it means to conduct best practice research. The study initially set out to provide ‘best practice’ guidelines, however, due to the range of views of what best practice looks like, the aims of the study evolved from ‘best’ to ‘better’ practice. It is also important to note that views on ‘better’ practice for conducting research with disabled people and people with long-term conditions will evolve, and are reflective of the time period within which the research was conducted.

This report aims to represent the views of all of those we spoke to. Where appropriate quantifiers such as ‘many’, ‘most’ ‘a few’ are used to help guide the reader on prevalence of view. However, the findings are reflective of qualitative research insights and should not be considered representative.

1.5 Report layout

The report is structured around key areas of research studies, from recruitment of participants to reporting of findings. Each chapter is split into three sections:

- A summary of stakeholder findings – a bulleted list of the key points to emerge from the interviews.
- Recommendations – the recommendations drawn from the interviews, grounded within an understanding of practicalities and limitations when conducting social and market research studies. Research commissioners need to balance research objectives alongside timelines and budgets, and these recommendations are intended as a guide on how to balance competing demands alongside the needs of the research participants.
- Full stakeholder insight – this explores the stakeholder finding in more detail. Quotes from stakeholders are used throughout to exemplify the points made; these have been attributed in line with stakeholders’ consent.

1.6 Choice of language

Throughout this report we have chosen to primarily use identity-first language; in practice this means that we refer to disabled people (as opposed to person with a disability). This was generally the preferred terminology used by the stakeholders spoken to, although we recognise that it is not the preferred terminology by all. However, there are some specific instances where we use person-first language, in line with stakeholder recommendations, this is primarily, but not solely, in the context of mental health and neurodiversity. In most instances we have chosen to use the word ‘condition’ rather than ‘impairment’; the word ‘impairment’ was a preferred term for some, but particularly contentious to others. Our intention with the use of language is to be respectful and considerate. We are aware that our language choices will not reflect the preference of everyone reading this report. Different preferences are explored in more detail in Chapter 2 (Language Considerations). Quotes from stakeholders have been used throughout to illustrate our points. The language used reflects stakeholders’ preferences, as far as possible.

2. LANGUAGE

2.1 Summary of stakeholder findings

- Stakeholders were clear that the language used at every stage of the research process is important, however, there is no 'universal language' for conducting research with disabled people and people with long-term conditions.
- All agreed that, wherever possible, individuals should be able to self-define and express their own preferences for their identity.
- The intentions behind language can play a key role in ensuring individuals feel included in research, and stakeholders stressed the importance of this when it is not possible to allow individuals to self-define.
- The use of person-first vs. identity-first language was debated by stakeholders, although in the UK identity-first language tends to be used more frequently. For instance, this means that 'disabled person' is generally the preferred terminology, as opposed to 'person with a disability'.
- Stakeholders did not agree on use of the term 'impairment', with some viewing it as merely descriptive and others viewing it as a negative term.
- It was not only terminology for describing disabled people which mattered, but also how reports could be written in an inclusive and non-victimising way. Ensuring that the barriers for disabled people are given primacy is one way of writing in an inclusive way.
- All agreed that language which potentially victimised or stigmatised individuals should not be used.

2.2 Recommendations based on stakeholder insight

Researchers should be sensitive to individuals' language preferences at all stages of the research process from recruitment through to reporting. They should be aware there is no consensus on some terms and uncertainty around language and terminology should not present a barrier to conducting research with disabled people and/or people with long-term conditions. It is important for researchers to be sensitive, transparent and willing to adapt. More specifically:

Reflect participants' personal preferences in how they choose to describe themselves as far as possible.

Language and identity are unique to individuals. Avoid making assumptions about how disabled people identify and describe themselves and mirror the terminology participants use once known, wherever possible. In qualitative research, request this information at recruitment, or upfront in the discussion. When using quotes and case studies to report findings, use the terms participants use to describe themselves where possible.

Unless there is a reason not to, use 'disabled people' as the standard term.

Personal preferences should be reflected where possible. However, most stakeholders we spoke to argued for using the term 'disabled people' as this best reflects the social model of disability, in that people are disabled by their environment. If writing briefs or any research materials or reports about disabled people, this should be the default option unless there is a reason not to.

Use language which does not stigmatise disabled people or portray disability as negative.

The language used in research is important for disabled people to feel that the research is for them and about them. Using language which stigmatises disabled people (e.g., struggle, vulnerable, weak, poorly, issues, problems) may impact upon trust in the research and the researchers. For research which aims to recruit 'vulnerable people' the focus should be on the circumstances or situation, rather than presuming that a disabled person is necessarily vulnerable. If a participant describes themselves in a specific way, mirror participants' language where possible but be clear that this language is the preference of the participant. For example, 'Amy, 51 years, describes herself as housebound and confined to a wheelchair' as opposed to 'Amy, 51 years, who is housebound and confined to a wheelchair'.

Be consistent in using inclusive language throughout reporting.

When using inclusive language, it is important to go beyond simply using preferred terminology (e.g., "disabled people" vs. "people with disabilities"). Ensure that inclusive language is used consistently throughout the project, from commissioning to the final report. Consider how to strike a balance between reporting an individual's condition and the barriers they face. For example, if someone is unable to contact a service provider via telephone, rather than focusing on any conditions which might impact that (e.g., being Deaf, being neurodivergent, having a learning disability) it may be more relevant to focus on the barriers they encounter, such as a lack of alternative means to contact them, whether face-to-face, web chat or e-mail. By emphasizing the barriers rather than the individual's condition, reporting can more effectively highlight the need for inclusive solutions and accommodations.

Be transparent about the justifications for choice in language.

Whatever choices are made about language, there should be transparency about the decision. All research materials and reports should include a brief explanation for the language used and the reasoning behind it. Examples will be specific to each research project but may include: explaining that the term 'disabled person' has been used in a recruitment screener because it aligns with the social model of disability; and explaining that the term 'disabled people' when reporting may also include people who do not identify as disabled but has been used for ease of reporting.

2.3 Full stakeholder insight

Stakeholders consistently noted that language choices are important in ensuring that disabled people feel included in research.

There was no one preference for how individuals prefer to refer to themselves either in terms of specific conditions, or as a disabled person. Some reports reviewed as part of the literature review noted that the term 'disability' could be deemed problematic as the prefix 'dis' could be seen as a negative. It was noted by many stakeholders that the language used can never be perfect for all. People have personal preferences and may feel that certain labels do not work for them. The need to be respectful of disabled people in the language choices made was highlighted by stakeholders.

> *'The language matters a lot to people. If you make somebody feel 'othered' or not included they are less likely to be involved in the research.' (Gordon McCullogh, Research Expert, Research Institute of Disabled Consumers)*

> *'Some people who have a disability do not like the word disability and they wouldn't use it to refer to themselves. There are other people who are actually very protective of the word and think the word disability should be used.' (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*

Different stakeholders used identity-first and/or person-first language when referring to disability.

There was a divide in whether to use identity-first or person-first language, and some stakeholders noted that this is very much a personal preference.

> *'There are many people who are saying they want to be recognised as their disability first. And there are just as many saying actually the disability is something I have and not*

> *something I am, and therefore it's me as a person [that] is more important than the disability.' (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

Identity-first language refers to individuals putting their identity as a disabled person first (e.g., disabled person, autistic person, d/Deaf person). Person-first language emphasises that individuals are people first and foremost and their disabilities or conditions are simply one facet of who they are. In the United Kingdom, identity-first language tends to be used more commonly by charities and academics, as it aligns with the social model of disability.

> *'We follow the social model of disability, that disabled people are disabled by society. However, we recognise that people have personal preferences.' (Fazilet Hadi, Charity, Disability Rights UK)*

> *'The capital D [in disabled] is really important for me in writing because it's a really core part of my identity and that's a really visual way of bringing it to life.' (Consumer Body)*

Most of those who used the social model of disability reported that using person-first language (e.g. person with disabilities) was problematic as it locates the disability within the individual rather than within society. It can also feel demeaning to some people.

> *'We don't use people-first language as it feels quite archaic.' (Charity)*

On the other hand, person-first was preferred by some who did not see their disabilities as defining them. This did not necessarily entail a rejection of the social model of disability, but rather was a preference for not defining someone by their condition.

> *'At the end of the day I'm Simon. I'm not a disabled person. Yes, I have a disability but that shouldn't be the thing that defines me.' (Simon Pearse, Charity, National Association of Deafened People)*

Person-first language was also the preferred terminology for certain conditions, such as mental health, learning disabilities or cognitive conditions e.g., person experiencing depression rather than 'depressed person'.

It was agreed by most stakeholders that it was important to be mindful of personal preferences whenever possible, such as when using quotes in reports or discussing disabilities with an individual. Where more general terms are used, stakeholders told us that it was necessary to be consistent and to provide a rationale for the choices being made at the outset.

> *'Everyone uses their own language. It is best to mirror the language they are using. If you are writing a blurb going out to a wide audience it is better to say what the audience prefers.' (Dan Holloway, DE&I Expert, University of Oxford)*

> *'You have to couch your language with "I'm using this language conscientiously with respect and with intent, and I know it's not going to include everyone and I apologise to those people that it doesn't include, but please know I turn up with intent". You always need to turn up with that level of humility, because there is no right answer that is pervasively true.' (Christine Hemphill, Research Expert, Open Inclusion, MRS Unlimited)*

Terms such as 'vulnerable' may not accurately reflect disabled people's lived experiences.

Some reports reviewed chose to use the term 'vulnerable' to refer to disabled people. Issues were raised by stakeholders about the use of this term as it presumes that disabled people are automatically less capable than non-disabled people.

> *'We don't like using the word vulnerable as it's projecting that onto other people who may not feel vulnerable.' (Government/Public Body)*

Although the term vulnerability can be used to refer to a variety of different circumstances (e.g., digitally vulnerable, economically vulnerable), disabled people themselves may not feel that they are 'vulnerable' and so using this term may not reflect their situation.

> *'Vulnerable can mean different things in different scenarios. People with declared disabilities are often the most able [out of all consumers] and know how their rights are protected and can extract value as a consumer.' (Scott Hamilton, Regulatory Body, Office of Rail and Road)*

It was noted that if using the term vulnerable, it was important to consider why someone was vulnerable and how this might impact upon the support that they require, rather than necessarily just using the term more generally for disabled people.

> *'So what type of harm, disadvantage, detriment, loss, difficulty, problem are people vulnerable to, and there we can work out what support we can give them and what support others might give them.' (DE&I Expert)*

There were differing views over the use of the term 'impairment'.

There were challenges in how to refer to an individual's condition, particularly if the focus was more on the barriers disabled people faced. The term impairment was often seen as implying a negative and as such some stakeholders were not in favour of it being used.

> *'I don't like the word 'impairment'. It's been fed back to us that actually this is quite offensive terminology because impairment is implying a negative.' (Government/Public Body)*

There was recognition that terms were needed which allowed for discussion of an individual's condition if it was relevant for the support they required. Terms such as 'health condition' or 'functional differences' were suggested as alternatives to impairment. A few stakeholders saw impairment as being simply a description, and so did not object to it being used when it was referring to a specific condition, or when it was being used simply as part of collecting demographic information.

> *'Talk about impairment rather than disability. Impairment is just a description, it's not medicalised.' (Gordon McCullogh, Research Expert, Research Institute of Disabled Consumers)*

Many of the reports reviewed in the literature used the term impairment to refer to certain conditions such as visual impairment. This was highlighted as being the most common terminology used and was widely accepted by a number of stakeholders, including stakeholders representing visually impaired people.

> *'I wouldn't use the term impairment. Although sometimes you have to, as visual impairment is often used. There is no social model compatible definition of visual impairment.' (Nuala Toman, Charity, Disability Action)*

There is no one agreed way to refer to specific conditions, and terms chosen will not always represent everyone within a group.

For individual conditions there are also differing opinions about precisely what terminology to use, and about identity-first or person-first language when it comes to individual conditions. Challenges were highlighted by stakeholders relating to a number of different conditions, including neurodiversity, hearing impairment, and visual impairment. For example, terms which were used to describe hearing impairment included:

- Deafness or partial hearing
- Hearing loss
- Being d/Deaf

- Deaf British Sign Language (BSL) users
- People who are deaf, have hearing loss or have tinnitus
- Sensory condition

Even organisations who work every day with disabled people told us that they sometimes had their language choices criticised, because people did not feel represented by the language chosen.

> *‘I’d probably say “anyone with sight loss” or “anyone who's got any challenges with sight loss that can't be corrected through spectacles or glasses” because I suppose I'd be trying to get to people who've got age related macular degeneration who'd never label themselves as blind. I'd probably get a few p****d off blind people, younger people going, ‘but I've never had sight loss’, but there's no perfect term.’ (Fazilet Hadi, Charity, Disability Rights UK)*

As with other language choices, being transparent and providing a clear rationale for choices was most important for being as inclusive as possible.

Inclusive language goes beyond terminology and can be reflected throughout reporting.[3]

When reporting research which includes disabled people, inclusive language can be reflected throughout the report, not just in the terminology used. The description of a situation may impact upon how disabled people are portrayed. If the barriers facing disabled people are positioned as the subject of the sentence, they can be better understood as presenting a challenge for disabled people. For example, “lack of ramps, narrow doorways and aisles, and produce trolleys positioned in the middle of aisles, can make shopping challenging for wheelchair users”. In addition, if language used in a report makes disabled people seem like they are less capable, then it can reinforce the view of them being victims. Stakeholders also noted certain terms which they avoided as being old-fashioned and stigmatising. These included terms like ‘handicapped’ or ‘confined to a wheelchair’ which make disabled people seem less capable than non-disabled people.

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[3] This section is primarily based on discourse analysis conducted on research reports.

3. DEFINING DISABILITY FOR RESEARCH PURPOSES

3.1 Summary of stakeholder findings

- Stakeholders highlighted that if disabled people are not being consciously included within research studies, they will be inadvertently excluded.
- There was agreement by stakeholders over the importance of providing an explanation and rationale for why the information is being asked for in the way that it is.
- Regulators and government bodies commonly used the GSS harmonised standard definition of disability, partly because it aligns with the Equality Act 2010 and equivalent equality laws in Northern Ireland.
- The wording of the GSS definition was seen to underrepresent those who overcome barriers, so their condition does not significantly impact their day-to-day life (e.g. wear a hearing aid, so no longer experience hearing loss), or people who have fluctuating conditions.
- Stakeholders provided a range of ways questions around disability can be asked if not needing to align with the Equality Act 2010 and equivalent equality laws in Northern Ireland.
- Self-identification as a disabled person was consistently recommended by charities and academics, but they and others flagged that only using self-identification risks not capturing people who do not identify as a disabled person.

3.2 Recommendations based on stakeholder insight

Provide a rationale when asking questions about disability to explain why the information is needed.

However questions around disability are asked, it is important to explain why the information is needed. If using the GSS standard harmonised definition for the purposes of benchmarking, explain to participants why they are being asked for this information. Similarly, if asking individuals to self-identify as disabled, explain what is meant by ‘disabled’ and why the information is needed. General principles when asking questions relating to disability include:

- Ensure there is a clear research need to ask about disability.
- Explain clearly why the questions are being asked in the way they are.

When defining disability, be guided by the purpose of the research and what the research seeks to measure or understand.

There are some studies where an understanding of barriers faced will be sufficient in meeting the research objectives, whereas others will require an understanding of conditions. The choice of question(s) and question wording should be led by the research objectives.

If the GSS harmonised definition is used, consider including a question on barriers and identity.

If needing to use the GSS harmonised definition, for example, to benchmark against the census data and to demonstrate the results as nationally representative by disability, the definition can be optimised by adding a ‘Prefer not to say’ option and explanation, as recommended by the Market Research Society (MRS). Consider adding a question around barriers related to the topic of the

research towards the end of the survey or recruitment screener. For example: *Which of the following, if any, influence your ability to change your broadband provider? E.g., issues accessing the website; lack of webchat service, having to phone up to cancel contract.*
In addition, consider asking a question allowing people to self-identify as disabled or not.

When conducting quantitative research where it is necessary to understand specific conditions, refer to the GSS harmonised question and consider amending answer options.

If it is not appropriate to be led by the research objectives when understanding conditions, consider referring to the GSS harmonised question, with revised answer options. The wording of some conditions could be tweaked to be more inclusive, including:

- Instead of ‘vision’ use ‘Blind or experiencing sight loss.’
- Instead of ‘hearing’ use ‘Deaf, experiencing hearing loss or having tinnitus.’
- Instead of ‘social or behaviour’ use ‘neurodiversity’.

In addition, a ‘Prefer not to say’ option should be included, as recommended by the MRS.

If there is no need to benchmark against data sources from Official Statistics, consider other ways of asking about disability.

It is possible for a series of questions to be asked which would provide more information about a person’s condition as well as how they identify. For example, a series of questions could be asked allowing people to self-identify as disabled or not, as well as asking about the barriers and limitations faced. In addition, when asking about specific conditions, more granular information could be asked for depending on the needs of the research e.g., asking about whether someone experiences hearing loss or whether they are d/Deaf, rather than just asking about hearing impairment or condition.

If categorisation is not necessary for the purposes of the research, ask people how they describe themselves.

If there is no reason to use the GSS harmonised definition, then consider asking participants how they choose to define themselves and their condition. Various examples can be used to ask if someone defines as a disabled person such as ‘Do you identify as a disabled person?’ and ‘Do you have lived experience of a disability, stemming from differences in how you see, hear, think, communicate or feel?’ In qualitative research, if a pre-identified sample has been selected, for example, from a representative group, ask what terminology the participant uses to describe their disability or condition. Researchers should note that solely using a self-identification question and not including questions around barriers faced, risks omitting people from research that experience barriers but do not identify as disabled.

For non-disability specific research, focus on the provision of support and understanding access needs.

For general qualitative research, the requirement is to ensure disabled people are not inadvertently excluded. Therefore, obtaining detailed information around a participant’s disability or condition, or how they self-define, is not needed. The key focus should be on what disabled people need to be able to take part in the research and to contribute fully and meaningfully. Please refer to Chapter 5 (Recruitment) for more information on how to ask this and examples of support to offer.

3.3 Full stakeholder insight

If disabled people are not consciously included in research, they are likely to be excluded.

Stakeholders emphasised the need to include disabled people within research, whether the research study has a specific focus on disability or not. Stakeholders, including researchers and research recruiters, shared that by not actively including disabled people, there has been inadvertent exclusion of disabled people across the research sector. This is considered particularly the case in qualitative research but also in quantitative research (see Chapters 5 and 6, Recruitment and Research Methods, for more detail).

> *‘They're usually excluded in recruitment unless people are deliberately including them. Most recruitment processes in mainstream research houses exclude them to some degree or to a significant degree by the tools and the skills of the people recruiting them.’ (Christine Hemphill, Research Expert, Open Inclusion, MRS Unlimited)*

Stakeholders discussed the importance of explaining why information around disability is needed.

There was widespread agreement amongst stakeholders that a rationale should be provided for any questions around disability, however they are asked. For example, stakeholders discussed that providing an explanation of the Equality Act and why benchmarking against it is needed for the study, may help individuals to understand why they are being asked for this information. Similarly, if asking individuals to self-identify as disabled, stakeholders discussed the importance of explaining what is meant by the term ‘disabled’ and why the information is needed for the study in question. This explanation may help individuals decide how they should answer the question.

> *‘There needs to be transparency and you need to explain why the question is being asked. If you use the Equality Act definition you need to explain why.’ (Dan Holloway, DE&I Expert, University of Oxford)*

The GSS harmonised definition was commonly used, particularly by regulators and research experts.

The GSS harmonised definition is frequently used, and was most commonly referred to by regulators, government/public bodies and research experts. This definition is based on the definition of disability from Equality Act 2010:

A person has a disability if the person has (a) a physical impairment and (b) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

The GSS harmonised definition allows for findings to be compared across different sectors and organisations. The most common way of asking this question is as two parts:

1) Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?
2) Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?

Organisations used the GSS harmonised definition because it allows for benchmarking against the Equality Act and equivalent equality laws in Northern Ireland, which may be necessary for some organisations. Its frequency of use allows for comparisons to be made across different datasets.

> *‘We use the ONS[4] harmonised questions – they’re tried and tested, that’s why we’re using them.’ (Government/Public Body)*

Stakeholders who used the GSS harmonised definition felt confident that it was appropriate to use because it has undergone extensive testing to ensure that it accurately captures disability. A clear benefit of the GSS harmonised standard is that it avoids using the term disabled, which some stakeholders found to be advantageous as individuals are not required to identify as something they may not want to. The questions were also developed in line with the social model of disability which

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[4] The ONS uses the GSS harmonised standard. They provide an explanation for asking the questions in this way in the census which refers to “helping to develop and monitor policies to make sure that everyone is treated fairly. These policies affect the way that public bodies provide healthcare and aim to reduce health inequalities. They also help work towards improving the general health of the people in their area and the rest of England and Wales.”

states that people are disabled by barriers in society. Disabled people who have found ways to manage the barriers society puts in place and/or their condition, so may not experience limitations on their day-to-day activities, would not respond ‘yes’ to the second question and would therefore purposefully not be classified as disabled according to this definition[5].

Some stakeholders discussed the drawbacks of using the GSS harmonised definition.

As noted by one stakeholder, there may well be a mismatch between what a participant understands when they fill out the questions and what the analysts understand.

> *‘A person may think carefully about this and go “I’m deaf, but does being deaf mean it’s a bad thing?”. I may experience some communication issues or waiting for an interpreter is an issue. ...If I click yes, what does it mean? The people who are analysing the data, what do they think clicking ‘yes’ means?’ (DE&I expert)*

Even though individuals are not required to self-identify as disabled when using the GSS harmonised definition, depending on their answers they are, then, for the purposes of the research considered disabled. The GSS questions also may lead to under-representation in the sample. For example, some individuals, such as people with neurodiverse conditions or people who are d/Deaf, may not see themselves as having a physical or mental health condition. Therefore, they may not answer ‘yes’ to the first question. Finally, people with fluctuating conditions may not always have issues with carrying out day-to-day activities, and the second part of the question does not reflect that.

> *‘People with disabilities experience disability as fluctuating, as fluid, and they feel more disabled on some days than others. A person in a wheelchair may not feel disabled at all. It’s only when something is out of the ordinary and they suddenly have to, say, use a different form of transport, where they experience their disability being a serious issue.’ (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

Being able to self-identify as disabled was preferred by some stakeholders, but there may be risks of under-representation.

Many stakeholders, particularly from charities and research organisations suggested that allowing people to self-identify as disabled is the best option, rather than using the GSS definition. It allows individuals to decide for themselves if they wish to be considered disabled for the purposes of the research.

> *‘There’s no crystal-clear answer, but best practice is to allow people to self-identify in a recruitment questionnaire.’ (Ella Fryer-Smith, Research Expert, Association of Qualitative Researchers)*
>
> *‘In the UN Convention anyone can identify as disabled. So we ask “do you identify as a disabled person”. It gives the person the opportunity and you’re not defining them.’ (Nuala Toman, Charity, Disability Action)*

However, there is the possibility that some people who would be captured as disabled by the GSS harmonised definition, or people who experience barriers to services, would not identify as disabled and so would not be reflected in the research if relying solely on self-identification. This was emphasised by stakeholders who noted that they did not refer to themselves or people their organisation represents as having a disability.

> *‘We don’t refer to our community as having a disability. For a large part of the community they do not consider themselves to be disabled.’ (Dr Hannah Semararo, Charity, RNID)*

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[5] GSS Harmonised Team, (2020) https://analysisfunction.civilservice.gov.uk/policy-store/long-lasting-health-conditions-and-illness/

> *'I am legally deemed to have a disability, but I wouldn't consider myself to be a disabled person.' (Graeme Whippy, DE&I Expert, Freelance Disability Consultant)*

Alternatively, as stakeholders noted, the aim of social research is to understand people's lived experiences and so a specific classification as disabled may not always be necessary.

> *'You're not doing clinical examination or tests. So you're relying on self report[ing], but I think it's always about giving people the opportunity to talk about their own authentic experience.' (DE&I Expert)*

There were a number of supplementary options cited for asking about disability or long-term conditions.

There were a variety of different suggestions for how disabled people could be identified in an inclusive way, which would allow people who perhaps would not be counted as disabled under the GSS harmonised definition to indicate relevant barriers or conditions. Some other ways of defining disability which were suggested included:

> *'Does your brain, mind or body work in a different way to other people?' (Graeme Whippy, DE&I Expert, Freelance Disability Consultant)*
>
> *'Do you have an impairment, condition or access need?' (Charity)*

Both these definitions do not rely on a disability having a specific impact on an individual's day-to-day activities. In addition, they do not ask about the length of time someone has had their condition, which means that fluctuating conditions are included. However, it is also possible that as these definitions are incredibly broad they would mean that lots of people would be included in them who perhaps would not be included in the Equality Act definition and equivalent equality laws in Northern Ireland, or if asking people to self-identify as disabled.

It is also possible to ask more broadly about personal circumstances or conditions. For example, one report in the literature review discussed a range of personal circumstances including physical, cognitive, psychological, sensory and cultural. These personal circumstances included conditions (e.g., hearing, visual) but also broader circumstances relevant to the research question – including migraines and pregnancy. This approach avoids the need to ask directly about disability, however, can also be so broad as to not fully allow for an understanding of the specific needs of disabled people.

Others suggested focusing specifically on needs or barriers in questions rather than on the condition. This may be things like discriminatory attitudes, lack of step-free access to buildings, being unable to find accessible accommodation, websites which are not screen-reader friendly, being expected to participate in group activities.

> *'Do you feel you could benefit from extra support due to any of the following [list of needs or barriers].' (Charity)*
>
> *'Would any of the following impact your ability to [cancel your broadband]? List the barriers as opposed to the disability.' (Stakeholder workshop)*

An alternative, which was highlighted by one stakeholder, was based on guidance from the Equality, Diversity, Inclusion in Science and Health coalition. This guidance (known as the Diversity and Inclusion Survey, or DAISY guidance) asks a series of questions which allows individuals to self-identify as disabled, to indicate whether they experience barriers or limitations, and to say what those barriers are.

The MRS does not advocate a single method by which to collect information on disability and long-term conditions, but in its best practice guidance offers a few examples. The questions are aligned with the Census, but include alterations to ensure compliance with the MRS Code of Conduct, namely the inclusion of 'don't know' and 'prefer not to say' answer options, and a brief explanation of what is meant by the terminology in the question:

Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

- Yes
- No
- Don’t know
- Prefer not to say

What we mean by “physical and mental health conditions or illnesses”: This is about health conditions, illnesses or impairments you may have. Consider conditions that always affect you and those that flare up from time to time. These may include, for example, sensory conditions, developmental conditions or learning impairments.

4. SAMPLE DESIGN

4.1 Summary of findings from stakeholders

- There were key challenges in building a sample frame, as it requires categorisation of people. Some rejected the notion of categorisation of disabled people in its entirety, others acknowledged the drawbacks but considered it necessary for inclusive research.
- Stakeholders noted that research agencies are encouraged to use ‘disability’ as a marker for creating a nationally representative sample, but there are challenges with relying on Census data to create quotas.
- Stakeholders reported that certain disabled people are more likely to be excluded from research samples than others as they are not considered at the sample design phase.
- Stakeholders discussed the risks in overburdening few participants by expecting them to represent the views of a diverse group and this must be considered during sample design.

4.2 Recommendations based on stakeholder insight

Clearly state who your target group includes.

People can have long-term conditions or face barriers to research but do not identify as disabled. It is important to be explain upfront who is captured by the term ‘disabled people’ and why you are using this term.

When undertaking nationally representative surveys, continue with standard data collection approaches but be open and clear about the drawbacks.

Undertaking nationally representative surveys often uses set quotas on a selection of demographics, including disability. Any reporting should be transparent on the limitations of the data collection method used regarding disability. There will be over- and under-representation of conditions dependent on the method used, and so any nationally representative survey by disability should not claim to represent the spectrum of different barriers faced by different disabled people.

Consider a minimum disability quota of 18% for nationally representative samples.

Whilst the most recent Census data requires that 18% of the population respond positively to the question, on the basis of multiple other sources concluding that the proportion of disabled people is much higher,[6] the 18% should be used as a minimum quota, when using quota-based sampling.

Multiple socio-demographic characteristics should be agreed upon at the sampling phase.

Disability is only a facet of a person’s lived experience and may not be a key influencing factor on the experience the research is looking to uncover. Therefore, it is still essential to collect additional socio-demographic data with which to undertake intersectional analysis and a rationale should be provided (for example, explaining that this information will allow us to understand the experiences of disabled people at a more granular level). Analysis should explore the data across multiple characteristics, and identify the factors that the participant has reported as influencing their experience.

In qualitative research, avoid overburdening the same people.

Researchers should avoid restricting their engagement to a group of participants who are frequently called upon to take part in research studies. This can result in an expectation that they reflect the

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[6] 24% is used by DWP Family Resources Survey, also quoted by Scope.

experiences of others, who may experience different barriers. Refer to Chapter 5 (Recruitment) for more information on achieving diversity of sample.

4.3 Full stakeholder insight

Some stakeholders argued that the categorisation of people required during sample design is not reflective of disabled people's lived experiences.

Some stakeholders challenged the notion of designing a sample that requires categorisation by disability, (i.e. categorising someone as disabled and/or by disability type or condition), particularly stakeholders specialising in disability specific qualitative research. Some argued that this it was not a realistic or possible action to take, noting that categories created to design a sample frame often used terms created by non-disabled people and do not necessarily reflect lived experiences. Others noted the difficulties in creating categories as disabled people are not a homogenous group.

> *'Often [for research studies] you've got to have a certain number of people with sensory impairments and physical impairments and so on. But people themselves don't necessarily think of themselves in those categories. And a lot of people literally have more than one impairment. I can remember a project where every time we tried to put somebody in a box, it turned out that, there was something else going on. A lot of people [in the study] would have perhaps a borderline learning disability and mental health issue and they might have a physical impairment as well.' (DE&I Expert)*

Stakeholders flagged risks in overburdening a few people to represent many differing experiences.

When designing qualitative sample frames to include disabled participants, stakeholders highlighted the difficulties in reducing many people's experiences to one or two people, emphasising that people experiencing the same condition (as per a pre-defined list) have very diverse lived experiences. Whilst all research looks to understand wider insights by consulting with a smaller group of people, some stakeholders felt the risks of drawing population-wide conclusions based on speaking to disabled people were higher than for other socio-demographic characteristics. In qualitative research, the risks of overburdening participants were highlighted as it was considered unfair to place the weight of responsibility and representation of disability on only a handful of individuals.

> *'When you talk to one person with disability, you speak to one person, not the whole group.' (Graeme Whippy, DE&I Expert, Freelance Disability Consultant)*

> *'The risk is that a handful of disabled people are being held responsible for the experiences of all disabled people in the UK.' (Charity)*

Many stakeholders noted that disabled people and certain 'types' of disabled people have traditionally been excluded from research design.

Stakeholders noted that some people with different types of lived experiences have often been excluded from research. Specifically, these included: people with long-term disabilities or health conditions; people with multiple disabilities; people whose conditions had differing levels of impact; people with episodic conditions. These 'types' of disabled have been excluded from research design as the sampling has not been designed to actively include them, and without active inclusion there is a high risk of exclusion. Question wording should therefore be considered, as discussed in Chapter 3 (Defining Disability).

Typically, when creating a nationally representative sample in quantitative research studies, age, gender, region and sometimes ethnicity are used. The MRS now advocates for the inclusion of disability in creating a nationally representative sample in its best practice guidelines, and encouraging full transparency in what nationally representative samples are representative of[7].

Many highlighted the importance of intersectionality when creating a sample frame.

Stakeholders emphasised that reducing a research participant down to a single characteristic, such as being a disabled person, is reductive. This is discussed further in Chapter 7 (Analysis and Reporting). To ensure that the research study builds a truer picture of differing experiences, multiple socio-demographic characteristics should be agreed upon at the sampling phase; this could encompass a wide range of characteristics, and stakeholders suggested including people protected under the Equality Act and equivalent equality laws in Northern Ireland.

> *'Intersectionality is a massive one for us. It's not just like somebody who is disabled, but perhaps an ethnic minority, a woman, and all those additional layers as well. And then what that intersectionality means in terms of their outcomes is really important for us.' (Government/Public Body)*

Stakeholders stressed the importance of considering exactly what information is needed from participants and why, when designing a sample. As with all data collection, it was considered crucial to justify the need to collect data on disability and only collect data if it is going to be analysed.

> *'Our view as researchers is that you shouldn't collect data if you're not going to at least analyse it. Don't just collect data for the sake of it, you've got to think early doors, are we going to analyse it, don't just collect it, because it causes participant fatigue and it's not ethical to collect data.' (Department for Digital, Culture, Media and Sport)*

Creating a survey nationally representative by disability can mean reliance on the Census data.

When creating the sample frame for setting quotas in, for example a nationally representative panel survey, the data is usually based on Census data. This data implies that 18% of the sample must identify as having a disability or long-term health condition for it to be representative by disability. However, stakeholders highlighted issues with this approach. In particular, the data is not considered fully up-to-date (this figure comes from the 2021 Census (for England and Wales), and the question wording in the Census is that of the GSS harmonised definition, which may lead to under- or over-representation of certain people (discussed Chapter 3, Defining Disability). Other data sources, such as the UK Disability Statistics, suggest that the 18% figure is an underestimate and that a truer reflection of the population would be 24% or higher.

> *'The robust nature of the Census is it means that that's the most reliable. So we sometimes find ourselves kind of hogtied to this which is not ideal. What you might find though is you're not then targeting that 18% that is referenced in the Census, you'll get much more, estimates are more like 40%.' (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*

Although the MRS includes a question example for categorisation of disability, it does not recommend setting individual quotas on categories to ensure a representative sample by disability.

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[7] MRS Representation in Research

5. RECRUITMENT

5.1 Summary of stakeholder findings

- Stakeholders cited numerous barriers when recruiting disabled people for research purposes.
- Stakeholders discussed the importance of providing sufficient context about the research upfront, enabling participants to make an informed decision about taking part and build trust in the research process.
- Various measures were undertaken to enhance accessibility of the recruitment process such as the use of easy read materials, translating materials into BSL and providing alternative means of contacting recruiters or researchers.
- Stakeholders undertaking qualitative research highlighted the importance of asking about additional support needs to enable disabled people to take part in research.
- There was widespread agreement that more than one recruitment source should be used to minimise the exclusion of some groups and reduce sample bias, including a combination of online and in-person engagement.

5.2 Recommendations based on stakeholder insight

Consider a specific budget to support accessibility in recruitment and fieldwork.

To truly take a participant-first approach, it must be feasible to make accommodations and adjustments. A set budget should be considered for all types of projects.

Provide sufficient context about the research project upfront.

Sufficient information enables participants to make an informed decision about taking part and builds participants’ trust in the research and encourages involvement. Information such as research objectives, what to expect from the research process and the impact and value of the research should be provided upfront.

Where possible, factor in additional time to support some participants.

Participants may require additional time to ask questions about the research and the research process before deciding to take part. They may also require additional support understanding screener materials. More time should be factored into the recruitment process to account for this.

Consider the use of easy-read materials, translating materials into BSL and screen-reader accessible materials.

The use of easy-read materials to explain the research objectives, the research process and to gain consent should be considered for all types of research to aid comprehension and obtain informed consent. This is particularly relevant within the context of qualitative research and when conducting research with people with learning disabilities and/or mental health conditions.

For some d/Deaf people and people with hearing loss, English is not their first or preferred language. When conducting research with these groups, consider translating screener materials into BSL to aid comprehension of the research and minimise exclusion.

In addition, to ensure materials are accessible to screen-readers, include Word formats in addition to other formats used, such as PDF. This will be beneficial to people who are blind or visually impaired.

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For qualitative research, focus on the provision of support and understanding access needs.

At the screener stage, proactively provide a list of support that can be offered, with a follow-up question to ask if anything else is required. Examples of additional support include research materials, such as research stimulus and question topics, sent in advance and in a larger font; needing the moderator to speak louder; and the option to take breaks throughout the research process.

Provide alternative means of contacting recruiters or researchers.

During qualitative recruitment or survey introductions, have a phone number available on materials, offer the ability to text researchers or offer different ways to complete a survey.

Consider the use of language when a participant is screened out.

If a participant is not eligible to take part in a qualitative or quantitative study, consideration should be given to the screen out language to prevent the participants having a negative research experience.

When conducting research with the general population, choose a recruitment method most appropriate for the research objectives, and then ensure measures are put in place to minimise exclusion.

We recommend starting with the research objectives in mind and selecting a recruitment and research approach most suitable to these. From there, additional measures should be put in place to ensure the research is not excluding disabled people, as outlined above.

Use multiple sources to recruit disabled people for disability-specific research and factor in additional time for recruitment.

Recruitment methods will heavily depend on the target audience, but wherever possible, we recommend:

- Not relying solely on online methods, but also using in-person engagement;
- If using representative groups, working with both smaller and larger charities; and
- Minimising reliance on one single representative group/charity.

Additional time should be factored in to recruit from multiple sources.

5.3 Full stakeholder insight

Stakeholders cited numerous barriers when recruiting disabled people for research purposes.

There was widespread agreement that recruitment processes present many barriers to disabled people taking part in research, leading to some degree of exclusion.

> *'The research sector as a whole is very immature in how researchers and research engage disabled people.' (Christine Hemphill, Research Expert, Open Inclusion, MRS Unlimited)*

One key barrier identified by stakeholders conducting qualitative research was the use of inaccessible recruitment materials, for example, screeners not being in BSL or easy-read formats, and fonts or colours not being appropriate or accessible to the target audience. Some stakeholders also discussed an increasing reliance on online recruitment methods, which can exclude disabled people who might be less digitally engaged such as older disabled people and people with specific conditions.

> *'[One barrier is] Disabled people not being aware of the call for involvement in research because it may not be accessible information or the potential participants may not*

> *engage with channels such as social media. You need to ensure the communication channels used for recruitment are accessible.' (DE&I Expert)*

Furthermore, some stakeholders discussed the use of inappropriate language at the recruitment stage; this may be language which does not resonate with the target group or is deemed offensive.

> *'For deaf people or people with disabilities it's best to check with them and get their input on language. For example, if you wanted to interview people from a minority ethnic background for example, and you would ask them personally 'What do you think about these terms or this language?' Is that offensive or not offensive and you can just do the same with disabled people. It would work the same way, so it's not one-size-fits-all.' (Dr Robert Adam, Charity, British Deaf Association)*

Amongst academics in particular, trust was cited as a key barrier to engagement of disabled people. Some highlighted that disabled people have historically been treated in an exploitative manner and this has led to disabled people being hesitant about taking part in research. Other stakeholders highlighted the lack of trust some disabled people have about the research leading to change.

> *'Be cautious that participants are likely to have been contacted many times before about research, they are likely to be hesitant to get involved as they lack trust that their time will be used to create actionable change.' (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*
>
> *'A lot of disabled people's communities are quite nervous of university researchers or research in general. There's a whole history of university research being quite abusive or problematic for disabled people. There's a nervousness about that, there's issues around confidence and esteem.' (DE&I expert, University of Sheffield)*

In addition, some stakeholders highlighted that assumptions can be made about some disabled people's capacity to be involved in research. For example, it was suggested that people with learning disabilities are often excluded from research due to a lack of awareness and knowledge from researchers or commissioners about what a learning disability is and not knowing how to communicate with the participant. One stakeholder discussed the importance of collecting detailed information about the participant and their condition prior to fieldwork.

> *'People may draw a line in their head about wanting to communicate with someone with a learning disability. Somebody with a learning disability may present in what people perceive as an 'odd' way. It's that lack of awareness and understanding of what a learning disability is.' (Charity)*
>
> *'Maybe our ignorance levels of impairments is also important. If you're talking about those with developmental or intellectual disabilities, and if we are not aware exactly of the level of their impairment and the accommodation needed, this may create a barrier… Collecting detailed information about people who are going to be interviewed beforehand would help us a lot to overcome a multitude of barriers'. (Dr Mostafa Attia, Research Expert, Disability Research UK)*

Stakeholders agreed that sufficient context about the research should be provided upfront.

There was widespread agreement about the importance of providing sufficient context around the research project, enabling participants to make an informed decision about taking part and build participants' trust in the research and encourage involvement. This includes information about the objectives of the research, what to expect from the research process and the impact and value of the research. It was considered particularly important for some disabled people due to the effort required in taking part.

> *'Because it is really, really exhausting and for a lot of people even answering a simple survey that will be their week. They're going to do this as the one thing they do, they have lots of past experience of research where nothing comes out of it. It's being absolutely clear about the good that'll happen, conveying good, not just conveying that something meaningful will happen, but conveying good faith.' (Dan Holloway, DE&I Expert, University of Oxford)*

> *'If you're not clear on the aims of the research, the scope of the research and what it's going to be used for, that can make people not willing to participate.' (Dr Armineh Soorenian, Government/Public Body, Cabinet Office)*

Various measures were undertaken to enhance accessibility of the recruitment process.

Multiple examples of best practice were identified from the stakeholder interviews and the literature review. Many agreed that additional time needs to be factored in at the screener stage of a qualitative research project to communicate the purpose of the research and gain consent. This also included factoring in additional time for any participant questions. One recruitment agency identified this as particularly important if the research topic is sensitive, such as the impact of a condition on an individual's life.

> *'We all go through a specific training for recruiting sensitive and vulnerable participants. We have to allow extra time to have that kind of sort of compassion and empathy with people, to not to necessarily sell them, but you know, to allow them to speak.' (Jordan Ashall, Recruitment Expert, Acumen Fieldwork)*

At the recruitment stage, it was considered particularly important to involve people with lived experience to ensure the research, and recruitment materials, were based on an understanding of the people the research is seeking to targeting. This was discussed particularly in relation to language and terminology. Many stakeholders advised reaching out to representative groups as a means in which to do this.

> *'I think it's about knowing [your audience], even if you're a total novice. I guess it's about doing your research and due diligence around the politics of those communities. What's the preferred language?' (DE&I Expert, University of Sheffield)*

In addition, the importance of the language used when a participant is screened out was stressed, to prevent the respondent having a negative research experience.

> *'If you're completing a survey link and for some reason you drop out because you're not right for it. It's around how you say to that person. You have to have a sensitivity, explaining why they couldn't go any further.' (Abi Fuller, Recruitment Expert, Acumen)*

Several examples were provided to ensure screener materials are accessible to disabled people. These include the use of easy-read materials to explain the research objectives and gain consent. This was particularly emphasised amongst stakeholders working on behalf of people with learning disabilities and mental health conditions. Other examples included translating everything into BSL for people who are d/Deaf, ensuring materials are screen-reader accessible and creating screeners in online and paper formats.

> *'Using multiple languages like we did in the project we did on deaf people where we used captioning around all our recruitment materials, they were available in BSL as well as written English. We've done projects where we've recruited using easy-read for adults with learning disabilities. So again thinking about access different formats and a range of those.' (DE&I Expert, University of Sheffield)*

> *'Online surveys are always in English. It means that they're not always accessible for everybody from the community. It's good for people if they can upload videos in sign languages as a response.' (Dr Robert Adam, Charity, British Deaf Association)*

> *'Even if the screening information is all online, that doesn't mean to say somebody who doesn't have the internet can't complete the screening questionnaire. We might have to print it out and post it to them, or we might have to sit next to them and complete it for them. We've done both of those in the past.' (Sarah Weir, Recruitment Expert, Intelligent Fieldwork)*

Some stakeholders also highlighted the importance of providing supplementary means of contacting recruiters or researchers, for example, by including a phone number on online recruitment materials in addition to an email.

Being upfront about the provision of additional support was seen as crucial.

A key recommendation from stakeholders was to be upfront that additional support can be offered, particularly discussed within the context of qualitative research. Some stakeholders recommended asking the question 'Would you require additional support to enable you to take part in the research?' whilst others suggested providing a list of support that could be offered with a follow-up question, asking if anything else would be required. Some examples of additional support from the stakeholder interviews and the literature review included: research materials and stimulus sent in advance and in a larger font; needing the moderator to speak louder; factoring in more time for fieldwork; the option of a pre-call to alleviate any anxiety and ask questions about the research; having another person present at the research stage such as a carer, personal assistant, parent or friend; a wheelchair-accessible venue; the option to take breaks throughout the research process; the option of allowing participants to type their answers if they do not feel comfortable talking; and being able to do an interview rather than a focus group if needed. For example, more time for fieldwork was specifically referenced as being beneficial to people with speech impairments who may need more time to formulate their answers; for research around sensitive topics; for people who are neurodivergent; and for people who may be anxious about taking part in research.

> *' Anticipating what they [accessibility needs] might be and putting people's minds at rest that they will be addressed is important. Will there be accessible toilets? Will the venue be accessible? Can people bring an assistant if they want to? Will material be available upfront?' (DE&I Expert)*

There was widespread agreement that disabled people should be compensated for their time when involved in any type of research. As stakeholders pointed out, this does not always happen. Many identified it as unethical to not pay disabled people for their time and that payment recognises participants' time and effort. For some stakeholders, disabled people should be paid more than people who are not disabled due to the potential additional effort required of them.

> *'We always pay. I think it's really important that you pay people for their time in people's lived experience because they won't necessarily have a job or a paid job that values them.' (Charity)*

Stakeholders discussed the importance of using more than one recruitment method to recruit disabled people.

Several recruitment methods were cited to recruit disabled people for research purposes. These included representative organisations or disability networks, for example, charity organisations and support groups; standard and specialist panels; social media such as using specific hashtags on X (formerly Twitter), or posting in disability-specific groups on Facebook; and in-person recruitment through attending events or conferences. Disability organisations and charities tended to rely on their own panels, networks or customer databases to recruit participants. Research agencies often partnered with recruitment agencies who undertook recruitment on their behalf. Recruitment agencies tended to rely on online methods of recruitment, for example, through their own databases and/or social media channels. Academics heavily relied upon the networks they had built over time, disability networks and social media.

Many stakeholders agreed that sample bias is inherent in all recruitment methods and that more than one source should be used to recruit disabled people to mitigate against the risk of excluding people, to represent a variety of voices and to ensure the findings are reflective of the population the research is seeking to target.

> *‘I think it’s using lots of different channels because it's trying to get people with different disabilities to participate. So they've got their online forms, they're piloting telephone, online events, physical events, events run by voluntary organizations who they think can reach some of the groups that would be harder for them to reach. So there isn't going to be one way.’ (Fazilet Hadi, Charity, Disability Rights UK)*
>
> *‘It’s about being as resourceful as possible to spread the net. So we don't just have one sort of seasoned respondent who is taking part in 20 other surveys that year, for example.’ (Research Expert)*

Representative groups were considered an effective means of recruitment, but stakeholders acknowledged that this can have limitations

The benefits of accessing representative groups, such as disability organisations and charities, were heavily cited: participants can be directly accessed; they allow underrepresented groups within the disabled population to be targeted; and they can be used to achieve a geographic spread.

> *‘They can involve people across all of England. They can send out all the invites and support people to get involved. Some people say yes, it's all the same people but you've got to start somewhere.’ (Charity)*

In addition, for some stakeholders undertaking qualitative research, attending support groups, events and conferences in-person had the added benefit of enhancing engagement through the process of snowballing i.e., a process by which existing participants recruit future participants to take part from their acquaintances.

> *‘I have attended a number of conferences where I basically just had leaflets and when I knew that there was going to be a keynote in the main room, I would just go through and just dish out my leaflets… Even people who did not have fibromyalgia themselves or may not have been disabled themselves would contact me and say, ooh I saw the leaflet, is it OK if I hand it over to someone?’ (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

However, many stakeholders were cautious of using representative groups as the sole source of recruitment. By only involving disabled people who are accessing services and receiving support, people who are most in need and disengaged from services are excluded from the research, leading to sample bias. Some stakeholders also discussed the risk of producing a biased sample by only involving disabled people who have a particular perspective based on the charity or group they are part of, as well as the potential issue of overburdening the same participants and hearing from the same voices. In addition, others discussed the risk of using one group of participants to represent all disabled people’s experiences.

> *‘The problem is there is also self-selection in those networks. Being a member, you’ve got the population and sub-population who are engaged, digitally included and willing to do research. So you are getting views but are you getting views of a particular type of group?’ (Government/Public Body)*
>
> *‘People who put themselves forward through networks are particularly self-selecting groups.... If you are well enough to put yourself in front of a panel, do you really have the issues of the people whose problems we are trying to solve?’ (Dan Holloway, DE&I Expert, University of Oxford)*

Stakeholders acknowledged that different charities have different goals and types of members. To ensure a range of perspectives are involved in the research and to accurately reflect the voices of disabled people it was considered important to not only speak to larger organisations, but smaller charities too.

> *'I'd probably speak to more grassroots organisations, and not just the large national disability charities, because I think there's definitely a feeling in disability communities that there's a really big historical divide around what large disability charities like Mencap, Rethink and RNID do and then what small and more localised, more grassroots organisations do.' (DE&I Expert, University of Sheffield)*

Stakeholders discussed the broad reach of social media but highlighted that it can be exclusionary.

For many stakeholders, social media was considered an effective means by which to access some disabled people, as it is perceived to have a broad reach. It was deemed particularly useful for accessing specific disability groups, such as people with rare health conditions, people with long-term health conditions and people who are neurodivergent.

> *'I literally just put it out on social media. I have been part of some or I'm still part of some support networks or some sort of specialist support networks on social media. And yeah, if you put it out there, people find you. People want to be a part of research and they want to be heard and they want their stories to be included. So I've never had any trouble finding people.' (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

Social media was also discussed as an effective means in which to gain wider access to disabled people, for example, by accessing carers' or parent groups when undertaking qualitative research to reach people with learning disabilities. However, many stakeholders identified risks of relying solely on social media to recruit disabled people as many people are not using social media. This was particularly discussed in relation to not reaching people who are digitally excluded and/or older participants and people with specific conditions, but also reflects that not everyone chooses to be on social media or would respond to a call to participate in research via social media.

> *'There are many types of disabled people that are digitally excluded. Adults with a learning disability and many visually impaired people. Social media isn't accessible to many.' (DE&I Expert, University of Sheffield)*

Research panels were identified as providing quick and easy access to participants but, for many, lead to a skewed sample of disabled people.

Some stakeholders used standard or specialist research panels to reach disabled participants. These consisted of a database of participants who have self-selected as having a disability and/or long-term condition. This was considered a quick and easy method of recruitment as participants have already self-defined as being disabled and/or living with a particular condition. In addition, for some, it allows for a broader reach and an opportunity to achieve a more representative sample. However, there was widespread agreement that panel samples can be heavily skewed due to self-selection bias, more so than other methods of recruitment, as participants have signed up to take part in research and consist of people who have the capacity to undertake research, as opposed to people who may be most in need of support. Stakeholders also discussed the exclusionary nature of online panels in particular; that they fail to engage people who cannot access them such as people with specific types of disabilities, people who are digitally excluded and/or older participants.[8]

> *'For 1,000-2,000 people, you can go via a panel, but it may be again, just people who are engaging or able to engage so it only gives you a sense of those people. It's only as good*

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[8] Some stakeholders had their own panels or used specialist panels. Various measures were employed to mitigate against the risk of self-selection bias and ensure diversity of sample.

as the range of channels, how inclusive, how accessible the organisation is really, so everything comes with a caveat.' (DE&I Expert)

'Some may have such issues that online or telephone panels won't reach them, and they are then seldom heard... You can't get fieldworkers out in the street anymore. The pool of respondents is getting smaller and there is an over-reliance on those who can be reached easily.' (Government/Public Body)

6. RESEARCH METHODS

6.1 Summary of stakeholder findings

- All stakeholders stressed the importance of designing an accessible research approach from the outset.
- Stakeholders discussed the importance of making accommodations and adjustments to enhance accessibility and allow disabled people to contribute to research meaningfully and on an equitable basis.
- There was widespread agreement that disabled people should be involved within the research design and process, however, views around what this should look like in practice varied.
- For some, co-production was seen to enhance the credibility and value of research findings, however, key challenges were cited, particularly within the context of resource constraints.
- Stakeholders consistently identified two key points to involve disabled people when conducting disability specific research - when setting up the project and when developing recommendations.
- Some stakeholders discussed the added value of advisory bodies to the research process and outputs, but their limitations were acknowledged.

6.2 Recommendations based on stakeholder insight

When designing research with the general population, accessibility should be considered at every stage.

In quantitative research, the platforms being used, and their functionality, should be assessed. When designing qualitative research, ensure flexibility is factored into the research design in terms of method of response and time/date most suitable to the participant. Furthermore, researchers should be proactive in offering other adjustments or accommodations (outlined in Chapter 5, Recruitment), in line with participants' access needs, and ensure moderators are fully briefed on participants' needs.

For qualitative research with disabled people, research should be designed with accessibility at its core.

Recognise that people with similar conditions will have different needs. A participant-led approach should be employed, led by the needs of the participant, and adjustments or accommodations (as outlined in Chapter 5, Recruitment) should be made in line with participants' access needs.

For qualitative and quantitative research with disabled people, involve disabled people throughout the research process if possible.

Ideally, disabled people should be involved at all stages of the research process from research design through to the dissemination of findings. Choose an involvement approach, such as co-production or a lived experience panel, with full acknowledgement of its advantages and limitations, and be transparent about this when reporting. The level of involvement will depend upon resources and timeframe. It should be clear to disabled people what their role will be, what the level of involvement is, and what they will be paid for this.

When conducting research with the general population, consider a lived experience panel or an advisory board to ensure the research is accessible and meaningful to disabled people.

This should be established at the outset of the research and, as above, level of involvement will vary depending on resources and timeframe, as well as project objectives.

For qualitative studies, build relationships with participants through regular communication.

This creates a more comfortable environment for the participant, helps minimise the power dynamic between researcher and participant and builds participants' trust in the research process. Ensure regular communication with participants throughout the research process, disseminating findings with participants and communicating the impact of the project. This will likely require collaborative efforts between research commissioners and agencies.

6.3 Full stakeholder insight

Stakeholders consistently highlighted the importance of designing research with accessibility at its core.

There was widespread agreement from stakeholders that additional resources should be factored into the design of the research to be able to address the barriers disabled people experience and design a research approach that is accessible. Stakeholders discussed multiple ways in which research methods could be made more accessible from the outset in both quantitative and qualitative studies. Examples included:

- the use of screen-reader accessible materials;
- ensuring in-person venues and online platforms are accessible;
- using accessible online channels when conducting online research;
- having additional support available, such as tech support for online calls, another moderator on hand to provide support if the discussion causes any distress or moderators with specific training;
- having a number to call when participants are being asked to complete a survey; and
- the use of a wellbeing checklist, outlining a set of measures and questions to ask participants to ensure participants feel comfortable.

> *'We ensure we don't cause any harm through wellbeing checks and making sure there is sufficient support when conducting fieldwork. An example is we have two moderators when conducting a focus group so if someone has a problem they can speak to someone outside the focus group.' (Richard McManus, Charity, Rethink Mental Illness)*

> *'If there's an online digital element to a project, whether it's a pre task or a diary, we're conscious to make sure that there are alternatives available to people. So whether it's a kind of traditional sort of pen and paper, it's an email version or whatever. And we've just always got to make sure we've got the time to put into these things because it does take a lot longer to plan and requires a bit more thought than a traditional project would.'(Research Expert)*

> *'In terms of telephone [interviews] the interviewers are trained to help people who present with different difficulties whether that's people who are older and can't hear well or may have some kind of learning difficulty.' (Research Expert, Regulator)*

Furthermore, all stakeholders discussed the importance of a flexible fieldwork approach, to allow for different modes of engagement, particularly within the context of qualitative research. If the primary research approach involves a group discussion, for example, alternative options should be provided for participants to contribute individually. Or, interviews may need to be broken up into smaller portions of time.

> *'For me 45 minutes is negligible, but for somebody who's chronically ill the energy drain is a lot bigger so the interview should be split in half. It's a very common piece of feedback that we're seeing is being really underestimated.' (Charity, The Brain Charity)*

In addition, some stakeholders discussed using non-traditional methods of engagement, such as drawing and using Lego to elicit participants' responses. An ONS report used traffic light cards for participants to signal a pause or end the interview. These tools were used with children who had special educational needs and disabilities (SEND), and not only allowed them to participate in the research by ensuring their comfort but prioritised them feeling empowered – either to direct the conversation or to choose when to end it altogether.

> *'I say "I want to find out about this part of your experience, how would you like to communicate with me?" and some people opt for an interview or writing long responses in narratives or creative responses - I've got datasets that include a large number of photographs, for example of 11 objects.' (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

To ensure accessible practices, one DE&I expert recommended adhering to the basic principles of POUR. POUR is an acronym which stands for Perceivable, Operable, Understandable and Robust. The concept was originally conceived by the World Wide Web Consortium (W3C) in its Web Content Accessibility Guidelines (WCAG). Although its aim was to make web content more accessible, and this was discussed within the context of research methods, the principles are considered universal and can be applied across all stages of the research project. Examples of the guidelines and their meaning are outlined below. We have created examples of how this can be applied within research context, based on stakeholder insight.

Table 1: POUR guidelines and examples

Guideline	Meaning	Example
Perceivable	Information needs to be perceivable by one of the primary senses.	When recruiting, ensure that screeners are in a screen-reader accessible format.
Operable	Everyone needs to be able to take part or use the materials.	Make sure that any in-person focus groups are held in accessible buildings and rooms. Offer alternatives to focus groups for individuals who may find group environments difficult.
Understandable	Information must be understandable by as many people as possible.	Consider the use of easy-read materials.
Robust	Materials should be accessible across as many platforms as possible.	Offer interviews via different means (telephone, face-to-face, different video software).

When conducting qualitative research, all stakeholders stressed the importance of making accessibility improvements specific to the needs of the individual.

Multiple examples were provided such as: providing the research topics to participants ahead of the research, to alleviate any anxiety and reduce the risk of any unexpected topics; providing the option of having someone else present at the fieldwork stages such as a carer or parent; offering support to participants to help them get to an in-person venue.

> *'There's lots of stuff to be done when supporting people to get to the venue. Typically that would be arranging taxis, meeting the participant from the taxi and guiding them into the venue as well as guiding them around the venue. You have to remember people might bring guide dogs with them so you need to have water provided as well. It's about making the process as smooth as possible for people so they can fully participate in the research.' (Hilary Ingleton, Charity, Royal National Institute of Blind People)*

In addition, when conducting qualitative research with d/Deaf people, one charity stakeholder discussed the importance of using moderators who can use sign language to allow for direct communication rather than relying on the interpretation of participant answers. They also suggested that d/Deaf people should have the option to respond in BSL via video contributions in quantitative surveys.

> *'It's better to do the research [directly] through sign language, not through interpreters if possible because it's more of a direct method and you can hear directly from the deaf participant themselves.' (Dr Robert Adam, Charity, British Deaf Association)*

Several stakeholders and reports referenced the use of briefing calls or pre-interview coffee-meets to help the participant feel more comfortable taking part in qualitative research. However, for some, an extra stage within the research process could place additional burden on the participant.

> *'When recruiting neurodivergent individuals [for research projects] we do a coffee meeting as we were finding that people were coming to the [research] interview really nervous and anxious, but as soon as the interview finished they became a different person because the context changed. We now have an informal discussion first where we get to know them and talk to them about the process and any adjustments they need.' (Laura Watkins, Charity, Donaldson Trust)*

For some stakeholders, taking the time to build relationships with qualitative research participants was considered important.

Although building relationships with participants requires extra time, for some, this step was considered important in qualitative research as it creates a more comfortable environment for the participants and helps minimise the power dynamic between researcher and participant; the participant is not simply seen as the subject of the research. Part of building that relationship includes regular communication with participants throughout the research process, disseminating findings with participants and communicating the impact of the project.

> *'If you take the time to invest when it comes to research with people with disabilities, the difference that can make in terms of that trust, the results and making sure the reporting is accessible, the difference it can make if you actually just care a little bit about putting the proper time in, can completely transform a project.' (Charity, The Brain Charity)*

Involving people with lived experience was considered essential when conducting research with disabled people, but views around the extent and type of involvement varied.

Stakeholders placed high value on the involvement of disabled people at all stages in the research process and many reported that without their involvement, a project's findings are less credible, relevant, valuable and inclusive. Many examples were provided of the different ways in which disabled people are involved in research. Co-production was considered the highest level of involvement, whereby participants co-deliver the project with researchers, often taking on equal roles throughout the research process and acting as peer researchers. Some charities and academics favoured this level of involvement and argued that co-production leads to higher quality and more credible research results. Without full co-production, they flagged a risk of only tokenistic involvement.

> *'I think research can only be the most valuable if it's addressing the needs of the people that the research is being conducted on, or ideally with. So I think disabled people should always be involved in that agenda setting.' (Charity)*

For some, full co-production has its limitations: there are concerns about the time and resources required to undertake it meaningfully; the additional burden it can place on participants; and using a peer researcher to represent a whole community. There was acknowledgement that co-production is not always practical for each project, particularly due to resource constraints, and the level and type of involvement should be specific to each research project.

> *‘Is it always the right methodology? Not necessarily. I think that there are different ways to approach research and it really does depend on what you're trying to achieve and what the objectives of a given project are. I think if we're talking about embedding lived experience into the research process then co-production makes a lot of sense.’ (Ella Fryer-Smith, Research Expert, Association of Qualitative Researchers)*

Other stakeholders involved disabled people in the research in different ways, requiring a lower level of involvement than full co-production. The type and level of involvement varied, examples included: collaborating with disabled people at key stages, such as when drafting research materials; consulting with disabled people to check terminology and question wording; and ‘sense checking’ materials and findings. Different methods were used to engage disabled people such as via panels, reaching out to representative groups and the use of advisory bodies.

> *'I think having an advisory committee, or having somebody on the commission panel can be very useful. It’s not the same as fully-fledged co- production, but it helps balance with how much time you've got and how much money you've got. You want to do something, but you can't do everything.' (Professor Tom Shakespeare, Research Expert, London School of Health and Tropical Medicine)*

Stakeholders consistently identified two key stages of involvement when undertaking or commissioning disability-specific studies: when setting up the project, for example, when developing recruitment screeners and research materials to ensure terminology and language is appropriate, and at the recommendations stage. Many stakeholders felt that involving disabled people at the recommendations stage added credibility and value to the research. Perceptions around level of involvement differed; some stakeholders discussed involving disabled people to ‘sense check’ recommendations, whereas others discussed disabled people being involved in drafting the recommendations.

> *‘I think an absolute minimum, you should have the opportunity to review the results. That can be as simple as you've got their contact details and you make sure that they get that email – for many people they might not be interested, but it’s an absolute baseline.’ (Consumer Body)*

Many stakeholders identified advisory groups as adding value, but their limitations were also acknowledged.

Advisory bodies were used by many stakeholders throughout the research process. This included groups made up only of disabled people and mixed advisory groups, involving disabled people as well as other stakeholders. Several benefits were cited of using advisory groups, for example, they enable direct access to disabled people and their knowledge and experience; can foster community relationships; can help when needing to draw out variations in experience; and can enhance accessibility of findings and fieldwork by having people to consult with and obtain feedback from.

> *‘It allows you to have a group of people you can run research materials by but also your recommendations to check the accessibility. It allows you to build up that community relationship.’ (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*

However, limitations of advisory groups were also addressed by stakeholders and included the logistical challenges of organising regular meetings, disagreements delaying the research process and the issues of representation. An individual should not reflect the views of all disabled people and it can be challenging to balance the needs of involvement with the risk of overburdening one person.

‘The worst ones are where there's one lived experience person who has to talk for the whole of disability. We've got a statistician and our tech person and then moving over to Jeffrey, he's going to represent the one in four UK adults with disability.’ (DE&I Expert)

7. ANALYSIS AND REPORTING

7.1 Summary of stakeholder findings

- When reporting qualitative findings, many stakeholders stressed the importance of being transparent with participants in how findings will be reported, and quotes and case studies will be used.
- Many stakeholders considered it best practice to analyse and report by themes or similar experiences, such as barriers experienced, as opposed to disability type or condition.
- There was widespread agreement amongst stakeholders that an intersectional approach to analysis should be taken.
- Stakeholders conducting research with proxies, such as carers or parents of disabled people, highlighted the need to differentiate the different groups of responses in analysis and reporting.
- When reporting qualitative findings, stakeholders used various measures to provide a richer, more holistic view of individuals such as case studies and quotes linked to participants' information.

7.2 Recommendations based on stakeholder insight

Be transparent about how findings are reported.

For all types of research, be clear upfront about how the findings will be reported. For qualitative research in particular, ensure participants are clear on how quotes and case studies will be used. If disabled people have conflicting views, ensure this is acknowledged in the reporting.

Use language which does not stigmatise disabled people or portray disability as negative and be consistent in using inclusive language.

Please refer to Chapter 2 (Language Considerations).

If sample size allows conduct intersectional analysis.

Intersectional analysis acknowledges the complex and multidimensional identities of disabled people, and the different experiences individuals may have. Consider supporting this by desk research to understand the factors that may influence disabled people's experiences and structuring the analysis based on this.

In general population qualitative studies, do not make assumptions based on a person's disability identity or condition.

Disability is only relevant to the experience if the participant has identified this themselves. When undertaking qualitative research with the general population, do not draw assumptions based on someone's disability or condition without sufficient evidence in which to do so i.e. if a participant tells you their conditions has impacted their experience.

In qualitative research, reflect participants' personal preferences in how they choose to describe themselves where possible.

When using quotes and case studies to report findings, use the terms participants use to describe themselves where possible.

In disability-specific research, consider reporting on barriers as opposed to disability type or condition.

People with different conditions may face similar barriers such as communication or sensory difficulties which may be more relevant to analyse and report on. If specific conditions are captured, consider aggregating them based on broader categories.

Reporting should be in accessible formats and, if possible, circulated to participants.

Findings should be accessible to people with different needs, particularly people who have taken part in the research. If practical and appropriate, findings should be circulated with participants.

When reporting qualitative findings, report in ways which capture the nuance of disabled people's experiences.

To provide a richer, more holistic view of each individual, make use of case studies, personal stories and quotes linked to more information about the participant, where possible.

7.3 Full stakeholder insight

A common theme identified by stakeholders was the importance of being transparent when reporting.

Stakeholders identified the importance of being transparent with participants at the reporting stage, particularly within the context of qualitative research, such as explaining how the findings will be reported and how quotes and case studies will be used.

> *'Always be transparent with participants, especially about if the disabilities explored are going to be grouped together.' (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*

In addition, when disabled people are brought in at the recommendations stage to review and consult on recommendations, sometimes there is no consensus. One stakeholder discussed the importance of acknowledging the competing views of disabled people at this stage and making it clear when reporting that not everyone is in agreement.

> *'If you have two different types of participants who were saying, actually we think the opposite in terms of what this should mean for policy development. A recommendation from your research can be there are still conflicting views in this area and even though we've got great insight, we think it should be tested with a larger panel' (Department for Digital, Culture, Media and Sport)*

Furthermore, an MRS representative explained that reports should adhere to the updated MRS guidelines and be transparent around the definition of a nationally representative ('nat rep') sample i.e. what demographic characteristics have been used within the 'nat rep' definition.

> *'As long as it's very transparent. One of the changes that MRS have introduced around the code of conduct, which is now a mandatory compulsory change, is that now when researchers or clients, anyone uses the word Nat Rep, they have to footnote it. They have to declare what demographic characteristics they've used. So if you make a decision that, in this instance, we cannot afford to include a quota on sexual orientation, for example, or we've decided not to, we've decided it's not relevant to the research, that's fine, but you have to say underneath age, gender, region, ethnicity, disability, whatever has been decided.' (Rebecca Cole, Research Expert, Market Research Society Representation in Research)*

In the literature review, the reporting of qualitative findings was centred around potential barriers, whilst in quantitative research, the findings were broken down into conditions.

In qualitative research, the findings were often reported by barriers. These barriers may affect people with specific conditions in different ways, but the findings are not broken down by condition. For example, many reports highlighted the public perceptions of disability as being a barrier to participation in some aspects of society, because there is a presumption of disabled people being unable to do certain things. Conversely, in quantitative research, the findings were more likely to be broken down into disability type. This means comparisons are made between different types of conditions, depending on the focus of the research.

Stakeholders commonly avoided grouping disabled people by condition.

Many stakeholders discussed the importance of not analysing and reporting by condition, but by themes or similar experiences. If specific conditions are captured, it could be more useful to aggregate them based on broader categories. This was considered more aligned with the social model of disability. One stakeholder, for example, explained that people with different conditions may face similar barriers such as communication or sensory difficulties which may be more relevant to analyse and report on.

> *'At the analysis stage, it doesn't tell you much to know that X number of participants had autism and X number of participants had a visual impairment or condition for example. Because they may be affected by it in very similar ways and you could group them and do your subgroup analysis depending on how it affects them, you will have a much large number of people, for example, with communication difficulties or with sensory difficulties, and that is what is relevant for your analysis. It's not the name of the condition, it's how it affects people.' (Research Expert)*

In another example highlighted by a charity stakeholder, participants were provided with a range of options to describe the different types of deafness they may experience. At the analysis stage, responses will be grouped together in different ways for different types of analysis.

> *'We've launched our big RNID survey, which is very exciting. One of the first questions is about your hearing and we deliberately have made that you can select as many options as they like. So we have, I'm deaf, I have hearing loss, I have tinnitus, I'm deafblind....Then when we come to analyse it, we'll be able to filter the things that are relevant for each group. So sometimes we'll want to group together everyone who has hearing loss.' (Dr Hannah Semararo, Charity, RNID)*

Some stakeholders specialising in disability-specific qualitative research avoided analysis and reporting based on any type of categorisation altogether. For them, the focus is on the person's experience and categorisation is not relevant.

> *'I'm not interested in generalisations in that same sense, so I'm trying to find out what it means to be alive in this society in this century and to be disabled in that era. And then it doesn't matter whether somebody has got only a physical impairment or only a mental health impairment or both. Because it's about the experience in society and what it feels like to be in in that society, and, how you're being treated and how you overcome the challenges that are being put to you.' (Dr Nicole Brown, DE&I Expert, Social Research & Practice Ltd/University College London/London South Bank University)*

In addition, by reporting by disability type, some stakeholders noted the potential risk of 'pitting' different disabilities against each other; seeing findings broken down by disability may lead to one group benefiting or being considered more important at the expense of another.

> *'We're not going to play off different groups or the same people against each other. We're saying that these are all important findings for you to consider and act upon and these are actions that you could take to address these things. But we're not going to say serve this group at the exclusion of this group, because then we're not doing our job.' (Charity)*

Stakeholders discussed the importance of keeping the analysis and reporting separate of disabled people and people there to support them, as well as proxies.

Some stakeholders undertook qualitative research with disabled people with someone else present for support such as a parent, support worker, personal assistant or carer. Others conducted research using proxies whereby someone else such as a parent, support worker or carer are interviewed on behalf of a disabled person. This was mentioned amongst stakeholders working with people with learning disabilities and/or mental health conditions. Stakeholders were clear that the analysis and reporting of disabled people's responses and the responses of others should be conducted separately.

> *'I will make it clear that the interview is aimed at the disabled person and it also sets the scenes for the support worker or the carer to know they shouldn't be dominating the interview. And then I analyse the findings separately. So, what is coming from the carer is different from what is coming from the disabled person.' (Research Expert)*

Intersectional analysis was considered important to acknowledge the complexity of disabled people's experiences.

There was widespread agreement that various identities and experiences such as disability, socio-economic status, ethnicity, gender, and the presence of multiple disabilities intersect and interact with each other and heavily impact upon an individual's experiences. Intersectional analysis was considered important to acknowledge the complex and multidimensional identities of disabled people and the different experiences individuals may have. Furthermore, one stakeholder discussed the importance of taking an intersectional approach by also understanding the participant's social and political environment, such as the services available in the local area and any support accessed.

> *'[Experience of disability/condition] will be fed by postcode, where in the country you happen to be born or live and what the services were like in your local area... From a research perspective, you'd be using the HIAT which is the health inequalities assessment toolkit. It gets researchers to follow an intersectional framework for research outcomes to check that your methodology in the first place* is trying *to look at different issues such as concurrent conditions and also social and political factors in the local area.' (Charity, The Brain Charity)*

Some stakeholders agreed that the approach to analysis should be considered early on in the research process, for example, by undertaking desk research to understand the factors that may influence disabled people's experiences and structuring the analysis based on this. However, participant confidentiality needs to be taken into consideration, particularly if analysing and reporting on data where participants can be easily identified.

> *'For them to talk about their experience with multiple disabilities, the only issue with that approach can be participant confidentiality. I think that's really important, especially when you're looking at groups that are easier to identify because they're more niche. You know how many people in the country actually have all three of these disabilities and they're going to say this quote, for example…. So I think there's a balance to strike there.' (Department for Digital, Culture, Media and Sport)*

Several stakeholders identified the importance of not assuming which factors are significant to analyse and report on as individuals' experiences may not be a result of their disability, for example, but another factor. In qualitative studies, in particular, was considered important not to make assumptions and be guided by the individual.

Stakeholders employed various measures in qualitative research to bring disabled people's experiences to life.

Some stakeholders conducting qualitative research employed a case study approach; this allows the nuances of each person to be considered and provides a richer, more holistic view of disabled people. One charity expert used case studies and personal stories for reporting purposes, and differentiated between the two. For them, personal stories provide a more detailed account of someone's experiences and are more easily identifiable.

> *'We generate case studies and personal stories. I think I use the two terms because I do think there's a distinction between the two. I think when we're talking about personal stories, we're talking about usually where people are identifiable much more in depth, support received as a result. Through that case studies more kind of routinely generated and less kind of first person.' (Richard McManus, Charity, Rethink Mental Illness)*

Many stakeholders used quotes to enhance the richness of qualitative responses when reporting. Some stakeholders suggested using quotes identifying the barrier the participant experiences, as opposed to the disability itself. Another example included numbering each quote and linking this to a numbered list of participants, allowing the reader to find out more information about who said what, such as participants' needs and demographic information.

> *'You have a demographics table of participants. They [the participants] each have a number, who they were, what their needs were and their age and so on...And then when you're reporting the research, you're making sure you go through that table... As a reader you can easily look back and you think 'oh yes that was a person with behavioural challenges' and you know that is really difficult. You can sort of judge the findings by looking back at who the participants were.' (DE&I Expert, University of Bristol)*

Many stakeholders stressed the importance of reporting in accessible formats and, when reporting on qualitative research in particular, circulating findings to participants.

Stakeholders reported that a range of different formats should be used to ensure findings are accessible to people with different needs, particularly people who had taken part in the research. Several examples were provided such as publishing reports in Word, not just PDF to ensure they are screen-reader accessible; providing easy-read materials; translating content into BSL; and including alt text on visuals. It was also considered best practice to circulate findings with participants.

> *'It should be standard to have easy reading materials available. All documents should be accessible, pdfs aren't accessible, if you're worried about someone editing a pdf document then put a lock on it. Always have alt text on graphics. There is a shift more and more away from those because of need for alt text.' (Nuala Toman, Charity, Disability Action)*

> *'What we are always really clear on is that the reporting needs to be in very plain English. It should be really easy to understand, and accessible. We would always encourage researchers to be feeding back to the communities that they interviewed or that were involved in the research... Even when using advanced data science approaches, we would still expect researchers to produce something that could be understood and interpreted by members of the public.' (Government/Public Body)*

Some stakeholders acknowledged the difficultly in fully subscribing to the social model of disability when reporting.

Most stakeholders advised against using the medical model of disability when reporting. However, some acknowledged the difficulty in taking a truly social model approach. Stakeholders reported that some conditions may need to be asked and reported on, in line with the objectives of the research. In addition, the terms used to describe some conditions can inadvertently reinforce the medical model of disability. The term 'visual impairment', for example, was one term highlighted as not quite aligning with the social model of disability, of which there are very few alternative options. For some, a blended approach to reporting is considered more realistic.

In addition, some stakeholders discussed looking beyond the social and medical models of disability to also include the human rights model. This is a framework that views disability through the lens of human rights, emphasising the rights and dignity of individuals with disabilities.

8. CONCLUSIONS

This report has summarised the key findings from the literature review, 40 interviews with research and disability inclusion experts and the stakeholder workshop. The research has found that there is not one set of universal best practice guidelines for conducting research with disabled people and people with long-term conditions, but there is progress to be made.

The research includes detailed exploration of language, and whilst there is no agreed glossary to guarantee the use of inclusive language, the research identified that, wherever possible, an individual's preferred terminology should be identified and used. Where not known, the research suggests taking an identity-first approach (i.e. use of 'disabled person', as opposed to person with disabilities'), with some specific exceptions that are used as more standardised terms (e.g. visual impairment).

Actively including disabled people and people with long-term conditions in research is key for inclusivity, and this requires a certain level of definition to be made. Often, the research industry relies upon the GSS harmonised definition, but even those working with this definition acknowledge its drawbacks and limitations. Wherever possible, this research found that using barriers is a more appropriate way of defining people for research purposes.

Whilst important, language considerations can only take inclusive research so far. Consideration at sampling and ensuring that recruitment and fieldwork approaches are inclusive is essential in delivering a research study that is equitable. Whilst some of these recommendations will require additional funding and resource to action, in many cases only additional consideration and care is needed.

We recognise that it is not possible to provide specific recommendations for every research scenario, as a nuanced approach will always be required. The recommendations are grounded within the key themes that have emerged from the research; using these themes to guide research from design to delivery will support an approach inclusive of disabled people and people with long term conditions:

Positive intent: How are you thinking about the research and the participants? What are your intentions behind the research? Have these been communicated clearly to everyone involved in the research (researchers and participants)?

Transparency: Have you been open and honest in your reporting about the decisions you have made and any limitations?

Rationale: Have you considered and provided a reason for the choices you have made?