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Social model of disability: final report

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Social model of disability: final report

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1. Introduction and background

1.1 Background

Historically, the medical model of disability has shaped UK policy and legislation. It was used as a basis for the Equality Act (2010) and continues to influence how 'disability' is interpreted and understood today.

The medical model of disability views an individual's impairment as the root cause of any disadvantage, with 'disability' being defined as a problem emerging from within a person (Andrews et al., 2022[1]). It focuses on curing, reducing the severity, or managing impairments using medical interventions, with healthcare professionals as the experts (Crawford et al., 2012[2]; Cockburn et al., 2023[3]).

Across the UK, data collection and the generation of statistics relating to disabled people are currently aligned with the Equality Act. By extension, they are influenced by the medical model of disability.

In line with Government Statistical Service (GSS) guidance, government data collection has tended to use the long-lasting health conditions and illness harmonised standard and the activity restriction harmonised standards, or the impairment harmonised standard (Annex A). This ensures consistency and comparability in data collection, and alignment with the relevant legislation. However, as also noted in the GSS guidance, these harmonised questions may not accurately capture the neurodivergent population; those receiving treatment or medication; those with fluctuating, progressive or specific conditions; and those who have previously been 'restricted' by a past impairment or condition.

In 2002, the Welsh Government formally adopted the social model of disability, making Wales one of the first countries in the world to do so. This model makes an important distinction between 'impairment' and 'disability'. It suggests that 'disability' results from barriers that people experience in society, not an individual's impairment. The social model was developed by disabled people and is enshrined in the UN Convention on the Rights of Disabled People (UNCRDP), to which the UK is a signatory. The Welsh Government identified that new survey questions were

[1] Andrews, E.E., Powell, R.M., and Ayers, K. (2022). The evolution of disability language: choosing terms to describe disability. Disability and Health Journal, 15(3), 101328.

[2] Crawford, C., Dinca-Panaitescu, M., Fougeyrollas, P., and Rioux, M. (2012). Towards a statistical model for monitoring the exercise of human rights under the UN Convention on the Rights of Persons with Disabilities – Canadian Case Study. Review of Disability Studies: An International Journal, 8(4).

[3] Cockburn, L., Roberts, J., Lee, S., Nganji, J., Ho, N.C.W., and Kuntjoro, A. (2023). Considerations when asking about "disability" in disability inclusive research. Disability and Rehabilitation, 46(21), 5114-5133.

required to ensure that the social model is reflected in data collection and decision-making, and in the delivery of all services across Wales.

In 2024, the Equality, Race and Disability Evidence Units within the Welsh Government commissioned the National Centre for Social Research (NatCen) to develop and test a set of demographic survey questions, response options, and accompanying guidance. The questions needed to capture disabled people's experiences in line with the social model in a consistent and standardised way. The questions also needed to be suitable for use alongside measures needed for legislative (for example, the Equality Act) and policy-monitoring purposes, and for planning for service demand.

The intention was to develop questions that could be shared with public bodies, the third sector, and other producers of statistics. Learning from this research was intended to be shared with the GSS Harmonisation Team and other UK nations. This research aimed to encourage adoption of the new questions more broadly across Wales, and in government across the UK.

The research aims and objectives are listed below.

1.1.1 Research aims

- Develop a suite of survey questions, response options, and guidance documents that reflect the social model and enable a standardised, consistent approach to measurement.
- Research other models and ways of measuring the prevalence of disabled people in the population to assess whether questions based on the social model should be used alone, alongside, or supplemented with other measures (for example, the GSS harmonised standards).
- Develop questions that are suitable for use by the Welsh Government as a minimum, and ideally across the UK.
- Develop guidance and questions that are useable for adults and children across various collection modes.
- Produce the questions and guidance that are appropriate for people with a diverse range of accessibility needs, and in different languages and contexts.

1.1.2 Research objectives

- Understand the different models of disability and how these models are reflected in survey questions used to generate government statistics.
- Understand the different ways data users currently generate statistics related to disabled people or people with impairments from survey data, and the data gaps in existing statistics.

- Identify the full range of survey questions, response options, and guidance currently in existence that collect data on disabled people while reflecting the social model of disability.
- If no appropriate survey questions exist, create, refine, test, and evaluate a new suite of questions, response options, and guidance documentation to collect data based on the social model.

The remainder of this section provides an overview of the research phases and work packages, and arrangements for oversight and scrutiny of the research. Section 2 summarises the first stage of the research, the 'discovery phase'. The aims, methods, and findings from each work package in the second and final stage of the research, the 'alpha phase', are discussed in Sections 3 to 5. Section 6 has a summary of alpha phase findings, recommendations, and next steps.

1.2 Overview of research

In keeping with the Respondent Centred Design Framework, the research methodology divided the project into 2 stages: a 'discovery' phase, followed by an 'alpha' phase. Findings from each work package within these stages informed subsequent phases of the research.

The discovery phase aimed to assess currently available models of disability and survey questions; and explore what disabled people and those who use disability-related data would require of new survey questions. It consisted of 3 consecutive and related work packages:

- work package 1: mapping data user needs and literature review
- work package 2: review of existing survey questions
- work package 3: deliberation workshops with disabled people

The discovery phase was completed in April 2025. An interim report outlining the methodology and findings from this phase, and a separate literature review were both published in July 2025.

The alpha phase used the findings from the discovery phase to design, develop, and test new questions based on the social model of disability. It took place between May 2025 and January 2026, and also comprised of 3 consecutive and related work packages:

- work package 4: survey question design
- work package 5: cognitive testing of survey questions
- work package 6: quantitative field test

1.3 Research considerations

This research was conducted within clear constraints, including a requirement to complete the work by March 2026 and to remain within a fixed budget. As with all social research undertaken within defined parameters, these limits shape both the scope of the work and the interpretation of findings.

An early aim was to develop a broad set of survey questions. Evidence from the discovery phase showed that fully capturing the needs and experiences of all disabled people would require a large number of questions and potentially a standalone survey instrument. This was not feasible given time and budget constraints. The steering group therefore agreed to accept the recommendations of the discovery phase research and prioritise testing a revised impairment harmonised standard and a question on the barriers people with impairments face. A tension remained between capturing the full range of barriers and keeping questions concise and user-friendly.

A further aim was to design questions suitable for multiple data collection modes. As different modes can produce different response patterns, a unimode approach was adopted. Questions were cognitively tested in face-to-face and self-completion modes; and field-tested online and by telephone. While refinements were made based on these findings, the questions were not tested in paper self-completion format, and additional testing would be advisable for that mode.

Across all phases, the methodology aimed to be as inclusive as possible, but within study boundaries. The desk research conducted during the discovery phase was thorough but not exhaustive and limited to English-language sources. Although steps were taken to minimise omissions, there remained a risk that some nuances or recent developments were not captured, particularly in debates on models of disability. The review should therefore be seen as a high-level summary.

The research did not aim to address the full range of language or accessibility requirements present in Wales. Questions were developed in Welsh and English; and translated into British Sign Language (BSL) and an easy read format. Cognitive testing covered all 3 languages and easy read formats, but quantitative testing was carried out only in Welsh and English. Findings relating to BSL and easy read formats were based on small samples and should be interpreted with caution. Further testing would strengthen confidence that the questions meet the needs of a wider group of users.

As with all fieldwork, there is a risk of under- or over-representing certain groups, which may introduce bias. Mitigation measures were embedded at multiple stages and where possible, field test data were compared with external sources to assess accuracy.

The research design allowed for some iterative refinement, particularly following the first round of cognitive interviews, but full iterative testing was not feasible. Additional rounds of cognitive testing after the field test would have provided stronger validation.

A user-centred design approach was adopted throughout, ensuring disabled people and data users were involved from the outset. While this helped balance competing priorities, the final outputs would not reconcile all stakeholder needs.

Finally, integrating revised questions into existing surveys may present operational challenges. The production of guidance materials reduces some of these risks, but further work may be required to support implementation.

1.4 Project oversight

1.4.1 Project steering group

The Welsh Government established a steering group, comprising of policy officials, external experts, and people with lived experience of impairments and/or barriers, to oversee the research. Responsibilities of the steering group were to: feedback on the main project documentation; provide expert input; and to advise on ethics, accessibility of methods, and adherence to UK GDPR.

The first steering group meeting was held at the start of the discovery phase, where the group discussed the proposed research design. Where feasible, recommendations from the group were incorporated into the design before progressing to the ethical review stage.

A shorter session with the steering group took place prior to the deliberative research to gather feedback on the workshop structure and scenario exercises. Accessibility requirements and considerations for the deliberative workshops were discussed and agreed.

The next meeting was held following the completion of the discovery phase and prior to the commencement of the alpha phase. Findings from the discovery phase were presented to the steering group, alongside recommendations for the alpha phase, for review and approval.

The final steering group was held following completion of the alpha phase. Steering group members were presented with findings from work package 5 (cognitive testing) and work package 6 (field test), and final recommendations from the research.

Steering group members were also invited to engage with the research outside of the more formal meeting setting. Project documentation was periodically shared for feedback and review; for example, during the design of questions in work package 4, where steering group members were provided with early draft questions and given

the opportunity to share their feedback. Individual members also provided their expertise and advice at various stages of the research, including through suggestions of literature to feed into the evidence review, reviewing social model language and terminology, and advising on the accessibility of research methods.

1.4.2 Ethical review

During the research development process, the project underwent ethical scrutiny. This ensured the research processes and procedures in place were robust and ethical, and that the well-being of researchers and participants were protected.

The Government Social Research (GSR) ethics checklist was completed separately for both the discovery and alpha phases to ensure that the research was conducted in line with the 5 principles of the GSR Ethical Assurance for Social Research in Government.

Both phases of the project were separately reviewed by the National Centre for Social Research's own Research Ethics Committee (REC). The REC procedures also met the requirements of the GSR Code.

All project staff received a copy of the Social Research Association (SRA) ethical code and were bound by it. This code was selected as the SRA, a registered charity, is the UK's leading professional membership body for social researchers. The project team were also briefed on GSR professional guidance, and instructed to comply with The Magenta Book, Green Book, and Aqua Book in all aspects of the research. Full training was given to interviewers regarding potential sensitivities that might arise and how to address these proactively by facilitating participant comfort, choice, and control. Staff undertaking fieldwork were in receipt of an enhanced Disclosure and Barring Service (DBS) check.

1.4.3 Note on terminology

In summarising the literature and existing survey questions, the original language and concepts have been reproduced, to accurately represent the content. As a result, some of the terminology used in this report may not correspond with social model language.

Similarly, descriptions of how research participants responded to the survey questions presented to them accurately reflected the language they used. So not to misconstrue evidence or misrepresent participants' views, their own words (summaries and exact quotes) are used in this report. Quotes are unedited and will not always correspond with social model language.

2. Discovery Phase

2.1 Overview of discovery phase work packages

This section summarises the 3 work packages contained within the discovery phase, along with a brief overview of their respective aims and methods. The discovery phase interim report has a more detailed review of these work packages.

2.1.1 Work package 1: mapping data user needs and literature review

The literature review aimed to synthesise academic and grey literature on different models of disability, evaluating their advantages and disadvantages for survey research design and delivery. The outcome was a high-level summary based on the sample of publications identified through the inclusion criteria, rather than a comprehensive overview of the evidence base. In interpreting this summary, readers are encouraged to keep in mind that models of disability are evolving, as are the contexts and applications in which they are used.

A literature review research design was used to collate relevant studies within a limited timeframe, from which broad conclusions were drawn. The design included the following additional steps indicative of a more systematic approach. Peer-reviewed academic studies and grey literature were both shortlisted in 2 stages: a review of the title and abstract or executive summary, followed by a review of the full text. Approximately 50 studies were selected for inclusion in the review. A thematic analysis framework helped ensure central themes and evidence gaps were identified. The review of disability models and surveys was published as a standalone report.

To supplement the literature review, separate workshops were held with data users in the Welsh Government; government and public sector employees; and charity and third sector employees. These workshops aimed to gather insights from professionals who use or consult data about disabled people in Wales. The focus was on understanding the data they use, how and why these data are used, and their views on existing questions (especially the GSS harmonised standards) including strengths, limitations, and potential improvements to better reflect the social model. Having workshops with different types of data users unearthed the range of perspectives within groups, while also observing similarities or differences between data users from all 3 workshops. The data were thematically coded to broadly identify the common or prevalent views.

2.1.2 Work package 2: review of existing survey questions

The purpose of work package 2 was to conduct a comprehensive systematic review of existing survey measures used to capture information about disabled people. It focused on identifying and evaluating the extent to which these measures met, or

could be adapted to meet, the needs of data users and whether they align with the language of the social model of disability.

Relevant surveys aimed at collecting information on impairment and/or disabled people were identified, from the UK and internationally. In total, questions from 20 surveys were reviewed, with each being coded against a set of evaluative criteria developed by the NatCen research team. The criteria, listed in Annex D of the interim report, covered descriptive and contextual information, concepts measured, the extent to which they meet data user needs and administration features.

2.1.3 Work package 3: deliberation workshops with disabled people

Led by NatCen's Centre for Deliberation, deliberative research was conducted to understand disabled people's perspectives on surveys and data collection in Wales. Specifically, it aimed to gather: their thoughts about the concepts of 'impairment' and 'disability' and if these terms reflected their personal experiences; their views on the GSS harmonised standards and social model-aligned survey questions; and the benefits and trade-offs of the different survey questions.

A total of 40 participants took part in the deliberative research across 2 days, with 20 people allocated to each online workshop. Participants alternated between plenary sessions and breakout rooms. Qualitative analysis was conducted deductively, using themes and headings from the workshop exercises; and inductively, through close analysis of the notes and transcripts. Deliberative research enabled in-depth and reflective conversations to be generated, giving insight into participants' values and rationales that might not have been captured through other forms of engagement.

2.2 Synthesis of discovery phase findings

2.2.1 Literature review

The main models of disability discussed in the reviewed literature were the medical, social, and biopsychosocial models. Over time, there has been an increased focus in the literature on social and environmental barriers and facilitators; and moving away from a focus on biomedical aspects (Forstner, 2022[4]).

The main advantage of the social model was found to be its focus on identifying and advocating for changes in the environment itself. Reducing or removing environmental, systematic, and societal barriers, and addressing socio-political

[4] Forstner, M. (2022). Conceptual models of disability: the development of the consideration of non-biomedical aspects. Disabilities, 2(3), 540-563.

factors help enable disabled people's full participation in society (Bennani, 2023[5]; Burchardt, 2004[6]; Cappa et al., 2015[7]; Norwich et al., 2016[8]). However, some authors suggested that further recognition of the embodied nature of impairments is needed. Focusing on environmental and social factors and interpretations could potentially mean underestimating the intrinsic impacts and realities that impairments have on daily life (Beaudry, 2016[9]; Crawford et al., 2012).

Some authors suggested the biopsychosocial model provided a more nuanced understanding, with 'disability' occurring at the intersection between an individual's health condition, their impairment, and environmental and societal influences (Bennani, 2023; Norwich et al., 2016). However, the main critiques were related to its broadness and potential lack of application in a policy setting. The literature also contained concerns that, where the biopsychosocial model has been applied in practice, it had become impairment centred (Bennani, 2023).

2.2.2 Data user workshops

Data users (professionals who use statistics about disabled people as part of their work) described using different data sources to monitor and assess trends or evaluate and improve circumstances for disabled people; evaluate workforce diversity; and understand the needs of, and advocate for, communities they represent. Sources mentioned by data users were government-funded general population survey data; institutional survey data; and surveys of disabled people that collected data about their lived experiences.

Motivations for collecting data about disabled people were similar among data users - assessing the extent to which disabled people are excluded from society and to develop policies to improve their experiences. However, when it came to the survey

[5] Bennani, H. (2023). From experiences to numbers: the production of international disability statistics. Disability & Society, 39(7), 1859–1883.

[6] Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. Disability & Society, 19(7), 735-751.

[7] Cappa, C., Petrowski, N., and Njelesani, J. (2015). Navigating the landscape of child disability measurement: a review of available data collection instruments. European Journal of Disability Research, 9(4), 318-330.

[8] Norwich, B. (2016). Conceptualizing Special Educational Needs using a biopsychosocial model in England: the prospects and challenges of using the International Classification of Functioning Framework. Frontiers in Education, 1(6).

[9] Beaudry, J-S. (2016). Beyond (models of) disability? Journal of Medicine and Philosophy, 41(2), 210-228.

question(s) or data source(s) to use, data users felt strongly that this decision should be informed by the context in which the data were needed and aims of the research.

Conceptual limitations of current data collection methods were outlined, with the need to move away from a “deficit model” and have a “linguistic shift” to remove exclusionary features, such as dated or offensive language. Practicalities around the usability for participants and researchers, having different formats and modes of data collection, and comparison and tracking of data over time were explored. Some data users were interested in maintaining data comparability, while others were less concerned and acknowledged that methods and questions change over time. Questionnaire length was an important consideration for data users, who stressed it needed to be kept to a minimum. Any adaption of existing questions would require “rigorous testing” to ensure new questions would produce the desired data.

The desk review of questions revealed a wide range of surveys measuring 'disability' from both the UK and international sources. However, no question sets used the social model exclusively. Various questions were found that collect information about impairments in different formats. None of these were entirely free from language that suggested impairments impact activities or limit function in some way. Most question sets included references to health or health conditions. Even those questions that stated they were informed by the social model appeared to align more closely to the biopsychosocial model.

2.2.3 Deliberative workshops

During the deliberative workshops, participants discussed disability-related language but there was no consensus on preferred terms. Some favoured terms like ‘needs’, ‘differences’, and ‘conditions’ over ‘impairments’ or ‘being disabled.’ Social model language (for example, the distinction between having an impairment and being a disabled person) did not consistently resonate. Some viewed both terms negatively, while there were also different groups of participants who perceived one term negatively but not the other, and vice versa.

When deciding what questions should be used for future surveys in Wales, workshop participants felt the use of non-exclusionary language and reflecting the broadest range of possible impairments should be more important than data comparability. However, some participants were unfamiliar with comparability, basing their views on their experiences as survey completers rather than end users of statistics.

Some felt that outdated or unclear terms in the harmonised questions, such as the use of the term ‘disorder’, might lead to inaccurate data. It was suggested that improving questions for Welsh people should be the Welsh Government’s priority over maintaining consistency with past or UK-wide surveys.

Participants showed more support for using the GSS harmonised impairment question rather than the harmonised questions on long-lasting health conditions and

activity restriction. The language was viewed as more inclusive in the impairment question, though participants felt it could still be refined. Discussions centred around the differences between the harmonised questions. Some participants liked the inclusion of the 'Other' category and being able to select 'all the answers that apply'. These allowed people to self-identify with any impairment type and more accurately reflected disabled people's experiences. However, other participants found the level of detail and a more open approach difficult and overwhelming, preferring a binary 'yes or no' question. Some participants suggested having a longer list of impairments and refining some categories which were described as vague and subjective.

They were positive about including a question on societal barriers to supplement an impairment question, stating it could improve perceptions of the question set. Participants noted that any new barriers questions should be used for policy formation and not just to align with the social model. During the deliberative workshops, they were presented with a sample barriers question to assess. Discussion suggested that the question was too lengthy and that creating a simple, comprehensive question would be challenging.

2.2.4 Advantages and disadvantages of different approaches

Each of the main survey questions discussed during the discovery phase had advantages and disadvantages.

2.2.4.1 GSS harmonised standard questions on long-lasting health conditions and illness, and activity restriction

Advantages

- **Comparability:** using standardised questions means it is possible to measure trends over time and to compare data between different countries.
- **Alignment to legislation:** language aligns with the wording of the Equality Act (2010), including its definition of 'disability'.
- **Practicality:** quicker to administer; question guidance is available; and Welsh language translations have been validated.
- **Respondent identity:** questions do not refer to 'disability' directly - people do not need to self-identify as disabled.

Disadvantages

- **Exclusionary language**: use of medical model language potentially excludes those with an impairment who would not describe themselves as having an illness or health condition, for example deaf BSL signers or neurodivergent people.

- **Conflict with social model principles**: asking whether ‘a health condition or illness reduces your ability to carry out activities’ goes against the core social model principles.
- **Restrictive definitions:** inclusion of ‘long-term’ means it is unclear how people with fluctuating impairments or those who are unsure how long their impairment may last should answer.
- **Respondent preference**: this was the least preferred option by participants in the deliberative workshops.

2.2.4.2 GSS harmonised standard question on impairment

Advantages

- **Comparability:** less commonly used than the harmonised health condition and activity restriction questions but can still be compared across certain UK surveys and countries (Wales versus England).
- **Closer alignment to social model:** measuring impairments, rather than health conditions or illnesses, means its more aligned with the social model of disability.
- **Practicality:** there are more examples of what to include and exclude compared to the GSS harmonised disability questions; it is quick to administer; can be used alongside other socio-demographic questions; and Welsh translations are available.
- **More inclusive language:** it does not mention impairment directly - this word was seen as too negative by some participants.

Disadvantages

- **Exclusive language:** some language is not completely aligned to the social model as it refers to ‘health conditions or illnesses’.
- **Outdated or offensive terminology:** it uses some outdated and potentially offensive and stigmatising language, for example, the response option ‘Socially or behaviourally’ and ‘autism spectrum disorder which includes Asperger’s’ instead of ‘autism’.
- **Restrictive response options:** the list of impairments was considered incomplete and potentially ambiguous by some participants. There were concerns about how to measure impairments related to cognitive functioning and neurodiversity.

- **Utility for children and young people:** specific issues were raised around how parents should answer about disabled children, and children with Additional Learning Needs.

2.2.4.3 Existing and example questions on societal barriers that disabled people encounter

Advantages

- **Alignment to social model:** the question is aligned with the core social model principles and therefore the principles committed to by the Welsh Government.
- **Respondent preference:** participants had some positive reactions to the sample question trialled during the deliberations, especially the reference to ‘discrimination’ as a barrier.

Disadvantages

- **Lack of existing standard:** existing barriers questions were designed to supplement questions on health conditions and/or impairments, rather than as a standalone alternative.
- **Respondent burden:** existing barriers questions tend to be asked in the context of longer surveys about disabled people’s lives. There were no existing questions that could be added to a multiple topic survey without impacting length. A higher number of questions can discourage participants and impact adoption of questions by data users.
- **Need for further refinement:** reactions to the sample question were mixed with some participants suggesting it was too long-winded or did not include enough options of barriers encountered.
- **Practical limitations:** a single question could not collect information on all types of potential barriers. The challenge is to include as many potential barriers as possible for different groups of disabled people, while keeping the question brief and user-friendly.

No single question-set, that met the needs of all groups, was identified during the discovery phase. The tension between the conflicting priorities of different stakeholders means it is unlikely that such a question-set could be created in practice.

2.3 Recommendations from the discovery phase

Based on the findings from the discovery phase, the following options for questionnaire development were prioritised for the next project phase.

2.3.1 An updated impairment question

It was recommended, by the NatCen research team, that the alpha phase should prioritise developing an updated impairment question based on the GSS harmonised impairment standard. The focus was to fine-tune the existing impairment question to address some of the issues and disadvantages raised in the discovery phase by:

- removing outdated terminology related to ‘disorders’ and ‘illnesses’
- removing outdated and stigmatising language relating to conditions that affect people ‘Socially or ‘behaviourally’
- providing clarity for fluctuating impairments
- ensuring the new question works for parents who answer about their children

Development work should include reviewing the various impairment questions identified in the desk-review, with the idea of ‘cherry-picking’ the best features from the different questions. It was also recommended to test the new question and establish whether it is suitable for self-completion surveys.

2.3.2 A new question on societal barriers

The second recommendation from the discovery phase was that a new question should be created on the societal barriers encountered by people with impairments. It should be a single question with a ‘select all that apply’ list of possible options. Participants who state they have impairments would be asked to describe whether they have experienced any barriers because of their impairments and identify what these barriers were. Participants noted that a single question was unlikely to collect granular information on all types of barriers that people encountered. Question development should focus on forming a high-level list of barriers relevant to policymakers and a broad range of disabled people.

Central to the questionnaire development was to work with disabled people to create and refine a clear list of the barriers that they feel are most pressing, and that are most relevant to different types of impairment.

2.3.3 Next steps for the alpha phase

Recommendations from the discovery phase were reviewed and approved by the steering group in May 2025, along with proposed refinements to the alpha phase. A delayed start date, in combination with a fixed completion date, meant the scope of the alpha phase research was reduced to focus on designing and testing questions for adults and parents only. Design and testing in the alpha phase would not include children and young people. Cognitive testing was also reduced from 2 rounds to 1 to ensure the end of project completion date was met.

3. Alpha Phase - Work package 4: question design

3.1 Aims

The agreed aims of this work package were to implement the recommendations from the discovery phase and develop:

- an updated impairment question, based on the GSS harmonised impairment standard
- a new survey question on societal barriers that people with impairments experience

These new survey questions needed to be suitable for use with adults, and parents answering about their children; and available in English, Welsh, British Sign Language (BSL), and easy read format. Most people who participated in the discovery phase were in favour of an impairment question and a social model-style question being asked together and emphasised the necessity of linking both questions. Once developed, these new survey questions would undergo cognitive testing in work package 5.

A team of 4 researchers from NatCen's Questionnaire Development and Testing (QDT) Hub systematically drafted, reviewed, and refined question wording for the new survey questions. Feedback from the Welsh Government and the steering group throughout work package 4 influenced the development and refinement of the new questions. Multiple versions of the new questions were designed so that these could be trialled during the cognitive interviews.

The iterative design process was informed by findings from each of the work packages in the discovery phase and guided by the following overarching principles.

- Using plain language and short sentences, and a requirement for questions to be clear and straightforward to understand and answer.
- Avoiding known biases such as leading questions, complicated instructions, and order effects[10].
- Use of definitions should be kept to a minimum to reduce the length and complexity of survey questions. If required, definitions and clarifications should form part of the question stem instead of being provided as

[10] Krosnick, J. A. (2018). Questionnaire design. In Vannette, D. L. and Krosnick, J. A. (Eds). The Palgrave handbook of survey research, Cham: Springer International.

supplementary instructions. This is to maximise the likelihood of them being read, for example: ‘How old are you? Please provide your age in whole years’.

- Designing questions for use in surveys that may collect responses in different ways: in-person, by telephone, online, or on paper. Different modes of data collection can impact how questions are answered[11,12]. These impacts are known as measurement errors and can make it difficult to compare responses to the same question asked in different modes. Applying unimode question design principles would mean the questions could be presented as similar as possible, across different modes.

- Designing impairment and barriers questions to function as standalone measures, independent of each other and of any previous prior questions.

- Following the social model of disability principles when drafting questions. These principles emphasise the lived experiences of disabled people, shift the focus from an individual’s impairment to the barriers they encounter in society, and avoids medical terms (for example, naming specific illnesses or conditions) and deficit language (for example, focusing on what people cannot do, or are limited from doing).

- Designing questions to be inclusive of neurodivergent people and deaf BSL signers.

- Designing questions suitable for adults (age 18 and over) and parents answering about their children.

It was agreed that the adult version would be drafted first and that any changes made to the parent version would be kept to a minimum.

3.2 Development of new impairment questions

The starting point for the development of the new impairment questions was the requirement to address the known limitations of the current GSS harmonised impairment standard. The design process began with a review of the findings and recommendations that emerged from workshops with data users and disabled people in the discovery phase. Retaining an impairment question would meet the needs of data users. Most disabled participants in the deliberative workshops stated

[11] D’ Ardenne, J., Bull, R., Das, A., Perera, Z., and Sexton, O. (2025). ‘How to mitigate against measurement effects when surveys move online’. Survey Futures Survey Practice Guide 2. Colchester, UK: University of Essex.

[12] Schouten, B., van den Braken, J., Buelens, B., Giesen, D., Luiten, A. and Meertens, V. (2020). Mode-specific measurement effects in mixed-mode specific surveys, design and analysis, Chapter 3 CRC Press.

a preference for the GSS harmonised impairment standard over other measures. It was therefore recommended to develop a new impairment question, based on the GSS harmonised impairment standard. However, it would need to address the issues identified in the discovery phase.

The initial plan was to develop 3 alternative versions of the impairment question to test alongside the GSS harmonised standard. Early in the alpha phase it became clear that testing 3 impairment versions, in addition to testing new barriers questions, would be challenging in one cognitive interview. The response burden for participants would be considerable and there would be limited time for cognitive probing on each version. The NatCen research team agreed with the Welsh Government to reduce the number of versions of the impairment question to test, to 2.

Both versions of the impairment question were designed to:

- measure the concept of impairment, as defined by the social model of disability
- function as standalone questions without prior inquiries – they should not need the harmonised long-standing illness and activity restriction questions as precursors
- list impairments using social model of disability language and examples, ensuring that these descriptions are inclusive of neurodivergence and fluctuating conditions
- strike a balance between having more impairment response options that were identified from people's lived experiences, and managing the response burden
- maintain some comparability with the GSS harmonised standard impairment question
- provide comparable data across data collection modes

Both versions followed the structure of the GSS harmonised impairment standard, with a question stem and a list of response options. The majority of these response categories were consistent across the harmonised impairment question and both versions of the new impairment question. However, the category 'Socially or behaviourally' was amended in both of the new versions. Recommendations from the discovery phase suggested changing the language in this category to remove outdated and offensive terms and some participants in the deliberative workshops stated communication impairments were not captured adequately. Therefore, it was split into 2 separate categories: 'Social interaction or communication' and 'Sensory processing'. The aim of this was to better capture the lived experiences of neurodivergent people and to add a category that included communication.

Two additional categories were introduced in both versions: one for autoimmune conditions, and one for pain. The second phase of the ONS review of disability data harmonised standards found that pain was commonly recorded in the 'Other, please specify' category. Sleep, diet and weight, and incontinence were also frequently recorded in the 'Other' category. These latter 3 impairments were not included as new categories because they were thought to be covered in existing categories. For example, sleep is included in the category relating to energy levels.

The response options in both new versions followed the same format: a high-level description of the impairment category in bold text (for example, 'Hearing'), followed by examples.

The 2 versions also included deliberate wording differences, enabling the NatCen research team to experiment with and test different phrasing that addressed the recommendations from the discovery phase.

The wording of the high-level description and examples differed between the 2 versions, as did the wording of the question stem. Different terms for 'impairment' were used in the 2 versions to test the impact of language and terminology. It also reflected findings from the discovery phase, which found no consensus on preferred terminology but suggested alternative wording to test.

Other points raised during the discovery phase were deliberately different in both versions. The aim of this was to establish which versions were preferred during the cognitive testing stage. These differences are described in the following sub-sections.

3.2.1 Version 1 of the impairment question

Version 1 was designed to be more closely aligned to the GSS impairment harmonised standard in terms of the wording and structure of the question stem and response categories. However, some of the wording was amended to better reflect social model language.

The question was designed for a self-administration mode (web or paper), which meant written instructions were provided as part of the question.

As with the harmonised impairment standard, participants were instructed to check all the response categories that applied to them. The list of response options included 'Other, please specify' and 'None of the above'.

The question stem used the terms 'impairments or conditions' instead of 'health conditions or illnesses' and did not explicitly have a statement on including fluctuating conditions. It included the phrase 'long-term' when referring to a person's condition, but not the 'areas' which made up the list of response options. A definition of 'long term' was not included, so participant understanding could be assessed as part of the cognitive testing.

The response options used most of the wording included in the harmonised standard for the impairment headings, such as ‘Vision’ and ‘Dexterity’. Some headings were amended to align with findings from the discovery phase, and additional response options were added. Unlike the GSS harmonised standard, each of the impairment headings were followed by one or 2 examples to help with participant understanding.

3.2.2 Version 2 of the impairment question

Version 2 was designed to be less closely aligned with the GSS impairment harmonised standard, making more extensive changes in line with social model language and principles.

The question was designed to be asked by an interviewer, with instructions forming part of the script that was read out to participants. The interviewer read out the question stem and participants were shown a list of impairments. They were required to provide a ‘yes’, ‘no’ or ‘prefer not to say’ answer.

The question stem asked whether participants ‘experience issues or differences’, reflecting terminology findings from the discovery phase, and recommendations from the steering group. It did not use the terms ‘impairment’ or ‘condition’ or include the phrase ‘long-term’. It did have an instruction to include ‘anything that may come and go or vary over time’. This was to capture fluctuating conditions which are not explicitly referenced in the current harmonised impairment question. This was identified as a limitation by data users and disabled people consulted in the discovery phase.

3.2.3 Design of impairment questions for parents

It was agreed with the Welsh Government that there should be minimal differences between the adult versions of the impairment questions and the versions for use with parents. The adult version was designed first then minimal adaptions were made for use with parents about their children. The question stem was adapted to ensure it would work with a parent answering about their child. Response options were then systematically reviewed to assess the appropriateness of the headings, and accompanying examples. The adult and parent version of the impairment questions can be found in Annex B.

Initial drafts experimented with the addition of child-centred examples, but these tended to add to the length of the category descriptions. Since many of the examples included in the adult version were appropriate for children, for example ‘blindness’ and ‘reading, counting, following instructions’, it was agreed that child-centric examples should only be used when an adult example was not appropriate.

The response headings and examples used in the adult and parent version 1 impairment questions were identical. For version 2, all response headings were identical, and the examples were the same for 8 of the 12 response options. For the

remaining 4 responses in version 2, the differences between the adult and parent were:

- **Hearing:** the parent version was simplified and excluded the example of 'following conversations in noisy places'
- **Using your hands or fingers:** examples in the adult version of 'dressing, writing, or using a keyboard' were amended to 'dressing themselves, holding a pencil, picking up a toy, using a keyboard'
- **Remembering or focusing:** the adult version of this response option included the example 'remembering recent events' which was amended to 'remembering what they did at school'
- **Energy levels or breathing:** the examples of 'wash, cook' were replaced with 'play' in the parent version

3.3 Development of new barriers questions

The starting point for the design of a new survey question on societal barriers encountered by people with impairments was the question drafted to stimulate discussion among deliberative workshop participants at work package 3. Participant feedback on the question was collated and reviewed to identify strengths and limitations of this draft question. Alongside this, work package 1 findings were reviewed to ensure the views of data users also informed question design. Discovery phase findings, aims of cognitive testing, and a set of overarching design principles guided the decisions when designing new barriers questions. They also influenced the extent to which the question design needed to differ from the initial draft question reviewed during work package 3, which is included in the discovery phase interim report.

It was originally intended that both versions of the barriers question taken forward to cognitive testing (work package 5) would measure the same construct (experience of barriers). The versions would have known differences and the impact of these would be assessed at the cognitive testing phase. One version was to be fully aligned with the social model and the alternative version, while less aligned, would still avoid measuring medical model concepts or using medical model language.

During the design phase, it became apparent that the response options included in the draft question from work package 3 were attempting to measure different concepts, all within the one survey question. Some response options were capturing the broader types of barriers a disabled person might experience (for example, a 'lack of accessible information'), while others attempted to capture experience of barriers in particular areas or domains of life (such as 'barriers to accessing and using public transport'). In survey question design, it is vital that response options

are consistent and clearly aligned with the concept being measured, ensuring participants can provide accurate and meaningful answers.[13]

Together with the Welsh Government, NatCen researchers revisited the intended aims for the barriers question, exploring and agreeing on which constructs the new questions should measure. Findings from the question review of work package 2 indicated that international examples of survey questions on barriers tended to measure the areas of life a person has experienced barriers in, for example health, employment, or transport. In addition to drafting a question on experiences of barriers in particular domains of life, the Welsh Government expressed an interest in exploring the feasibility of measuring the types of barriers a person may experience, for example attitudinal or environmental. It was suggested that different versions of a barriers question could have different practical applications across surveys.

This change to the scope of the work package meant revising the aim of the design process. The new aim was to come up with separate and unrelated survey questions that captured the different dimensions of barriers in areas or domains of life, and broader barrier types.

3.3.1 Version 1 of the barriers question – experience of barriers in different domains of life

The starting point for this version of the barriers question was the surveys identified in the work package 2 question review which included questions on environmental and societal barriers. In addition to the Life Opportunities Survey and the UK Disability Survey, researchers reviewed the breadth of life domains asked about in barriers questions in Canada and New Zealand's standalone disability surveys. The Welsh Government website was also reviewed to ensure that any proposed response options captured the main policy areas under remit of the devolved Government for Wales. The output, a list of life domains one might experience barriers in, was reviewed by the Welsh Government and revised until a final question stem and list of 9 response options was agreed.

3.3.2 Version 2 of the barriers question – experience of different types of barriers

When designing response options for version 2 of the barriers question, the research team were guided by a common social model classification of 4 barrier types (attitudinal, institutional, environmental, and communication). The descriptions and language used by disabled participants during work package 3 (deliberation workshops) were also reviewed. These were considered when developing wording

[13] Groves, R. M., Fowler, F. J., Couper, M. P., Lepkowski, J. M., Singer, E., and Tourangeau, R. (2009). Survey methodology (2nd ed.). Wiley.

that best reflected the different barrier type response options and examples included to help illustrate each of them.

3.3.3 Comparison of barriers questions - versions 1 and 2

In addition to the requirement for a different set of response options to be used, other deliberate differences were introduced when drafting versions 1 and 2 of the barriers question. These differences were based on points raised during the discovery phase and would be tested and assessed during cognitive interviews.

- **Use of the word 'barriers', an alternative term, or nothing:** participants in the deliberative workshops discussed whether the term 'barriers' was easily understood. Version 1 included the word 'barriers' in the question stem, while no equivalent term was used in version 2.
- **Explicitly linking experience of barriers to the presence of an impairment or condition, or not**: the version 1 question stem included text asking participants to think about their long-term impairments or conditions when answering, while no equivalent was included in version 2.
- **Different dimensions of barriers:** version 1 asked about experience of barriers in different areas of life, while version 2 asked about types of barriers experienced.
- **Impact of a 'Prefer not to say' response option:** version 2 included an explicit 'Prefer not to say' option, version 1 did not.
- **What reference period, if any, needs to be included:** neither version included a specific reference period. This was to allow for the generation of qualitative data on the typical time periods disabled people think of when considering their personal experience of barriers. In the question stem for version 1, participants were asked 'which barriers do you experience', while version 2 asked participants which barriers 'have you experienced'.

Both versions of the barriers question:

- needed to align with the social model of disability
- were appropriate for use with adults, and with parents of disabled children
- allowed participants to select 'all that apply' from the list of responses
- included a 'None of these' response option
- included an 'Other' response option to provide participants with the opportunity to say something else and describe, in their own words, any other experiences of barriers they might have had; it was also an opportunity to assess how well the response options drafted captured common barriers

3.3.4 Design of barriers question for parents

Once the question wording and response options for both versions of the adult barriers question were approved by the Welsh Government, attention turned to any necessary revisions needed to ensure both versions of the survey question were suitable for a parent to answer about their child. The first step was to update the wording of the question stem and response options. This was to ensure it was clear that the survey question was asking parents about their child or young person, and not themselves personally.

The response options for the adult versions of the questions were then systematically reviewed. It assessed the appropriateness of response option headings and accompanying examples, for use with a parent answering about their child or young person. It was agreed with the Welsh Government that amendments made to the parent versions developed should be kept to a minimum. Updates should only be made if a response option, or accompanying examples, were not applicable or appropriate to a child or young person. Versions 1 and 2 of the barriers question for adults and parents can be found in Annex C.

3.3.4.1 Version 1

Just one response option from the version 1 adult barriers question was deemed unsuitable for inclusion in the version of the question drafted for parents – ‘Voting and political participation opportunities that do not support my needs’. Parents were answering on behalf of their child aged 15 and under, meaning they would not be old enough to vote in the UK. ‘Employment and job opportunities that do not support my needs’ was retained and updated for the parent version.

Many of the examples included in the version 1 response options for adults were appropriate for use with parents answering about their child. For example, ‘appointments that do not work’ was applicable to children as well as adults, under the response option relating to ‘Health care and support’. The same was true for examples like ‘not enough adaptations to existing home’ (under the ‘Housing and independent living arrangements’ response option) and ‘activities held in spaces I cannot access’ (an example used in the ‘Opportunities to take part in community and social activities’ option).

The examples used for the ‘Education and training’ response were updated to include ‘lack of support in the classroom’ and to refer to ‘school staff’ instead of ‘tutors’. Similarly, the examples for ‘Transport and travel’ were updated to specifically reference barriers around transport to ‘school and nursery’.

3.3.4.2 Version 2

Version 2 of the barriers question, capturing experience of the types of barriers, required fewer updates to enable the question to work with parents. The 4 types of barriers asked about in this version were applicable to both adults and children. The

examples used to help put response options in context were all generic enough that they applied to parents answering about their child with no update required. Minimal language changes were made to reflect that the question was being asked of parents about their child, for example ‘treating my child differently’ rather than ‘treating me differently’.

3.4 Production of alternative versions of questions

Once final wording of the adult and parent versions of the survey questions for impairments and barriers were agreed, the process of producing the questions in alternative formats commenced. In advance of cognitive testing, versions were produced in Welsh, easy read English, and easy read Welsh.

3.4.1 Welsh language

Welsh translation was carried out via a translation agency that employs professionally qualified linguists working in their mother tongue. As with the English versions of the questions, there was a requirement for social model aligned language to be used. Once translated, these versions were reviewed by Welsh speakers Welsh Government.

3.4.2 Easy read format

For easy read versions, final copies of all the impairments and barriers survey questions were provided in English to an external accessible communication specialist provider. The provider is a member of the UK Association for Accessible Formats and used experienced in-house experts to provide a first draft of all easy read versions in English. Subsequent iterations were produced by the agency using the feedback provided from the NatCen research team and the Welsh Government. Final easy read English versions were used to produce Welsh language equivalents. Final accessible PDFs, conforming to accessibility standards of WCAG 2.1 at Level AA, were then produced.

3.4.3 British Sign Language (BSL)

Cognitive testing of British Sign Language (BSL) versions of the survey questions took place slightly later than the English, Welsh, and easy read cognitive testing. Since BSL fieldwork coincided with the quantitative field test (work package 6) of English and Welsh questions, these questions were adopted as the starting point for the BSL translation.

NatCen collaborated with researchers at Social Research with Deaf People (SORD) on the BSL requirements for work packages 4 and 5. SORD are experts in the methodology of question design for BSL and have experience in translating and adapting standardised assessments into BSL. This translation procedure included ensuring that the common challenges of translating assessments into BSL were addressed, based on their previous work.

3.4.3.1 Translation of survey questions

A forward and back translation process was used to translate the adult English language versions of the field-test questions and other respondent documents into BSL. This process aimed to ensure the original meaning, cultural nuance, and accuracy of the original questions were kept when producing a BSL version. There were 8 stages in the translation process.

1. NatCen briefed the SORD team on the scope of work, the question design process, and provided survey questions for translation from English to BSL.
2. Two forward translators independently translated the survey questions into BSL (first draft). One is a qualified registered sign language translator (RSLT) and registered relay intralingual interpreter. The other is a trainee relay interlingual interpreter. Both are Deaf[14] people who are fluent bilinguals, have undergone qualifying training, hold the Registered Sign Language Interpreter (RSLI) designation, and are registered with the National Register of Communication Professionals working with Deaf and Deafblind People (NRCPD).
3. SORD researchers met with the forward translators to discuss any difficulties arising from the translation, which were noted.
4. SORD edited the first draft BSL versions for back translators to view, without seeing the original English version of the questions.
5. Two back translators independently translated the first draft of the BSL versions back into English. The back translation team are qualified registered sign language translators as well as registered relay intralingual interpreters.
6. SORD researchers met with the team of translators to discuss the comparison between the original and the back-translated English version, for each first draft of the BSL version. As everyone in attendance was bilingual in BSL and English, these meetings happened in BSL and without interpreters, enhancing the quality and efficiency of the research process. Where there were differences between English and BSL versions, the origin of these were examined. The aim was to find a balance between needing to ensure the intended meaning was preserved, that it worked with the intended audience, and to minimise the likelihood of misunderstandings in BSL.
7. A second draft of the BSL version was produced by one of the forward translators. Forward and backward translators met and agreed a revised

[14] The upper case ‘D’ used here refers to those who identify as culturally Deaf.

version. The forward translator, with support from a back translator, reproduced the second draft for use in the cognitive interview.

8. The second draft was edited by the SORD team and checked by one of the back translators.

3.4.3.2 Considerations for BSL translation

In addition to the forward and backward translation process, the BSL translation team considered the usability of the questions. The questions were not quite structured in a way that works for BSL, for example, the questions were very long. When reading a text version this matters less because a reader can go back and review the written question as they need. When watching a question, there is more of an expectation to grasp the full question straightaway. This is one reason why it is more usual to have shorter and more direct questions in BSL. There were also a lot of response options to consider. The cognitive load for a participant is far greater when watching and retaining options, compared to a reader who can scan back across written text. BSL compatible structuring of questions is just as important as accurate translation to create effective questions and equivalence of participation for the BSL population.

Some examples of the challenges raised by the BSL translators are included below.

- The translation is not only from English to BSL, but from one modality to another (written to visual). This influenced the translation of some items. For example, as participants would be watching the questionnaire rather than reading text, pronouns needed additional consideration and were changed from ‘I’ to ‘you’.

- Language and wording in English deliberately chosen to highlight a specific perspective may not have equivalents in BSL that make the same distinction. For example, the signs for ‘condition’ and ‘illness’ can be the same, apart from differences in silent lip patterns. It was agreed to use different signs for ‘condition’ and ‘illness’ but the sign for 'condition' may not be as familiar to some participants in this context.

- Unfamiliar words in BSL can be translated from English using fingerspelling, but that does not ensure understanding. For example, forward translators raised the issue that simply fingerspelling ‘Dexterity’ would not be sufficient. It was agreed to use the sign for ‘Dexterity’ that was commonly used in a specialist mental health service for deaf BSL signers in England.

- The implications of some words and signs may be different between BSL signers and hearing communities. These culturally embedded implications affect how a word is received and reacted to. Whilst translating these words into BSL are straightforward, the implications are not equivalent. Some

examples are the terms ‘impairment’, ‘deafness’, and ‘partial hearing’ as they are commonly seen as reinforcing the medical model, even when used within a more social model orientated format of questioning. Furthermore, the medical model is more usually understood by deaf people as the opposite to, or undermining, the cultural and linguistic identity of deaf BSL signers.[15]

- There were some outdated terms that are not specific to BSL that were translated and included, for example, ‘Asperger's’.
- There was concern that some of the question appeared overly wordy, abstract, and burdensome, potentially impacting on how they are interpreted and understood. This posed a dilemma because it was also important for the translation to stick as closely as possible to what the questions were asking and how they were asking it, rather than reword or restructure prior to field testing.
- There was a need to be more explicit in the translation. For example, the English instruction to ‘please select all that apply’ when referring to option responses became ‘pick which’ in BSL.
- Some words required more discussion for the exact meaning to be precise when expressed in BSL. For example, the sign for ‘fatigue’ does not necessarily mean tired; it can mean worn out or exhausted but not needing to sleep. Discussing this meaning was important in making choices about which sign to use and how to sign it. For example, the sign for ‘tired’ might be altered in different ways through movement or repetition or facial expression to indicate intensity and the chronic nature of the condition, even where the same base sign is used.
- The signs for some terms are changing, just as any language evolves. For example, the sign for ‘autism’ used in the forward translation was found to be outdated. The review of the first draft led to a more current sign being used in the next draft.
- The importance of emphasising some main terms in how they are signed to reinforce the meaning. For example, for ‘coworkers…leaving me out’ in version 2 of the barriers question, a simple translation of ‘left out’ would have missed the intentionality of the meaning of being left out. Therefore, in the BSL version the sign for ‘being excluded’ was used to make the point clearer.

[15] Ladd, P. (2003). Understanding deaf culture: in search of deafhood. Celvedon, Multilingual Matters.

3.4.3.3 Producing the translated questions

The BSL translated questions were inserted into Qualtrics in the form of videos that accompanied the written question text. The use of embedded videos within a computer-assisted questionnaire ensured there was a consistent visual representation of the written form of the question.

To manage the amount of effort, thought processing, and memory activity (cognitive load) participants needed to use, the BSL videos were edited into multiple shorter clips rather than a single continuous sequence. As the materials were translated entirely into BSL, participants could not quickly scan or reread text; they had to watch each video in full to access the information. Having several answer options within one video would need a higher cognitive load as participants would have to retain and compare each option from memory, without easily revisiting specific parts.

To reduce this demand, each question was shown in one video, followed by separate videos for each option. This structure enabled participants to rewatch individual options as needed, supporting memory and decision-making while minimising unnecessary cognitive effort. Published research noted similar issues related to cognitive effort and information processing in signed materials.

However, this approach had the potential disadvantage of not producing an equivalent experience to that of completing an English language questionnaire. The videos for each question and each response option must be opened sequentially, meaning that either a respondent must hold in their mind all the choices and parts of each question, or scroll back to other video segments to see the question or response options again. In an English language self-completion document, questions and response options are simultaneously presented on one screen or page.

3.5 Work package 4 output - questions to cognitively test

The final outputs from work package 4 were:

- 2 different versions of a survey question on impairments
- 2 new survey questions capturing different dimensions of people's experience of barriers

Both adult and parent versions of these questions were produced at the design stage. Welsh language, easy read (in English and Welsh), and BSL versions were created afterwards. All questions were taken forward to work package 5: cognitive testing. Annex B lists the 2 different impairment questions for both adults and parents. Annex C lists the adult and parent questions for both dimensions of barriers: areas of life and types of barriers experienced.

4. Alpha phase - Work package 5: cognitive interviewing

This section presents findings from cognitive interviewing, which tested the new impairment and barriers questions developed in work package 4. The 2 versions of both the impairment and barriers questions were tested with disabled adults and parents of a disabled child. Questions were tested in English, Welsh, and easy read format (English and Welsh). Findings are presented for each version in the following order:

- English and Welsh language versions
- easy read English and Welsh versions

The British Sign Language (BSL) cognitive testing took place at the same time as the field test (work package 6). It therefore tested the questions included on the NatCen Panel, rather than those used in work package 5. Discussion of the BSL cognitive testing is discussed in Section 4.8.

4.1 Aims

Work package 5 aimed to:

- test 2 different versions of the impairment question and 2 different barriers questions with adults and parents of disabled children (aged 0 to 15) in English, Welsh, easy read English and Welsh, and BSL
- identify any problematic terms or phrases that should not be used
- identify if any (further) instructions are required to ensure that participants understand the questions and response task
- identify if participants preferred version 1 or version 2 of the impairment and barriers questions
- assess whether the order in which the questions are asked (impairment then barriers, or barriers then impairment) has any impact on how the questions are interpreted
- identify any issues or preferences relating to the mode (self-completion versus interviewer-administered)
- identify any issues with translation (Welsh, easy read English and Welsh, BSL)
- generate evidence to inform the finalisation of questions to be tested on the NatCen Panel in work package 6

4.2 Overview of methods for cognitive testing

Cognitive interviewing is a commonly used method that enables researchers to assess whether survey questions are measuring what was intended, are clear and unambiguous, and whether participants were willing to answer them[16]. The method involved asking participants to answer survey questions and to talk whilst they do so, vocalising their thought processes. This is known as 'think aloud'[17]. The interviewer also asked probing questions[18], either concurrently or once the participant attempted to answer the question, to explore in more depth:

- how the participant went about answering the question
- their understanding of the question
- how they recalled the information
- how they decided on their answer
- any particular difficulties or concerns the participant had when answering the question

Recruitment was led by Shift Insight following protocols designed by the NatCen research team. These protocols were developed in consultation with the Welsh Government and the steering group, and followed ethical practices outlined in Section 1.4.2. The recruitment protocols are contained in Annex D.

Shift Insight were given a screening questionnaire and quotas (targets) to ensure that interviews were carried out with a diverse range of adults and parents. These targets included age, sex, type of area (urban or rural), ethnicity, highest educational qualification, and type of long-standing illness or condition. The screening questions designed to recruit people with a range of impairments and health conditions were deliberately different to the impairment questions being tested. All participants recruited lived in Wales. The screening questionnaire asked whether the participant (or their child):

- had any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more

[16] Beatty, P.C. and Willis, G.B. (2007). Research synthesis: The practice of cognitive interviewing. Public Opinion Quarterly, 71(2), 287-311.

[17] Willis, G. (2005). Cognitive interviewing: a tool for improving questionnaire design. Thousand Oaks, CA. Sage.

[18] d'Ardenne, J, (2015). Developing interview protocols. In Collins, D. (ed) Cognitive interviewing practice. London. Sage. Page 101-125.

- faced barriers in daily life but did not consider themselves disabled, for example, deaf BSL signers or neurodivergent people
- were affected by long-standing illnesses and health conditions in any of the ways listed

The screening questionnaire is included at the end of Annex F and detailed participant quotas in Annex E.

4.3 Fieldwork

Cognitive interviews (apart from those in BSL) were carried out by trained researchers from Shift Insight. NatCen developed the interview protocols and provided training in use of the protocols, oversight, and quality assurance.

Recruitment and fieldwork were conducted in alignment with the social model of disability to ensure all those who wanted to participate could do so. The recruitment screening questionnaire included questions that established whether someone wanted their interview to be in English, Welsh, or easy read. In advance of the interview, participants received verbal and written information, including in easy read, about what to expect at the interview and whether they would like support to take part. Everyone was informed that there would be a scheduled break; offered the opportunity to have someone with them during the interview for support or to help them take part; and asked if they had any accessibility or language requirements. This information was checked again at the start of the interview.

Scheduling of interviews was flexible, with participants choosing a time that was convenient to them. Participants could choose between in-person, videoconference (Zoom), or telephone interviews. In-person interviews were offered to also ensure inclusion of participants with limited digital access. These took place at home or at an alternative venue chosen by the participant.

Interviewers used a guide, which had been designed by NatCen and reviewed by the Welsh Government. The interview guide is detailed in Annex F and included:

- for the interviewer – a reminder of the aims of the testing
- an introduction, reminding the participant about the purpose of the research, the structure of the interview, and what would happen to their data
- confirming participant's agreement to take part
- checking support and accessibility needs
- an explanation and demonstration of the think aloud method
- the questions to be tested, with instructions for the interviewer on their administration and the recording of responses to the test questions

- the cognitive probes to be asked
- a reminder of what would happen next
- checking of screening information, for quality control purposes

Interviews were to last up to 60 minutes, with a formal opportunity for a break mid-way through. Interviews beyond 60 minutes were not recommended as there is an increased risk of participant fatigue, resulting in a loss of data quality. Feedback from interviewers after the first interviews indicated that not all probes could be covered within the allotted time. In discussion with the Welsh Government and NatCen, it was agreed that probes would be reduced to ensure interviews stayed within 60 minutes. This involved prioritising certain probes, with others being asked at the interviewer's discretion, time permitting.

The order in which the impairment and barriers questions were asked was varied for adults and parents. Half of these participants were asked the impairment questions first (group A), and the other half were asked the barriers questions first (group B). Allocation to group A or B was based on whether the case ID was an odd or even number. The question order was not randomised for participants who tested the easy read questions as there were too few cases to analyse any effect of the question order. The final interview guide for the adult testing is included in Annex F. Other versions for parents of disabled children, participants receiving the easy read questions, and BSL testing are available upon request.

Participants received a £40 shopping voucher as a token of appreciation for taking part. This was sent to participants after the interview.

Interviews were achieved with:

- 35 adults, of which:
    - 20 were conducted in English
    - 11 in Welsh
    - 4 were easy read - 3 English and one Welsh language
- 17 parents, of which:
    - 8 were conducted in English
    - 8 in Welsh
    - one was easy read (English)

4.4 Data management and analysis

Interviews were recorded with participant agreement. Interviewers referred to these recordings when making notes and summarising interviews using a proforma. This proforma was a series of matrices (worksheets in Excel). Each question was one matrix that contained details of each participant, their answers to the impairment and barriers questions, and their responses to the think aloud questions and each probe.

The completed matrices were reviewed by the NatCen research team who assessed the data for each question, reviewing the responses from each participant independently and collectively to answer the research questions.

4.5 Cognitive testing findings - impairment questions

Two versions of the impairment question were tested with adults and parents of disabled children (Annex B). Version 1 was given to participants to answer, mimicking a self-completion survey format. The question was closely aligned to the existing impairment harmonised standard and asked about 'long-term impairments or conditions'. Participants were asked to 'select all that apply' from a list of response options.

Version 2 tested more extensive changes to wording and was read aloud to the participant in an interviewer-administered format. The interviewer asked participants about whether they 'experience issues or differences' from a list of impairments they were given. The question specifically referred to fluctuating impairments, asking participants to 'include anything that may come and go or vary over time'. Participants could answer 'yes', 'no', or 'prefer not to say'.

The adult and parent versions of the test questions were designed to minimise differences in wording. Where there were differences, these were child-specific examples within the impairment categories listed.

The cognitive testing of these 2 questions aimed to assess whether:

- each version appropriately identified people with impairments or conditions – whether some people were missed, or included when they should not be
- there were any differences between the 2 versions in terms of the types of impairments that were captured
- the questions and response options were understood in the ways intended
- a 'long-term' definition of an impairment is needed or not, by testing if participants understood the questions were asking about long-term impairments or conditions when a definition was not supplied

- examples for each impairment type are helpful or not to address the tension between question length and comprehensive impairment categories
- new guidance included in version 2 on how to consider impairments that vary over time was necessary and helpful
- a ‘tick all that apply’ response or a ‘yes-no’ question response was preferred by participants
- participants preferred version 1 or version 2 - the goal was to end up with one version of the impairment question to field test on the NatCen Panel in work package 6

The cognitive testing also aimed to identify any issues or preferences relating to the mode (self-completion versus interviewer-administered).

Findings are presented for the English and Welsh language versions, and the easy read versions in English and Welsh.

4.5.1 English and Welsh language findings

4.5.1.1 Version 1 - understanding the question

This question asked participants “In which, if any, of the following areas are you affected by long-term impairments or conditions? Please select all that apply.”

Most participants understood and interpreted this question as asking about whether they or their child had any long-term health conditions, impairments, “disabilities”, or “issues”. They were described as something that had affected them over a long time – many months, years or since birth – and that are unlikely to get better. The terms ‘impairments’ and ‘conditions’ in the question stem were seen as meaning the same thing.

The ways in which participants understood the question reflected their own lived experiences. When first given the question, some participants said they had seen this type of question before. Adult participants recognised similar ones from benefit claim forms. Parents and adults mentioned being asked this type of question when interacting with public services, such as hospitals and schools.

Whilst there was no evidence of the term ‘impairments’ being unclear or unfamiliar to participants, some concerns were raised that the term might be unclear or unfamiliar to others.

There were some concerns about the Welsh word for impairments: ‘amhariad’. This is a relatively new term and was unfamiliar to some Welsh speaking participants. Until recently, another word, ‘nam’, was used, which now has negative connotations. Among Welsh-speaking participants, there was a clear preference for the term ‘conditions’.

4.5.1.2 Version 1 - response categories

The response category labels were in bold text. Participants commented that this bold text was helpful, enabling them to quickly identify the relevant response categories. There were also participants who commented that they were expecting to see the names of conditions that they had, listed in the response options.

The response categories included examples, which participants felt were helpful. However, some participants felt that there were too many examples, and therefore too much text for them to process. Those who expressed this view said that they tended to read only the bold text and not the examples.

The response option of ‘Sensory processing’ was well understood and selected primarily by ADHD and autistic participants. In some cases, neurodivergent participants explained how they considered whether to select this category or the ‘Hearing’ category. After deliberating, they chose the ‘Sensory processing’ category, as they felt it was the most appropriate option for them. The ‘Sensory processing’ category was also selected by a visually impaired participant, who chose it to reflect the impact that too much light had on their vision and wellbeing.

The following issues were identified with the response options and examples in version 1.

- **Dexterity:** This term was unfamiliar to some participants in English, and the term ‘deheurwydd’ was unfamiliar to some Welsh participants. One Welsh-speaking participant felt it had negative connotations and was associated with ‘dde’ (being right-handed).
- **Immune system regulation:** As intended, this option was selected by those with autoimmune conditions, but participants felt the wording of the category and the examples could be clearer.
- **Social interaction or communication:** Participants understood this category but the decision about whether to select it was not always straightforward. For example, some participants said they found social interaction draining but did not have trouble expressing themselves or maintaining relationships. However, they did endorse this response category overall.
- **Making sense of the world around you:** This example was used in the ‘Mental health’ option. Participants felt this phrase related to broader concepts of mental health and one's place in the world. However, some participants with mental health conditions found the phrase vague and would have preferred more specific examples, such as “anxiety” or “depression”.

4.5.1.3 Version 1 - acceptability

All participants answered the question, with no-one selecting the ‘None of these’ or ‘Prefer not to say’ options. There was a familiarity with being asked this type of question among participants, which made it a less sensitive experience for some.

However, for other participants there was some discomfort and sensitivity around answering the question and indicating which impairment categories applied to them. The disclosure of mental or emotional impairments and conditions felt more uncomfortable for some than the disclosure of physical impairments. Among parents, the question could be emotionally challenging to answer, as it brought home the impact of their child’s impairment or condition on their lives. Participants noted that the context and purpose in which the question would be asked would influence how intrusive it would feel.

4.5.1.4 Version 2 - understanding of the question

Version 2 of the impairment question asked participants “Do you experience issues or differences with any of the following? Please include anything that may come and go or vary over time.” Most participants understood the question as asking about which issues, difficulties, or barriers they or their child experienced in daily life. Alternatively, which aspects of life are affected by their condition.

The terms ‘issues’ and ‘differences’ were interpreted in various ways. Some participants found the term ‘differences’ to be vague and potentially negative. The term ‘issues’ was easier to understand but was sometimes seen as having negative connotations. In the Welsh language version, ‘issues’ was translated as ‘problems’, with some participants preferring this term over ‘issues’.

Having the instruction to ‘include anything that may come and go or vary over time’ encouraged participants to think of both constant and variable or fluctuating conditions. Participants with conditions such as MS and Parkinsons said that they found this wording helpful.

4.5.1.5 Version 2 - response categories

The presentation of the impairments categories in version 2 was similar to that used in version 1. The category descriptions were in bold text, followed by examples. However, version 2 did not require participants to select each of the impairment categories that applied to them or their child. Instead, it asked for an overall response of ‘yes’ or ‘no’. The categories were worded differently and based on verbs, for example ‘Seeing’, ‘Hearing’. Participants generally preferred these verb-based categories used in version 2, finding them easier to understand than those used in version 1. This format was seen as more straightforward and relatable to participants’ day-to-day experiences.

The following issues were identified with the version 2 response options and examples.

- **Mental wellbeing:** This term was broader and less clear than the response option of ‘Mental health’ used in version 1, leading to some confusion. Some participants associated ‘Mental wellbeing’ with changing feelings and emotions which could vary over time, and not with a mental health condition which was considered to be more severe. Some participants with mental health conditions felt strongly that the question should refer to ‘Mental health’ and not ‘Mental wellbeing’ for this reason.

- **Seeing or hearing things that others do not:** This example in the ‘Mental wellbeing’ option caused confusion. Some participants interpreted it as relating to sensory sensitivity, whilst others thought it was referring to conditions such as schizophrenia. It was intended to capture hallucinations, as experienced in psychosis.

- **Experiencing the world:** This term was seen as vague and led to varied interpretations of the response option, such as mental health conditions, autism, and sensory challenges like being in loud or crowded environments. Some participants preferred the term ‘Sensory processing’ used in version 1.

- **Immune responses:** This category was generally understood and was consistently selected by those with immune system conditions. Participants suggested simplifying the category description and using different examples that reflected their lived experiences. Suggestions were: “more prone to infections”, and “less able to fight off infections”.

4.5.1.6 Version 2 - acceptability

All participants answered version 2, with no-one selecting the ‘Prefer not to say’ option. The requirement to provide a ‘yes’ or ‘no’ answer was largely ignored, with participants wanting to indicate the impairments that applied to them or their child. As such, there were no data from the cognitive testing to determine whether a ‘yes-no’ answer format would be more acceptable to participants. If data were available, the more acceptable version would be expected to have fewer ‘Prefer not to say’ responses.

4.5.1.7 Version preference

Most participants were asked if they preferred version 1 or 2. Among adults, 12 expressed a clear preference for version 1. Reasons for preferring it were:

- the response options were shorter, making it easier for people to read

- liking the response format – being able to ‘tick all that apply’

- in some of cases, preferring the wording of the response options and the use of “medical” terms

An additional 4 participants stated a preference for version 1, but only if the mode was self-completion; it had a ‘yes or no’ response format; or used the language of version 2.

In contrast, 12 adult participants expressed a preference for version 2. These participants liked the language used in version 2, which was considered “less formal” and “simpler”. The inclusion of examples for every response option helped participants understand the category. Having the term ‘changes over time’ in the question stem was also appreciated. Some participants said that although they preferred version 2, they would have used a ‘tick all that apply’ response format rather than ‘yes or no’.

Among parents, there was a clear preference for version 2, with 11 parents preferring this version. Reasons for preferring version 2 were the simpler “more accessible” language, and the examples which helped participants understand the response category headings.

Version 1 was preferred by 5 parents and for similar reasons to the adult participants. It was “less wordy” than version 2, had a ‘tick all that apply’ response format, and it made specific reference to ‘long-term impairments’. In addition, one parent liked that it included an ‘Other’ category, which allowed them to include anything that was not covered on the list.

4.5.1.8 Mode differences

Version 1 was designed for self-administration. The cognitive interviewer shared their screen with the participant so that they could view the question and told the interviewer which response option(s) they would select. No issues were observed with this mode of administration.

Version 2 was designed to be administered by an interviewer, who read the question and showed the participant the list of impairments. It was common for participants to want to select each impairment listed that applied to them or their child, rather than respond yes or no. However, this list was lengthy and contained more examples than version 1. This meant that some participants could not remember the question after having read through the list of response categories and said they would have liked to have the question to refer back to.

4.5.2 Easy read (English and Welsh) findings

At screening, 4 adults (3 in English, one in Welsh) and one parent of a disabled child (in English) indicated they would like to be interviewed using the easy read versions of the questions. All participants were asked the 2 impairment questions first, then

the barriers questions. No issues were raised with the Welsh easy read version of the impairment questions.

Testing of the parent question highlighted a need for an instruction on what parents should do if they had more than one child with an impairment. The parent who participated had 2 children with impairments and decided to answer the questions in relation to their eldest child.

4.5.2.1 Version 1 – understanding the question

All 5 participants understood the question was asking about “conditions”, “illnesses” or “disability” that can last “months or years” and would not “wear off”. Two adult participants mentioned that they thought the question was asking about the impact of their impairments or conditions on their “ability to have a good quality of life” and on “how it makes you feel”. Participants’ understanding of the question reflected their personal lived experience. One participant was thinking about their responses to the question using the definition of “long-term illnesses or disabilities” used when applying for Personal Independence Payments (PIP). The parent of a disabled child defined ‘long term’ using the Equality Act definition, because they worked in the legal field. They wondered if others would know that ‘long-term’ meant 12 months or more. This participant included all their child’s conditions – diagnosed and undiagnosed, as there was no instruction that said not include undiagnosed conditions.

4.5.2.2 Version 1 - response categories

All 5 participants selected multiple response options, picking those that they felt best reflected their or their child’s lived experience. Participants felt the list of response categories was long. There was a suggestion from one adult participant to combine the following categories to shorten the list, because they felt the categories overlapped:

- ‘Moving or strength’ with ‘Feeling uncomfortable or in pain’
- ‘Learning’ with ‘Memory or concentrating’

Overall, participants were positive about the easy read format and images, which helped them with processing the long list of response options. However, one participant commented that the examples provided for the response category of ‘Senses’ were vague, and that the example of ‘you find it hard to sleep’ for the category ‘Breathing or feeling tired’ was not helpful, as someone could still feel tired even with good sleep. They also commented that the image used for ‘Mental health’ conveyed aggression. Both this participant and the parent who took part in testing commented that the ‘Fighting illness’ example ‘your body fights too much or not enough’ was confusing.

4.5.2.3 Version 1 - acceptability

All participants were willing to answer this question. However, the parent who participated said that there were some sensitivities around answering questions about their child's conditions. They would want to be assured about the legitimacy of the request for this information.

4.5.2.4 Version 2 – understanding the question

Participants stated they felt this question was asking about difficulties they or their child experienced and/or differences in their or their child's experiences from others. Some participants liked the term 'issues', feeling it was inclusive and implying that conditions did not have to be diagnosed to be included. There was also recognition that it could be seen as a negative term. The term 'differences' was disliked by some participants, because it had negative connotations.

The instruction to include 'anything that may come and go or vary over time' was important for one participant in particular. They included their child's hearing impairment which impacts their child when in noisy places. They would not have included it, had this instruction not been present.

4.5.2.5 Version 2 – response categories

The parent participant was initially confused by how to answer this question, seeking clarification from the interviewer. This may have been the result of the cognitive testing. They had previously been asked version 1, which required them to 'tick all that apply' rather than read through the list of impairments and answer 'yes or no'.

There were comments from one participant that the images used in the response options for version 2 were unclear:

- **Moving around**: it was difficult to see that the image was of stairs.
- **Using your hands or fingers**: the relevance of the image of 2 people standing in front of a clothes rail to the category label was unclear.
- **Wellbeing**: the image was confusing and interpreted as an angry face.
- **Energy and breathing**: it was unclear what the person in the image was doing.
- **Feeling uncomfortable or in pain**: the image of the person bending over did not convey the idea of someone in pain.

4.5.2.6 Version 2 - acceptability

All participants provided an answer to the question, and some participants stated a preference for version 2. Being able to answer 'yes or no' was "simpler" than having to look closely at each description of an impairment.

4.5.2.7 Version preference

There were mixed views on which version was preferred, with 3 participants favouring version 1, and 2 participants favouring version 2. Reasons for preferring version 1 were the shorter response options and having a ‘tick all that apply’ response format. Version 2 was preferred because participants found answering ‘yes or no’ was easier. They did not feel they had to read all the text for each impairment as carefully as they did for version 1.

4.5.2.8 Mode difference

Although version 1 was self-administered and version 2 was asked by an interview, both easy read versions included the visual presentation of the question and impairment categories to participants. No mode differences were observed.

4.5.2.9 Question order

In reviewing the cognitive testing findings, no evidence was found to suggest the question order of whether the impairment questions were asked before or after the barriers questions had any impact on the way the questions were understood or responded to.

4.6 Cognitive testing findings - barriers questions

Two versions of the barriers question were cognitively tested (Annex C). Version 1 was given to participants to answer, mimicking a self-completion survey format. Participants were asked if they experience barriers in any of life domains listed (such as health care, transport, and employment) and instructed to tick all the response options that applied to them.

Version 2 was read aloud to the participant, in an interviewer administered format. The interviewer asked participants “Which, if any, of the following have you experienced? Please select all that apply” and asked them to select all the response options on the card that applied to them. Response options aligned with the social model categorisation of barriers: attitudinal, institutional, communication, and environmental.

As outlined in Section 3.3.4, adult and parent versions of the questions were designed to keep differences to a minimum. Differences in the version 1 question related to response option examples, with some being amended to child specific ones. Response options for the adult and parent iterations of version 2 of the barriers question were identical.

The cognitive testing of these questions aimed to:

- assess whether versions 1 and 2 of the barriers question identified the barriers experienced by people affected by impairments or condition - if some barriers were missed or included that should not be
- assess whether the questions and response options were understood in the ways intended
- establish participants' willingness to answer the questions and identify factors that may impact this
- identify any preference for version 1 or version 2 and understand the reasons why
- identify any issues or preferences relating to the mode (self-completion versus interviewer-administered)
- examine whether the question order affected participants' understanding of the barriers questions

Findings related to version 1 and version 2 are presented for the English and Welsh language versions, and the easy read versions in English and Welsh.

4.6.1 English and Welsh language findings

4.6.1.1 Version 1 - understanding the question

The version 1 question asked "Thinking about (this/these) long term impairment(s) or condition(s) which, if any, of the following barriers do you experience? Please select all that apply." Participants consistently understood this question as asking about the extent to which their long-term impairment(s) or condition(s) meant they experienced barriers in different aspects of everyday life.

> "It's asking me … do any of these things stop me from enjoying my life."

There were 2 frames of reference used. One involved a more medical model of disability view, with participants using terms such as 'problems' and 'difficulties' when describing how they interpreted the question. The other involved a more social model of disability interpretation, recognising that the question was asking about things that are not in place to support a person's needs.

> "It's asking me about what could be done better to improve my son's life… what's causing problems."

> "The question is looking at how well the areas listed help and support people with disabilities like mobility issues or eyesight issues."

The number of response options and volume of text to process was noted, requiring re-reading by some. However, it did not appear to impact upon how the question was understood and interpreted, or willingness to answer. There was some evidence that parents did not initially understand that the question was asking about their child's experiences. However, all parents were able to answer the question.

Interpretation that the question was asking about barriers experienced in relation to a long-term impairment or condition was not universal. Being in a rural area, for example was cited as a reason for experiencing barriers with 'Transport' and 'Community and social activities'. Similarly, barriers related to gender identity were also selected. This issue largely appeared to relate to question order as it was more prevalent among the half sample of participants that were asked about barriers before impairments.

The word 'barriers' was generally well understood by participants. They described it as encompassing things that cannot be got around or that stop a person from doing things that others can do, or that prevents someone making the most out of opportunities. That said, it was interpreted as relating mostly, or exclusively, to physical barriers. This was particularly among those with physical impairments, and those who were not asked the impairment question before the barriers question.

The word 'barriers' was generally preferred over other terms, such as 'issues', with the latter being separately considered as too weak and too strong. Where there was a preference for 'issues' over 'barriers', this coincided with preferences for other words like 'challenges' and 'difficulties'.

The time period that participants were thinking of when answering the question varied. Among adult participants, experiences in childhood and growing up were considered when answering. There were no objections to restricting experiences to a 12-month period and evidence on the impact its inclusion had on response was mixed.

For the Welsh translation, there was some unfamiliarity with the term 'amhariad' (impairments) used in the question stem.

4.6.1.2 Version 1 - response categories

Nine of the response categories covered domains (areas) of life where barriers may be experienced. Each bold response option heading was supplemented with examples of possible barriers that could be experienced in this domain. There was no evidence that any response options were missing from the list, or that any of those listed should be removed. While parents initially queried the relevance of the response option related to 'Employment and job opportunities' when answering a question about their child, they recognised and appreciated that they were being asked about their child's long-term impairment, or impairments and barriers that affected them personally and their child, indirectly.

Views on the usefulness of text in bold were mixed, with it being seen both as helpful but also as repetitive. The inclusion of ‘does not support my needs’ was potentially off-putting, though the term appeared to be consistently understood.

While the inclusion of examples results in a longer question, views on their inclusion tended to be neutral or positive, though with a consensus that they were too long. They were considered as necessary in helping with understanding and interpreting the question. They also appeared to encourage participants to think about and consider non-physical barriers.

> “[The examples were] the only way I’m going to understand it.”

Participants suggested a range of options for improving the examples. These included reducing the number provided and hiding them behind an information button that could be accessed, if required.

The following issues were identified with specific response options.

- **Health care and support:** there was feedback that too many examples related to physical barriers. It was also observed by participants and the research team that many of the examples were universal issues – they could also apply to people without a long-term impairment or condition.
- **Education and training:** participants tended to reflect on experiences at school when answering, sometimes from several decades ago. This interpretation highlighted the need for a reference period or guidance to be included, if the intention was that historical education experience should be excluded when answering.
- **Voting and political participation opportunities:** there was uncertainty about what was being asked about, with evidence that voting was the only thing considered when answering. Understanding of the example ‘take part in public life’ was mixed. Participants who did not understand the term tended to only consider barriers related to voting when answering.

The main issues relating to the Welsh translation of version 1 response options were:

- ‘nad ydyn nhw’ was considered a very formal translation of ‘do not / does not support my needs’, with ‘sydd ddim’ viewed as more appropriate
- ‘hygyrch’ used across multiple response option examples as the translation of ‘accessible’ was not a commonly used term in Welsh
- in ‘Financial support and services’, ‘budd-dal’ (benefit) was suggested as more appropriate - ‘lles’ (welfare) was considered too formal

4.6.1.3 Version 1 – acceptability

All participants answered the question, with one adult and one parent selecting the 'None of these' option. Participants selected a frequency of between 1 and 6 options when answering. Participants were comfortable answering the question, and where discomfort was expressed, this related to reflecting on difficult and challenging experiences. This lack of comfort was, however, coupled with an acknowledgement that it was important that the question was asked. There was no evidence that the question was considered intrusive or too personal to answer. The question was viewed as positive and an acknowledgement of disabled people's experiences. One participant reported feeling "kind of passionate" about the question.

There was a consensus that the question was too long, with it taking too long to process and answer. Having the question and response options available while formulating a response was appreciated, allowing participants the chance to re-read sections and process the information at their own speed. There was sufficient feedback to suggest that not having both the question and response options available may impact ability to interpret and answer the question. Views on how to resolve the issue of length were mixed. While the breadth of the life domains and the usefulness of the examples were appreciated, simpler more concise language was also requested.

4.6.1.4 Version 2 - understanding of the question

The second version of the barriers question asked participants: "Which, if any, of the following have you experienced? Please select all that apply". The question was understood as asking the extent to which someone experienced barriers related to their long-term impairment(s) or conditions. Participants tended to use medical model language when describing what the question was asking. Evidence suggested that the question was generally, but not always, interpreted as asking about barriers experienced across a broad range of life domains. One participant said:

> "You're asking me about things that should be in place, but aren't, and which make life difficult for me as a disabled person…making work or something accessible".

Those that interpreted the question narrowly in terms of the life domains it was asking about, tended to reflect heavily on their own lived experiences when answering. For example, a wheelchair user understood the question to be asking about access related barriers in the built environment.

Issues that caused confusion, but which did not appear to impair understanding included:

- lack of clarity regarding whether the question was specifically about barriers related to impairments

- lack of a reference period in the question stem
- large volume of text
- perceived complexity of some of the sentence structures
- some of the Welsh translations were considered too formal, making the question more difficult to understand

4.6.1.5 Version 2 - response categories

Version 2 was designed so the response options each captured one of the types of barriers used in common social model classifications. An 'Other' response option was also included. It allowed participants to describe in their own words any other barriers experienced, and to help assess the completeness of the response categories. Each bold response option that described a barrier type was supplemented with examples.

There were mixed views on the usefulness of the response option headings as they were considered both as sufficient and clear, and as too long and wordy. Views on the examples were also contradictory. A participant described the question as: "clear, concise, and gave really good examples".

There was also evidence that the examples provided were too vague for some and too complex for others.

The following issues were identified with the version 2 response options and examples.

- **Buildings and indoor and outdoor spaces that are not suitable**: There was a tendency to only consider, or give greater weight to, the physical barriers those with a physical long-term impairment or condition might encounter.
- **Information and communication that is not accessible:** The Welsh translation included unfamiliar terms such as 'hygyrch' (accessible). While causing confusion, it did not impact on ability to answer the question.
- **Rules, policies, and practices that are not supportive:** There were different interpretations of this response option. It was understood as asking about the extent to which professional staff in domains such as health or education, are trained, sensitive and supportive to individual needs. Other interpretations were much broader, and broader than intended. A participant that chose this option as they felt there "was a lot of ignorance about neurodivergence". Participant narratives also pointed to confusion between this and response option 4 of 'Views and behaviour from others that are not supportive'. Confusion seemed to relate to the interpretation of the example

'things being done in a way that means I am treated unfairly' and whether unfair treatment by professional staff due to lack of training should sit under response option 3 or 4.

- **Views and behaviour from others that are not supportive:** There was felt to be an overlap between this and option 3 of 'Rules, policies and practices that are not supportive'. The implication was that those who should have selected response option 4, selected response option 3 instead.

4.6.1.6 Version 2 – acceptability

One participant answered 'None of these' to version 2 of the barriers question, with everyone else selecting a frequency of between 1 and 4 responses. Participants felt neutral or comfortable about answering. An interviewer noted that:

> "...the respondent was happy to answer this question and thought they are helpful questions to ask to improve facilities and attitudes towards disabilities."

Where discomfort was expressed, this either related to personal preference of not wanting to think about experiences; or was tied to feelings of guilt over the perceived lack of the severity of a long-term condition. There was no evidence that the question was considered too sensitive to answer. One participant noted that the inclusion of a 'Prefer not to say' option was:

> "...worthless. If people can refuse to answer it, what would be the purpose of doing this survey anyway?"

This participant did not feel the question was asking for information that was "too personal or identifiable".

While participants were willing to answer the question, there was a general feeling that it was too long and took too much time to process. There was evidence that this increased participant burden, with participants suggesting a variety of ways to improve the question. Examples included moving the bulk of the text to the question stem, removing some examples, adding images, and improving presentation.

4.6.1.7 Mode differences

Version 1 was designed to be administered in online self-completion mode, with the question stem visible alongside response options. Version 2 was delivered in face-to-face interviewer format. As is typical for survey questions administered this way, the interviewer read out the question stem and the accompanying showcard included response options only. For version 2, findings suggested that not having the question stem on the showcard may have made the question more difficult to answer. One participant reported it was harder to understand what this question was asking compared to version 1, and several explicitly stated a preference for having the question wording on the card. There were no explicit findings relating to the mode of

version 1. However, feedback from version 2 and the general finding that version 1 was long and demanding suggest that having the question stem visible when answering may help some participants.

4.6.2 Easy read (English and Welsh) findings

Easy read versions of the 2 barriers questions were tested with 4 adults and one parent of a disabled child. Four interviews were carried out in English, and one adult interview was conducted in Welsh. The parent who participated had 2 children with impairments and answered the barriers questions in relation to their eldest child.

4.6.2.1 Version 1 – understanding the question

The question was understood as asking participants the extent to which they experienced barriers in daily life related to having a long-term impairment or condition. Participant accounts of what the question asking tended to include the term ‘difficulties’ or other terms rooted in medical model language, including ‘challenges’ and ‘problems.’ One participant described the question as:

> “…asking me, what things do I have problems with because of my disability … what are the things that could be done in a better way for me.”

There was evidence that question was unclear for some participants. Reasons for this lack of clarity were twofold. A minor textual error in the parent version of the question resulted in some uncertainty about whether a parent was meant to answer about themselves or their child. The volume of text, and specifically the large number of response options, also made interpretation difficult.

Participants considered the last month, last year, or recent years when answering, which did impact response selection. A parent, thinking about the last month, noted that they would have selected more options for their child had they been asked about their experience of barriers in the last year. Conversely, a 12-month reference period would have resulted in one participant deselecting ‘Education’ as they were reflecting on school days when answering.

The Welsh translation ‘cyflyrau’ (‘conditions’) was queried, with the singular ‘cyflwr’ being more familiar.

4.6.2.2 Version 1 - response categories

All participants answered the question, selecting a frequency of between 1 and 8 response options for barriers in areas of life. Views on the number of response options available were mixed. The list was considered too long and made it difficult for some participants to understand the question.

Views on the response option headings and examples were also conflicting. Some participants expressed no concerns about length or clarity, whereas others suggested the headings could be shorter and clearer. Participants stated that it

should be made explicit that the examples provided were not an exhaustive list. One parent initially found it confusing that some response options appeared to relate to the experiences of their child while others seemed more relevant to them as a parent. This impacted their ability to answer the question as intended.

Participants were positive about the easy read format and images, acknowledging that it helped with processing the long list of responses. A participant noted:

> "…it would have taken me ages to go through this if it was in a normal format, without pictures."

Suggestions for improvements included:

- **Healthcare**: replacing the image of 2 people on the phone with an image of a doctor, nurse, or someone at a doctor's surgery
- **Your local area**: specific examples or images of the types of 'local buildings' would have helped a participant who was uncertain over whether a library would fall under this definition, or not
- **Activities and events:** replacing the image with actual activities or a combination of events like cycling and swimming

No issues relating to the Welsh translation of the response options were raised.

4.6.2.3 Version 1 - acceptability

All participants were willing to answer this question. Any confusion and uncertainty that was expressed did not impact on willingness to answer the question. Valid response options, including 'Health care' were selected by the participant who considered health a sensitive topic to ask about.

4.6.2.4 Version 2 – understanding the question

Participants understood that the question was asking the extent to which they experienced the barrier types listed on the card. As with the English and Welsh findings, the adults and parent interviewed all interpreted the question as asking about barriers experienced in relation to long-term impairments or conditions. Some interpretations were expressed in medical model language, while others were social model aligned. For example, a participant noted that this question was asking if any of the options listed have been "unsupportive" for your condition.

Interpretations about the areas of life the question was asking about tended to be quite broad. The exception was the parent who understood the question to be asking about difficulties accessing services, and the extent to which reasonable adjustments were not in place for their child. The parent's justification for their response options however, suggested they were thinking more broadly than service provision when answering.

When answering, adult participants appeared to consider current experiences, or those within the last year. The parent participant reflected on barriers their child had ever experienced. Including a 12-month reference period would have impacted on the response options selected.

Clarification on the meaning of the term ‘profi’ (to ‘experience’) was sought by the Welsh participant, who interpreted it as meaning to prove or testing something.

4.6.2.5 Version 2 - response categories

Four participants answered the question, each selecting between 2 and 5 responses. The fifth participant did not answer this question due to time constraints. One participant noticed that versions 1 and 2 were asking about different dimensions of barriers and noted a preference for being asked about types of barriers experienced (version 2).

Views on the number of response options were neutral or positive. Five options were felt to be an appropriate number, and preferable to the larger number in the version 1 barriers question. Feedback on the examples included within each response option were mixed. Some participants found the examples and accompanying images clear and relevant. They were also viewed as too vague and having more specific examples would have been helpful.

- **Rules that do not support your needs:** There was evidence that only employment was being considered when answering.
- **Being treated differently:** This heading was understood in different ways, with a participant interpreting it as a positive thing to be different. This participant selected this option to reflect their experience of a family member supporting their needs and sending them post they could read. Participants also felt that the accompanying example was not a good match with the heading.
- **Something else**: A participant selecting this response option assumed that it was obligatory to provide a comment.

Feedback on the images used was generally positive and participants found it useful having the questions in an easy read format. Specific feedback included the suggestion to replace the picture for ‘Spaces or buildings that are hard to use’ with a picture of a disabled entrance to a building. Other suggestions included replacing the image for ‘Rules that do not support my needs’ as it was confusing; and improving the image for ‘Being treated differently’ by replacing it with an image of a person in a wheelchair.

There were no issues with the Welsh translation of any of the response headings or accompanying examples.

4.6.2.6 Version 2 - acceptability

All participants who received the easy read version of this question were able and willing to answer it. That said, there was evidence that re-reading the question several times was required to help interpret and answer it. It was viewed as a sensitive question but if it was being asked for a legitimate reason, then it was considered justified.

4.7 Proposed wording of questions for the NatCen Opinion Panel (work package 6)

Recommendations were made by the NatCen research team for the wording and format of the impairment and barriers questions to be tested on the NatCen Opinion Panel, in work package 6. Cognitive testing findings, steering group feedback, and findings from data users and disabled people in the discovery phase informed these recommendations. This section summarises the rationale for the proposed questions taken forward to work package 6.

4.7.1 Impairment question

In testing 2 versions of the impairment question, it was possible to experiment with different wording and response formats. Feedback from disabled adults and parents of disabled children who took part in the cognitive testing found no clear preference for one version over the other. Instead, the NatCen research team identified question features that participants preferred in versions 1 and 2, to incorporate into the single version to be quantitatively tested.

4.7.1.1 Question wording

The question should ask about ‘long-term conditions or impairments’, similar to version 1, rather than ‘issues or differences’. Evidence from the cognitive testing indicated that the phrase ‘issues or differences’ had negative connotations for some participants. ‘Condition’ was the preferred term in the cognitive testing and was favoured by some participants in the deliberative workshops. The term ‘impairments’ was viewed positively by some participants in cognitive testing and negatively by others. Its use is recommended because the term is central to the social model of disability. Use of social model of disability terminology was recommended by the steering group and in findings from the discovery phase.

The question should contain an instruction to include conditions ‘that may come and go or vary over time’. Cognitive testing indicated that this instruction was helpful to adults and parents of children with fluctuating impairments or conditions. This encouraged participants to include these conditions when answering the question.

4.7.1.2 Response format

The ‘select all that apply’ format used in version 1 was recommended. Cognitive testing indicated this was acceptable, with all participants answering the question. This format was based on the GSS harmonised impairment standard, which was received positively by some of the disabled people who took part in the discovery phase. The updated response options and question wording would provide data users with more information on the nature of impairments, and in more detail than the current harmonised impairment standard. During the discovery phase, some data users suggested response options in the existing harmonised impairment are quite broad and not detailed enough to provide guidance for policymakers.

4.7.1.3 Response categories

Response categories should use the verb-based language from version 2 as this was preferred by participants in cognitive testing, over the language used in version 1. It was recommended that the following version 2 category headings be retained:

- Seeing
- Hearing
- Moving around
- Using your hands or fingers
- Learning new things
- Remembering or focusing
- Interacting with other people
- Being in pain or discomfort

The response categories of ‘Mental health’ and ‘Sensory processing’ should be retained from version 1.

The remaining response option headings should be used with the following modifications.

- The ‘Energy levels or breathing’ category should be renamed ‘Managing energy levels or breathing’ to follow the recommended verb-based language. The inclusion of ‘managing’ was also proposed to convey that this category can be used by people whose energy levels fluctuate. Whilst there were findings from cognitive interviews that breathing should be in its own response category, the recommendation was to keep it with energy levels. Splitting this category into 2 would add to an already long list of response options, increasing respondent burden.

- The category relating to immune systems should be renamed entirely. The recommendation is to use the example from version 1 as the category heading: ‘Having an over or under active immune system’. This change aimed to make the category description clearer, using everyday language.

A recommended maximum of 3 examples should be included for each category, keeping the text as concise as possible.

More specific changes were recommended to the examples used within the following response categories.

- ‘Mental health’ examples should be revised to make the descriptions more concise and have a clearer focus on mental health conditions rather than feelings or emotions more generally. The wording of version 1 ‘managing moods, emotions or thoughts’ and version 2 ‘feelings about yourself and others, managing your emotions’ should be combined and expressed more concisely as ‘managing thoughts or feelings’. Similarly, participants found the version 2 example ‘seeing or hearing things that other people do not’ confusing, so this should be rephrased as ‘experiencing hallucinations’.

- ‘Having an over or under active immune system’ examples should be recognisable to those with autoimmune conditions. The example used in version 1 became the category heading, and the example in version 2 was found to be confusing. Based on suggestions from participants in cognitive testing, the following wording was proposed at the revision stage: ‘being prone to infection or inflammation’.

4.7.2 Barriers question

Based on the recommendations put forward by the NatCen research team, the Welsh Government decided both versions of the barriers question should be included in the quantitative field test.

4.7.2.1 Version 1 – barriers in domains of life

Question wording

To minimise the likelihood of participants only thinking of physical barriers, consideration should be given to removing the term from the stem. Instead, participants should be asked if they have experienced any of the things listed.

The question stem should include a reference period to reduce the likelihood of adult participants selecting responses based on experiences from childhood and growing up. The recommended reference period should be 12 months.

Response format

Most participants selected multiple response options, indicating disabled people can easily identify all the areas of life they experience barriers in. It was recommended that the ‘select all that apply’ format was retained.

Response categories

The volume of text used in the response options and accompanying examples should be reduced. This could be achieved in a combination of ways, including removing unnecessary text and repetition, and rewording examples to make them more concise while maintaining clarity. It was also recommended that the number of examples in each response option should be reduced to 3. This would address the general findings from testing that the question was long and had a lot of text to read.

The examples listed under each bold response option heading should be reordered so the first example is not an environmental barrier. This may help reduce the likelihood of some participants only considering physical barriers when responding.

More specific changes were recommended to the following categories.

- ‘Employment and job opportunities’ should appear before ‘Education and training’. This will help to mitigate against participants who experienced barriers in job related training categorise it under the ‘Education and training’ response option.
- ‘Opportunities to take part in community and social activities’ should be shortened to ‘Community and social activities’ to address participant feedback that the question was too long with too much text to process.
- ‘Voting and political participation opportunities’ should be reworded to ‘Voting and opportunities to get involved in politics’, to use plainer language than ‘political participation’.
- Version 1 did not have a ‘Prefer not to say’ option, and there was limited evidence suggesting the question was sensitive. This response option should be included in the work package 6 quantitative field test to establish the percentage of participants selecting it, as this will provide evidence on the acceptability of the question.
- An ‘Other’ response option, with optional write-in, should be retained to assess how complete the existing predefined response options are in capturing the range of life domains barriers experienced. Retaining this would also provide participants with the opportunity to describe, in their own words, their personal experience.

- The bold text in each response option included the phrase ‘do not or does not support my needs’. The Welsh translation of ‘nad ydyn nhw’ was considered very formal by Welsh participants. ‘Sydd ddim’ was suggested as a more appropriate translation.
- Participants noted that ‘hygyrch’ (accessible) was used across examples in multiple response options and was not commonly used in Welsh. Based on participant feedback, this was replaced with ‘ddim yn addas’ (not suitable) instead.
- In ‘Financial support and services’, ‘lles’ (welfare) was considered too formal and ‘budd-dal’ (benefit) was suggested as a more appropriate translation.

4.7.2.2 Version 2 - types of barriers experienced

Question wording

To ensure participants consistently consider the same time period, a 12-month reference period should be added to the question stem.

Based on participant feedback that it was difficult to remember the purpose of the question when it was read out by an interviewer, the question stem should be included alongside the response options on a showcard.

Response format

As with version 1 of the barriers question tested, to reflect the lived experience that many disabled people experience barriers across multiple areas of life, the ‘select all that apply’ format should be retained. Evidence from the cognitive testing showed that disabled participants had experienced more than one type of barrier.

Response categories

All response options and accompanying examples should be reviewed to address participant feedback that the question should be clearer and not as long.

To mitigate against the confusion observed during testing, the 4 barrier type response options should be reordered so that the environmental barrier (‘Buildings and indoor and outdoor spaces’) does not appear first.

The order of the institutional and attitudinal response options should be swapped to improve clarity around the distinction between the 2 options. This may also help mitigate against participants incorrectly selecting the ‘Rules, policies and practices’ option to describe experience of unfair treatment, negative behaviours, and attitudes. This should be categorised as attitudinal under ‘Views and behaviour’, and not institutional barriers.

The examples should be revised to reflect barriers across all domains of life. This will address the evidence that some participants found the examples very broad.

More specific changes were recommended to the following:

- ‘Buildings and indoor and outdoor spaces that are not suitable’ should be reduced to ‘Buildings and spaces that are not suitable’
- examples in ‘Information and communication’ should be reduced to 3 to contribute to the aim to shorten the question
- examples in ‘Rules, policies, and practices’ should be revised to improve clarity and encourage participants to consider options other than employment and government service provision; this is in line with an earlier recommendation to draw on examples across all areas of life
- an ‘Other’ response option should be retained and any write-in responses used to assess the completeness of the response options
- while evidence from testing indicated that an explicit ‘Prefer not to say’ option may not be necessary, it was recommended that this should be investigated further in work package 6
- participants noted that ‘hygyrch’ (accessible) used across examples in multiple response options was not commonly used in Welsh - based on participant feedback, this was replaced with ‘ddim yn addas’ (not suitable) instead

4.8 British Sign Language (BSL) cognitive testing

The original plan was for the British Sign Language (BSL) cognitive testing to take place at the same time as the English, Welsh, and easy read cognitive testing. However, due to contractual and administrative delays, the BSL cognitive testing took place in parallel with the quantitative field test (work package 6). This provided the opportunity to cognitively test the impairment and barriers questions being field-tested, with adult deaf BSL signers. The questions tested were:

- the GSS impairment harmonised standard
- the social model-aligned impairment question
- revised versions of the 2 barriers questions

Further details on the questions included in the quantitative field test (work package 6) are provided in Annex G.

The aims of the BSL cognitive testing were to assess:

- whether the impairment questions
    - accurately identify people with impairments or conditions
    - resulted in some people being missed who should be included (false negatives)
    - resulted in people being included who should not be (false positives)
- whether participants understood the questions and response options as intended
- whether the wording of questions can be improved, and if so, how
- if participants preferred versions 1 or 2 of the impairment and barriers questions

NatCen collaborated with researchers in the Social Research with Deaf People (SORD) group at the University of Manchester. NatCen provided SORD with the adult version of the English language questions being field-tested, and the probe sheet. The easy-read English language versions of the privacy notice and participant information sheet used in the earlier cognitive testing were provided. Working closely with NatCen, SORD adapted and translated these for BSL.

4.8.1 Methods

The BSL cognitive testing followed a similar approach used in earlier testing in English, Welsh, and easy read English and Welsh, with modifications. Similarities were the use of purposive sampling to recruit participants with a range of socio-demographic characteristics, and the use of think aloud and probing to explore participants' understanding of the questions. However, the BSL testing did not involve varying the mode of administration or the order in which questions were asked due to practical constraints. All the questions were delivered in online self-completion mode with no randomisation of the order that test questions were asked in.

4.8.1.1 Recruitment

SORD recruited participants via known networks of deaf BSL signers living in Wales, using a screening questionnaire. A target of 4 BSL interviews was agreed with the Welsh Government, with at least 1 interview being achieved with participants in each of the following age groups: 18 to 29, 30 to 64, and 65 and older.

BSL versions of the participant information sheet and privacy notice used in the testing of questions in English easy read were produced, edited, and checked by qualified BSL/English interpreters.

4.8.1.2 Fieldwork

Four cognitive interviews were carried out in December 2025 by 2 members of the SORD research team, using a protocol developed in collaboration with NatCen. The characteristics of those interviewed were as follows:

- 2 participants aged 18 to 39; 2 aged 40 or above
- 2 male and 2 female
- all currently in or waiting to take up work or training
- 1 living in an urban area; 3 in a rural area

The BSL questions were tested in the following order: GSS harmonised impairment standard, social model-aligned impairment question, barriers question version 1, then barriers question version 2.

Interviews were carried out using the video-conference platform Zoom and Qualtrics for viewing the standard versions of the survey questions in BSL. Screen sharing was used to enable participants and interviewers to view the survey items simultaneously in real time. Interviewers navigated through the test questionnaires on behalf of participants, who were asked to respond with ‘yes’ or ‘no’ to each response option. This approach ensured consistent data entry across interviews, while allowing participants to focus on the content of the questions and their comprehension. Interviews were recorded, with participants’ agreement.

During the interview, participants viewed a maximum of 2 videos on the screen at a time, with the interviewer scrolling down to view the remaining videos.

At the end of the cognitive interviews, participants were provided with a further support information sheet, which was modified to reflect resources in BSL and the wider deaf community. Each participant also received a thank you email, including an e-code for a £40 online shopping voucher.

4.8.1.3 Data management and analysis

The data management and analysis process was similar to that used in work package 5: cognitive testing. Interviews were recorded and referred to by interviewers when making notes and summarising interviews, using a proforma provided by the NatCen research team. This proforma was a series of matrices (worksheets in Excel). Each question was one matrix that contained details of each participant, their answers to the impairment and barriers questions, and their responses to the think aloud questions and each probe. SORD researchers received training from NatCen on this process.

The completed matrices were reviewed by the NatCen research team, who assessed the data for each question in turn. The responses from each participant independently and collectively were examined to answer the research questions.

4.8.2 Findings - impairment questions

The 2 impairment questions included in the NatCen Panel test (work package 6) were cognitively tested in BSL: the GSS harmonised impairment question and the social model-aligned impairment question.

There are several factors that should be taken into account when interpreting the cognitive testing findings for the impairment questions. These relate to the language (BSL) and how the English language questions were expressed in the BSL questionnaire; the presentation of unfamiliar words in BSL; and how different identities, and social, cultural and language contexts among deaf BSL signers can shape responses to a social model-aligned impairment question.

4.8.2.1 GSS harmonised impairment standard

Participants understood the question to be asking about whether they had any of the ‘conditions’ or ‘illnesses’ listed. The reference to illnesses and conditions in the question was interpreted in different ways: as referring to “disability”; “problems” and “frustration” with the barriers they face. One participant did not understand the signs for ‘conditions’ and ‘illnesses’ and asked for these terms to be finger spelt, i.e. the visual expression of the English words using the BSL two handed alphabet.

All 4 participants selected the ‘Hearing’ response option, along with other options. The other options selected by participants reflected how being deaf impacted them – their learning, fatigue, and memory.

The term ‘Dexterity’ was unfamiliar to some, supporting the feedback from BSL translators (in Section 3.4.3.2).

Whilst all participants answered the question, some participants did not like the question and the wording of the ‘Hearing’ category, which referred to ‘deafness’ and ‘partial hearing’. These terms were seen as “outdated” and negative. One participant queried what ‘deafness’ meant:

> “Does it mean fully deaf? I need more context about what the question is wanting to know”.

Another participant initially understood the word ‘Hearing’ as referring to a “hearing person” rather than a way of expressing deafness (as in partially hearing). Consequently, they would not have selected that option. It was only the presence of the interviewer that led them to read the full description and watch the full video, and in doing so understand that the category applied to them.

4.8.2.2 Social model-aligned impairment question

There were different interpretations of this question. Of the 4 participants, 2 thought it was asking if they were affected by the impairments listed. One participant thought that it was asking “if I can do that”. Another initially thought it was asking “about my body and my health”.

Participants found it more difficult to select from the list of impairments for this question than for the harmonised impairment question. This was due to the length of the response options and the way in which the question was presented.

Participants were asked about the ‘Hearing’ response option and how they understood it. One participant did not select the ‘Hearing’ response category. They did not endorse this option because they felt it did not apply to them as they are deaf. The other 3 participants selected ‘Hearing’. As with the harmonised impairment questions, one participant initially interpreted ‘Hearing’ as referring to a “hearing person” and would not have endorsed the category. The presence of the interviewer led them to read the whole of the response option and watched the video fully. In doing so, they realised that their initial interpretation was not correct. Had the interviewer not been present, the respondent said that they would not have read or watched the video beyond “Hearing”. Another participant was unsure what the phrase ‘understanding noises around me’ meant. They did “have issues with background noises” from time to time and endorsed the category.

Whilst all participants answered the question, 2 participants disliked the question asking about ‘impairments’, with one of these participants saying that they would not complete a questionnaire that used this term.

The signs for the phrase ‘may come and go or vary over time’ could be clearer, with one participant suggesting the phrase should be “up and down like a rollercoaster” and not signed “gone then back then gone”, to more clearly reflect the “highs” and “lows”.

Participants were asked which version of the impairment question they preferred. Views were mixed, with some preferring the harmonised impairment standard and others preferring the social model aligned version. One participant found the social model version clearer than the harmonised standard but said they did not like either version because of the terms used (‘deafness’ and ‘partial hearing’ in the harmonised standard, and ‘impairment’ in the social model aligned version).

4.8.2.3 Expressing English language questions in BSL

More than one participant saw the examples of what constituted the meaning of the impairment category label (for example, ‘Dexterity’) as being positive examples of ability, rather than as examples of impairment. This may have resulted from the way in which BSL is structured. It is not unusual in BSL to form a negative meaning about something by stating the positive and then negating it, for example ‘walking up the

hill – can't'. This structure is not aligned with the social model that guided the way the version 2 question was constructed. The social model moves away from saying what people can and cannot do, which presents a linguistic challenge for BSL.

In addition, the impairment question stem was shown separately to each impairment response category. This risks the purpose of the question (conveyed in the question stem) being forgotten when the participant is looking at the response category. This separation creates additional cognitive burden in a visual language (BSL) when presented in this format. If a deaf BSL signer was creating this part of the survey from scratch, they would not necessarily use this structure regardless of the content of the questions as it is not BSL-friendly.

4.8.2.4 Bilingual presentation of unfamiliar words

Fingerspelling is a way of presenting a written word as signed letters of the alphabet using the fingers. It is sometimes used as a means of highlighting a term or concept in English that has no direct equivalent or lacks a familiar, in-use term in BSL. For example, in the early days of the Covid-19 pandemic, the word C-O-V-I-D was fingerspelled until a specific sign emerged from the deaf BSL community. However, where a respondent asks for an English word to be spelt out by fingerspelling because they are unsure of the sign for that word, it does not mean that they will understand the concept that the word represents. Instead, it can result in further misunderstandings. The source questions (written in English) used terms such as 'Dexterity' that were accurately translated to BSL but were unfamiliar to some participants. The spelling-out of these terms did not necessarily improve understanding.

4.8.2.5 Impact of identities, and social, cultural, and language contexts

For deaf BSL signers, being deaf is often a linguistic and cultural identity, not an impairment. This was clearly seen in the example of the participant who expressed uncertainty about endorsing the 'Hearing' category because from their perspective they "[are] Deaf".

The term 'hearing' in general is also more commonly understood from a deaf perspective as an identity marker, not a description of a condition. Consequently, asking a deaf BSL signer a question with 'Hearing' as a response option can be confusing when seen through an identity lens. That was the case for most of the participants.

This cultural positioning impacted on how participants decided whether to select any of the other impairment categories listed. For example, one participant selected the 'Seeing' option in the social model-aligned version because if it were a dark room they would not be able to see lips and signing well enough to follow and engage in conversation. They did not respond to the question in terms of sightedness as an aspect of impairment, but rather obscured vision as a potential obstacle to

communication. Another participant selected the ‘Vision’ category in the harmonised standard because:

> “watching signing or the interpreter on the TV can be very tiring visually. It makes me feel distracted and unable to concentrate. It is not like hearing people who rely on their ears to listen; we have to watch visually. We also have to drive and rely on our eyes to stay safe, as we cannot hear. So our eyes become our responsibility. It is exhausting”.

Another example was the decision to select the ‘Learning new things’ response category. One participant reflected that deaf BSL signers might endorse this category because of the barriers to communication, lack of adaptations to people’s preferred ways of learning, lack of access in BSL, and the often-lower educational attainment of deaf BSL signers. This reflection was highlighted in the responses of another respondent, who selected the harmonised standard response category of ‘Learning or understanding or concentrating’:

> “…because I am not able to understand hearing people when they talk. When they speak, I do not understand and would need translation. There are a lot of barriers, especially in my life”.

In some cases, the effect of different identities, and social, cultural and language contexts among deaf BSL signers was that participants missed what was being implied, especially in the social model aligned version. Participants interpreted the options more concretely from a deaf point of view. For example, the category ‘Interacting with other people’ was designed to capture neurodivergent people. However, interacting with others is far more of a practical issue of communication and so more likely to be ticked for that reason. As one participant said about why they endorsed the category: “Yes, with hearing people”.

4.8.3 Findings - barriers questions

The 2 barriers questions included in the NatCen Panel test (work package 6) were cognitively tested in BSL: the first question asked about experience of barriers in different life domains; the second asked about the different types of barriers experienced. Both questions asked participants to consider the last 12 months when answering.

4.8.3.1 Experience of barriers in different life domains

All 4 participants were able to answer the question on barriers in different life domains. Three participants selected ‘yes’ to all 9 barriers listed. This overall picture of experiencing barriers across many life domains is very much in alignment with current research about deaf people in the UK and the range of social and health inequalities they experience.

Understanding of the question appeared to be mixed, with all participants reporting thinking about deafness when answering. One participant, whilst clearly unhappy with being asked the question, did understand that it was asking about their personal experience of barriers from a social model perspective. Another described it as asking about “what I’ve been going through in the last 12 months”.

As observed with the impairment questions, there was evidence that expressing the English question in BSL caused problems for some. The question stem was shown separately to each response option, creating additional cognitive burden in a visual language when presented in this format. For one participant, this impacted upon interpretation and selection of some of the early response categories listed.

> “That is a big problem. What is the question? It just asked me straightforwardly. Whoa… what is going on? What is the question about? The options did give some clarity, but I would prefer the question to explain, for example, “In the past 12 months, have you had any issues with communication, access, or society?” I would understand that better. The question was far too brief and had no context.”

> “I need more context. She signed the question without context, and it did not make sense to me. I would like it to be changed.”

No participants reported finding the question easy to answer, with views either being mixed or finding that it was difficult. Reasons for the difficulty related to lack of clarity and the confusing nature of it. These views were backed up by the request to repeat videos multiple times.

The requirement in the question stem to consider the last 12 months when answering, contributed to the difficulty for 3 participants. That said, it was clear that participants were correctly considering this reference period when selecting responses.

Participants were, on the whole, able to articulate their rationale for choosing options, and justifications matched the responses selected. There were a few specific issues related to the question about barriers experienced in different life domains.

- One participant talked about issues related to staff training when explaining why they chose the ‘Education and training’ response option. This should have come under the ‘Employment and job opportunities’ response.
- The only participant that did not select ‘Employment and job opportunities that did not support my needs’ was self-employed. It is unclear whether the participant did not think the response applied to them or whether they were aware that it applied to them but did not experience barriers in this domain.

- Many ‘Other’ responses recorded could have been backcoded into pre-defined categories. For example, “adult education” fell under ‘Education and training’ while “opportunities to volunteer, and participation in community clubs” could have been recorded under ‘Community and social activities’.

One participant objected to being asked the question in principle and questioned the value of the data collected.

> “… But the social model of disability still does not explain the individual. It focuses on problems as barriers, for example, healthcare not supporting my needs, appointments, communication breakdowns. The problem is because of that, but it still does not recognise me as a person with diversity, language, and culture. That part is missing.”

Others’ views on acceptability tended to be described in terms of improvements that needed to be made to the question.

> “…The first video needs to be changed…. I think if we change the first question to be clearer and provide context, I would understand the options more clearly from the start.”

> “I feel there should be more examples or more details. I think the main question should give the options briefly, and then we can expand these options with examples further.”

Another, more specific suggestion, was to use a less formal description for ‘Education and training’.

The only translation issue raised related to the sign for the word ‘training,’ with one participant being unfamiliar with it.

4.8.3.2 Experience of different types of barriers

All 4 participants were able to answer the question on the types of barriers they had experienced in the previous 12 months, with the number of responses selected ranging between 3 and 5. All participants reported experiencing communication, attitudinal, and institutional barriers.

Participants all appeared to understand that the question was asking about barriers experienced as a deaf BSL signer, even if their views on how easy it was to answer the question were mixed.

> “The words are good and I understand them. There are no difficult or posh words. The language is simple. I have dyslexia, so reading is hard for me, but I understood it straight away. If the text were too long, I would have difficulties. It is good enough and it is brief.”

One participant described the question as easy to answer, while everyone else reported it as difficult. As with version 1, the question stem caused confusion and was perceived as being both too brief and lacking clarity. This largely appeared to be due to the way the question was asked in BSL. Showing the question stem separately to each barrier type increases the cognitive burden in a visual language. For one participant, the confusion carried over into interpretation of the first few response options, before the intended purpose of the question became clear.

Another participant expressed uncertainty over whether they were meant to be thinking of their condition when answering.

> “It should add more context and be more descriptive. Is it linked to my condition? I feel it is very brief and does not really explain what it means.”

> “It is not clear…?”

As with the barriers question in different life domains, there were concerns over the requirement in the question stem to consider a 12-month period. However, this did not appear to impact on participants ability to interpret and answer the question.

Aside from the question stem, issues relating to the response options were also raised. One participant expected to see ‘language’ alongside ‘Information and communication’. Instead, they logged it under ‘Other’. This confusion potentially arose as it is typical in BSL to present language and communication together. This is to reflect basic linguistic rights and sufficiency and quality of communication.

> “Where is language? Language is missing.”

One participant felt that bright lighting and being difficult to see through windows should be mentioned in ‘Building and spaces’. This is a priority for people using a visual language. Another considered having to request for captions to be on when watching things in public.

Many ‘Other’ responses provided fell under existing pre-defined categories. For example:

- “training and resources available for Deaf people” falls under ‘Information and communication’, as does “language”
- “the lack of change in Disability students' allowance (DSA) over the years” falls under ‘Rules, policies, and practices’

As discussed above, the 12-month reference period was questioned by participants. It was coupled with a consensus that deaf BSL signers experience barriers beyond this period and frequently within it. While participants did not explicitly report finding the reference period unacceptable, there is scope to further investigate the restriction to 12 months. If there is a widespread view among deaf BSL signers that this did not

accurately reflect their experiences, this has the potential to influence views on acceptability and willingness to answer.

> "…not just in the last 12 months. The history of barriers is also missing. The 12-months timeframe is too short. The impacts go way beyond 12 months. This is not new; it is an old story that stretches much further back."

Recommended changes largely related to improving the question stem through additional context and making the link to conditions more pronounced:

> "The question should say, "We will show you the options. The options are this, this and this... Which of these have you experienced in the last 12 months?"

> "It should add more context and be more descriptive. Is it linked to my condition?"

4.8.3.3 Administration and translation issues

Participants provided some general and specific feedback relating to the signing and administration of the questions; for example, in the response option of 'Rules, policies, and practices', 'politics' was incorrectly signed instead of 'policies'. In addition, one participant disliked the balance the signer struck between achieving neutrality of expression and preserving the required grammatical components of facial expression. The signing was however correct for this context.

It is important to acknowledge that a deaf BSL signer may experience the listed barriers for reasons that are different to other people. Findings suggest there are specific interpretations of the meaning and implications of some barriers for deaf BSL signers that would not readily spring to mind for other people.

The narrative frequently related to the communication requirements of deaf BSL signers not being met. For example, one participant said:

> "Language is missing. Building and spaces: not suitable. But there is nothing about issues like bright lights. Light is mentioned, but windows too. For example, in office work or meetings, bright windows can be a problem, or if there is a door behind knocking, you cannot hear. These examples feel like they are missing. The window is difficult to see because of reflections. The same with booking train tickets, train conductors, etc. You cannot really see through the window. The examples only think of one-off things, like a ramp, but there are more. Buildings can have many more examples."

Another participant presented a different set of examples. Again, however they are defined, barriers are experienced because of their link with communication and language primarily, even those that might be seen as physical barriers:

> "Building and spaces: There are no signs, interpreters, or captions wherever I go. I would ask someone to put captions on if I am watching something in

public, so it is a barrier. Views and behaviour from others: Yes, they talk to me. I would tell them that I am Deaf. I could help them, but they would just give up and ask someone else because I am Deaf. So yes. Rules, policies and practices: One hundred percent. There is still not enough staff awareness and training. We need more awareness. There is also a problem with staff turnover, so we see new staff who do not know anything about Deaf people or Deaf awareness. For example, at my GP, they gave me an attitude for asking them to add a third chair for the interpreter. This needs to be improved. There needs to be more awareness of booking interpreters. They could book through an organisation, and some of them do not know that."

5. Alpha phase - Work package 6: quantitative field test

Findings from work package 6, the final alpha phase work package, are presented in this section. Work package 6 was a quantitative field test of revised versions of the survey questions that underwent cognitive testing. The survey questions were included in NatCen's random probability Panel (hereafter referred to as the Panel) to generate quantitative data on how the questions perform in a general population web-telephone survey. The specific aims of this work package are followed by a methods section outlining the main features of the Panel. Findings are presented in detail under 3 headings: understanding impairments, understanding barriers, and measuring prevalence of disabled people.

5.1 Aims

The agreed aims of work package 6 were to:

- collect adult prevalence estimates of disabled people, using the newly developed social model survey questions: the revised impairment question and each of the new questions on barriers
- compare the adult responses for the newly developed social model questions to data from current harmonised standards
- collect feedback from participants on the newly developed social model questions, in a general population context

Only adult versions of the survey questions were included in the Panel, in English and Welsh. Since it was not possible to participate in the Panel in either easy read or BSL, these versions of the survey questions were not included in the field test. While the Panel includes a substantial percentage of parents, it was agreed with the Welsh Government that testing of parent versions of the questions would not be pursued in work package 6, as it would be too burdensome to ask participants to answer both the adult and parent versions of the questions. Alternatively, asking them to answer only the parent versions of the questions would substantially reduce the sample of participants responding to the adult versions. This would greatly reduce analytical potential and the ability to draw meaningful conclusions from the data.

5.2 Methods

The quantitative field test was carried out in the November 2025 wave of the Panel. The main features of the Panel are described here, and further details are provided in Annex G.

5.2.1 Sampling

For this study, all 'active' panel members aged 16 and over recruited from the British Social Attitudes survey and the Consumer Detriment Study were eligible to be

invited. A random sub-sample of 4,383 were selected, maintaining the probability-based design. Selection probabilities were adjusted by sampling in proportion to weights, reflecting the extent to which panel members characteristics were over- or under-represented in the eligible panel. This aimed to enhance the representativeness of the issued sample as much as possible.

The November 2025 wave of the Panel included a boost of 750 panel members living in Wales. This resulted in a total of 896 panel members in Wales selected to take part. Results for those living in Wales were compared with those living elsewhere in Britain to check for any significant differences in how the questions were answered.

5.2.2 Fieldwork

Fieldwork followed a sequential mixed-mode design. Panel members were initially invited to participate in the research online. If there was no response within 2 weeks, they were contacted by NatCen's Telephone Unit, if phone numbers were available.

Fieldwork took place from 13 November to 14 December 2025. Most participants completed the survey within the first week. The one-month timeframe ensured that all individuals had the opportunity to participate, rather than only those who were immediately available.

A 57% response rate was achieved, and a total of 2,507 interviews were conducted. Of these, the vast majority were web interviews (2,361) and a small number of telephone interviews (146).

5.2.3 Survey content

Participants were able to select whether to complete the survey in Welsh or English. There were 10 participants who completed the survey in Welsh; 9 of these were living in Wales and one in England.

The module comprised of 2 'sets' of questions plus a participant debriefing question:

- set 1 - harmonised standards: comprised of the current GSS harmonised standards for long-lasting health conditions and illness and activity restriction, as well as the GSS impairment harmonised standard
- set 2 - social model: comprised of a revised version of the harmonised impairment standard, one question on barriers experienced in different life domains, and one question on types of barriers experienced

All participants were asked all questions in the module, according to the routing instructions. To control for any priming effects, the following separate randomisation exercises were built into study design:

- half the sample was asked ‘set 1 - harmonised standards’ followed by ‘set 2 - social model’, while the remaining half were asked the same 2 sets in the opposite order
- half the sample were presented or read out the list of response options with ‘Don’t know’ and ‘Prefer not to answer’ responses included; these responses were only visible or offered to participants in the remaining half if they tried to proceed past a question without answering
- the order in which response options appeared in the list was randomised in ‘set 2 – social model’ for the impairments question and the question on experience of barriers in different life domains

Unless otherwise stated, the figures presented and discussed here are based on the full combined sample.

5.2.4 Analysis

Descriptive and bi-variate analysis were carried out in SPSS, and all differences were tested for statistical significance. Figures are based on weighted data unless stated otherwise.

In line with standard practice on UK social surveys, all ‘Other’ write-in responses were reviewed and, where necessary, backcoded into the appropriate listed response option prior to analysis.

5.3 Findings

5.3.1 Understanding impairments

The Panel included 2 survey questions on impairments. The standard version of the current GSS impairment harmonised question was included, along with a revised social model aligned version of the question. An overview of the question design process for the development of the social model aligned version is provided in Section 3.2. Cognitive testing findings and subsequent refinements are provided in Sections 4.5 and 4.7.1.

In the descriptive and bivariate analysis conducted on both versions of the question, response patterns were systematically explored for any inconsistencies or biases. For the harmonised impairment standard, accuracy and consistency were further assessed through comparison with an external source (Family Resources Survey (FRS)). Rates of 'Other' responses and non-responses were also analysed to establish if there were potential issues with question design or participant engagement. Figures presented are based on data before backcoding, unless specified otherwise. Table descriptions indicate whether figures presented are based on weighted or unweighted data.

5.3.1.1 Measuring impairments using the GSS harmonised question

Participants who responded “yes” to the long-lasting health conditions and illness question were asked the GSS harmonised impairment question. In line with published guidance, ‘None of the above’ and ‘Prefer not to answer’ (‘Refusal’ in the GSS version) were not presented upfront. They could be selected by participants who tried to proceed past the question without answering, or by telephone participants who spontaneously mentioned either response to an interviewer.

Using the harmonised impairment question, around a third (35%) of participants reported having one or more impairment. The types of impairments reported are presented in Table 1. Results are presented for everyone who was asked the question (i.e., those with a long-lasting health condition or illness), and those who also met the Equality Act definition of disabled (participants with a long-lasting health condition or illness, and their activity was limited ‘a lot’ or ‘a little’).

Based on the harmonised impairment question, the most common impairment types were ‘Mobility’ (47%) and ‘Mental health’ (46%). ‘Stamina, breathing and fatigue’ (hereafter referred to as ‘Stamina’) was also commonly reported (38%). The ‘Other’ response option was selected by 9%. Non-response (‘Don’t know’ and ‘Prefer not to answer’, combined) for the harmonised impairment question was 0.5%.

Table 1: Proportion of impairment types using the GSS harmonised impairment question, for all participants and participants who met the Equality Act definition of disabled [note 1]

GSS harmonised impairment type	All participants (%) [note 2]	Disabled participants (Equality Act definition) (%)
Vision	8	9
Hearing	16	16
Mobility	39	47
Dexterity	21	25
Learning or understanding or concentrating	17	20
Memory	19	22
Mental health	43	46
Stamina or breathing or fatigue	35	38
Socially or behaviourally	18	21

GSS harmonised impairment type	All participants (%) [note 2]	Disabled participants (Equality Act definition) (%)
Other	10	9
None of these [Note 3]	7	2
Don’t know [Note 3]	0.3	0.3
Prefer not to answer [Note 3]	0.1	0.2
Weighted base (number)	**950**	**773**

Table description: The table shows that the proportion of disabled people (as defined by the Equality Act, 2010) reporting each of the 9 impairment types was higher than for all participants who were asked the harmonised impairment question.

[Note 1] This question was asked of all who said ‘yes’ to the long-lasting health conditions and illness harmonised standard.

[Note 2] ‘All participants’ refers to those who were asked the GSS harmonised impairment question, after answering “yes” to the long-lasting health conditions and illness question. Column totals sum to more than 100% because participants can report more than one impairment.

[Note 3] ‘None of these’, ‘Don’t know’ and ‘Prefer not to answer’ were all hidden response options.

An advantage of using the GSS harmonised impairment question is that it was possible to compare the Panel’s findings with already published data. Recent data from the 2023 to 2024 Family Resources Survey (FRS) were based on a different population sample and used different data collection methods, meaning direct comparisons should be interpreted with caution. That said, it is still reasonable to anticipate that the findings on impairment from both sources would be broadly similar. ‘Mobility’, ‘Mental health’ and ‘Stamina’ were the 3 most commonly reported impairments by disabled people on both the Panel and FRS, with similar proportions recorded (Table 2).

Table 2: Proportion of participants with each GSS harmonised impairment type, a comparison of NatCen Panel (2025) and the FRS (2023 to 2024) [note 1]

GSS harmonised impairment type	All disabled participants (Equality Act definition) NatCen Panel (%) [note 2, 3]	All disabled participants (Equality Act definition) FRS (%) [note 4]
Vision	9	13
Hearing	16	13
Mobility	47	48
Dexterity	25	25
Learning or understanding or concentrating	20	16
Memory	22	17
Mental health	46	48
Stamina or breathing or fatigue	38	36
Socially or behaviourally	21	15
Other	9	17
None	2	x
Don’t know	0.3	x
Prefer not to answer	0.2	x
Weighted base (number)	**950**	**9,686** [note 1]

Table description: The table shows that the proportion of disabled people (as defined by the Equality Act, 2010) reporting each of the 9 impairment types was similar among NatCen Panel and Family Resources Survey participants. Results for some response options are not included for Family Resources Survey participants.

[Note 1] Source: DWP, Family Resources Survey: financial year 2023 to 2024, disability table 4.5b. The FRS data are based on a sample size of 9,686. The source does not describe whether these are weighted or unweighted data.

[Note 2] Column totals sum to more than 100% because participants can report more than one impairment.

[Note 3] ‘None of these’, ‘Don’t know’ and ‘Prefer not to answer’ were all hidden response options.

[Note 4] ‘x’ denotes where data were not available.

5.3.1.2 A social model approach to measuring impairments

Unlike the standard version of the harmonised impairment question which is only used when a respondent has said “yes”, they have an existing medical condition, using the long-lasting health conditions and illness question, the social model impairment question was asked of all participants. They were asked in which of the areas listed they were affected by long-term conditions or impairments. The question stem advised participants to include any that may come and go or vary over time, and to select all options that applied. There was an explicit ‘None of the above’ option, while ‘Don’t know’ and ‘Prefer not to answer’ were listed or read out for a random half of the sample and hidden for the remaining half. For the latter half, these options could be selected if a participant tried to proceed past the question without answering or mentioned spontaneously to the telephone interviewer.

Over half (57%) of all participants had one or more impairment under the social model version of the question. In Table 3, the types of impairments reported are presented separately for all participants, and for those classified as disabled according to the social model definitions:

- social model 1 (SMD1): one or more impairments reported and have experienced barriers in one or more ‘domains of life’ options
- social model 2 (SMD2): one or more impairments reported and have experienced one or more of the ‘types of barriers’ options

For all participants, the most common impairment types using the social model question were: ‘Being in pain or discomfort’ (25%), ‘Mental health’ (22%), ‘Managing energy levels or breathing’ (20%), and ‘Remembering or focusing’ (20%). There were 43% who reported having none of the impairments listed, 2% reported an impairment in the ‘Other’ response option, and non-response (‘Don’t know’ and ‘Prefer not to answer’ combined) was low at 0.1%.

Published data using the standard version of the GSS harmonised impairment question tends to focus on disabled people, routed from the long-lasting health conditions and illness question. To allow for comparison, Table 3 presents figures for all participants and for those classified as disabled according to the social model definitions for SMD1 and SMD2.

Irrespective of the social model definition of disability used, the impairments reported were similar. The most frequently reported impairments were ‘Mental health’ (50% for SMD1, and 53% for SMD2) and ‘Being in pain or discomfort’ (49% for SMD1, and 52% for SMD2). The proportion of disabled participants reporting impairments relating to ‘Managing energy levels or breathing’ and ‘Remembering or focusing’ were also high. These impairment types were most frequently reported for all participants.

Table 3: Proportion of impairment types using the social model impairment question, for all participants and participants who met the 2 social model definitions of disabled

Impairment type	All participants (%) [note 1]	Disabled participants SMD1 definition (%) [note 2]	Disabled participants SMD2 definition (%) [note 2]
Seeing	9	15	16
Hearing	15	26	25
Moving around	15	32	32
Using hands or fingers	8	17	18
Learning new things	9	23	25
Remembering or focusing	20	44	47
Mental health	22	50	53
Managing energy levels or breathing	20	44	45
Interacting with other people	16	38	39
Being in pain or discomfort	25	49	52
Sensory processing	9	24	25
Having an over or under active immune system	10	23	22
Other	2	4	4

Impairment type	All participants (%) [note 1]	Disabled participants SMD1 definition (%) [note 2]	Disabled participants SMD2 definition (%) [note 2]
None of these	43	z	z
Don’t know [note 3]	0.0	z	z
Prefer not to answer [note 3]	0.1	z	z
Weighted base (number)	**2,507**	**686**	**706**

Table description: The table shows that the proportion of disabled people (social model aligned definitions) reporting each of the 12 impairment types was higher than for all participants.

[Note 1] Column totals sum to more than 100% because participants can report more than one impairment.

[Note 2] Some cells are ‘z’ because to be disabled ‘social model aligned’ required presence of an impairment.

[Note 3] 'Don't know' and 'Prefer not to answer' were visible along with other response options for a random half of the sample. These options were hidden for the remaining half.

5.3.1.3 Comparing different approaches to measuring impairment types

Analysis focused on exploring consistencies and differences between the harmonised impairment question and the social model version of the question. The distributions of responses were compared where possible, as well as ‘Other’ responses, and non-response - ‘Don’t know’ and ‘Prefer not to answer’ combined.

The first of several factors considered was the differing number of response options used in the 2 different versions of the question. The starting position was that some options can be broadly considered as functional equivalents and can be compared. An example of this was ‘Vision’ in the harmonised question and ‘Seeing’ in the social model equivalent. However, some options were not equivalent. Response options ‘Being in pain or discomfort’, ‘Sensory processing’, and ‘Having an over or under active immune system’ were all added to the social model version of the question. This was done to address some of the known limitations of the existing harmonised impairment standard, and limitations raised by participants during the discovery phase. Where there was not an assumed functional equivalent for a particular response category, this has been noted.

Another analytical consideration when comparing results was the handling of non-responses. There are different approaches to this when reporting survey findings, with different implications for results. In social surveys it is not uncommon to exclude ‘Don’t know’ and ‘Prefer not to answer’ responses when presenting results. However, since this was a methodological study with particular interest in understanding levels of item non-response and any implications this might have on data quality, there was a strong case for including these in analysis.

Comparing responses

Table 4 shows the results for both versions of the impairments question, for all participants when ‘Don’t know’ and ‘Prefer not to answer’ were included. The difference observed in impairment rates was particularly pronounced for the harmonised question option of ‘Memory’ (7%) compared to the social model aligned option of ‘Remembering or focusing’ (20%). A 9 percentage-point difference was observed for ‘Hearing’ (6% for the harmonised question and 15% using the social model question). In contrast, there were no differences between the harmonised standard option of ‘Mobility’ and the social model equivalent of ‘Moving around’, both with 15%. The harmonised standard option of ‘Dexterity’ and the social model equivalent of ‘Using hands or fingers’ were also the same, at 8%. The categories ‘Socially and behaviourally’ and ‘Interacting with other people’ are not equivalent and the observed 9 percentage-point difference should be treated with caution.

Table 4: Proportion of all participants reporting an impairment type, comparing the GSS harmonised impairment version and the social model version

Impairment type **(GSS harmonised description / social model description)**	**All participants, harmonised impairment question (%) [note 1]**	**All participants, social model impairment question (%)**
Vision / Seeing	3	9
Hearing	6	15
Mobility / Moving around	15	15
Dexterity / Using hands or fingers	8	8
Learning, understanding, concentrating / Learning new things	6	9
Memory / Remembering or focusing	7	20

Impairment type (GSS harmonised description / social model description)	All participants, harmonised impairment question (%) [note 1]	All participants, social model impairment question (%)
Mental health	16	22
Stamina, breathing, fatigue / Managing energy levels or breathing	13	20
Socially or behaviourally	7	z
Interacting with others	z	16
Being in pain or discomfort	z	25
Sensory processing	z	9
Having an over or under active immune system	z	10
Other	4	2
None of these [note 3]	3	43
Don’t know	0.1	0.0
Prefer not to answer	0.0	0.1
Weighted base (number)	**2,507**	**2,507**

Table description: The table shows that where there were equivalent impairment types, the proportion of all participants reporting these was similar or higher on the social model aligned version of the question than for harmonised standard version.

[Note 1] Column totals sum to more than 100% because participants can report more than one impairment. To present the ‘all participants’ figure, those who were not asked the question were classified as having no impairments.

[Note 2] ‘z’ means this option was not listed as a response option.

[Note 3] For the harmonised impairment question ‘None of these’, ‘Don’t know’ and ‘Prefer not to answer’ were all hidden response options. At the social model version, 'Don't know' and 'Prefer not to answer' were visible for a random half of the sample and unhidden for the remaining half.

As previously mentioned in relation to FRS findings, published outputs based on the harmonised impairment standard tend to base the findings on participants identified

as disabled, according to the Equality Act definition. As discussed in detail in Section 5.3.3, the Panel included questions which allowed 'disability' to be estimated in 3 different ways: one used the Equality Act definition and 2 were different social model aligned approaches. Table 5 presents impairment data for disabled people using these different approaches to defining disability.

The most frequently reported impairments for disabled people (Equality Act definition) were 'Mobility' (47%), 'Mental health' (46%), and 'Stamina, breathing or fatigue' (38%).The most frequently reported impairments for disabled people based on the social model-aligned definitions were 'Mental health' (50% for SMD1 and 53% for SMD2), 'Pain or discomfort' (49% for SMD1 and 52% for SMD2), 'Energy levels' (44% for SMD1 and 45% for SMD2), and 'Remembering or focusing' (44% for SMD1 and 47% for SMD2).

Generally, where a category is in both versions of the impairment question, the prevalence rates tended to be higher under the social model aligned definitions of disabled. This pattern was seen for 7 of the categories. In contrast, the harmonised standard prevalence rates were higher for 'Mobility' (47%) compared to 'Moving around' (32% for both SM1 and SMD2); and 'Dexterity' (25%) compared to 'Using hands or fingers' (17% for SMD1 and 18% for SMD2).

Table 5: Proportion of impairment types using different versions of the impairment question and different definitions of disabled [note 1]

Impairment type **(GSS harmonised description / social model aligned description)**	**Equality Act disabled (%)**	**Social model (SMD1) disabled (%) [note 2]**	**Social model (SMD2) disabled (%) [note 2]**
Vision / Seeing	9	15	16
Hearing	16	26	25
Mobility / Moving around	47	32	32
Dexterity / Using hands or fingers	25	17	18
Learning or understanding or concentrating / Learning new things	20	23	25
Memory / Remembering or focusing	22	44	47
Mental health	46	50	53

Impairment type (GSS harmonised description / social model aligned description)	Equality Act disabled (%)	Social model (SMD1) disabled (%) [note 2]	Social model (SMD2) disabled (%) [note 2]
Stamina or breathing or fatigue / Managing energy levels or breathing	38	44	45
Socially or behaviourally	21	z [note 3]	z
Interacting with other people	z	38	39
Being in pain or discomfort	z	49	52
Sensory processing	z	24	25
Having an over or under active immune system	z	23	22
Other	9	4	4
None of these [note 4]	2	z	z
Don’t know	0.3	z	z
Prefer not to answer	0.2	z	z
Weighted base (number)	**773**	**686**	**706**

Table description: The table shows that the proportion of disabled people (social model aligned definitions) that reported having an impairment type (social model aligned) was sometimes higher than the proportion of disabled participants (Equality Act definition) reporting equivalent GSS harmonised impairment types. For some impairment types the opposite was observed.

[Note 1] Figures presented in Equality Act disabled column use the GSS harmonised impairment types and the Equality Act definition of disabled. Figures presented in SMD1 and SMD2 are for social model aligned impairment types and use social model definitions of disabled.

[Note 2] Some cells are ‘z’ because to be disabled ‘social model aligned’ required presence of an impairment.

[Note 3] ‘z’ means this option was not listed as a response option.

[Note 4] For the harmonised impairment question ‘None of these’, ‘Don’t know’ and ‘Prefer not to answer’ were all hidden response options. For the social model version, 'Don't know' and 'Prefer not to answer' were visible for a random half of the sample and unhidden for the remaining half.

Comparing selection of the ‘Other’ response option

The proportion of participants selecting the ‘Other’ response can be used as an indicator of a question's effectiveness in capturing the range of possible responses. A lower proportion selecting ‘Other’ may suggest the list of available response options adequately captured all relevant answers. For the harmonised impairment version, 12% of participants reported having an ‘Other’ impairment. This percentage is based on those participants who met the Equality Act definition of ‘disability’. The social model question had substantially lower ‘Other’ responses, at 3% (Table 6). This suggests the response options for the social model version better captured the range of possible answers. Even after backcoding had been applied, the proportion of ‘Other’ responses was still substantially higher for the medical model version (11%) compared with the social model version (2%).

Table 6: Percentage of ‘Other’ responses in the GSS harmonised impairment version of the question and social model impairment question

	‘Other’ (harmonised impairment question) (%)	**‘Other’ (social model impairment question) (%)**
No backcoding	12	3
Backcoding applied	11	2
Unweighted base (number)	**1,027**	**2,507**

Table description: Table 6 shows the social model aligned question had substantially lower proportions of participants responding with ‘Other’, both before and after backcoding had taken place.

Around a third (36%) of the 78 participants who selected ‘Other’ for the harmonised impairment question provided an accompanying description. Responses that could not be backcoded were a mix of impairments and conditions. Some of these were aligned with an impairment category on the social model question (for example, “pain”, “general tiredness”, “auto-immune issues”) and some were not (such as, “type 2 diabetes”, “incontinence”, “bowel issues”).

For the social model version, 45 participants selected ‘Other’ and just over half (51%) provided an accompanying description. Of these, 16 were reassigned into another category. For example, where a participant recorded “anxiety” under ‘Other’, this was backcoded and reassigned to ‘Mental health’. Anxiety, breathing issues, and

fatigue were the most common impairments to be reassigned to a preexisting response category. Write-in responses that could not be reassigned included “bowel conditions”, “prostate issues”, “muscular problems”, “osteoarthritis”, “neuropathy”, and “lifting”. None of the ‘Other’ descriptions remaining after backcoding aligned to existing GSS harmonised impairment responses, either. Issues relating to the bowel and prostate appeared as ‘Other’ responses in both the GSS harmonised and social model versions of the impairment question.

Comparing non-response

Non-response rates are another indicator of potential issues with a question. A high proportion of people choosing not to answer a question can suggest issues such as clarity, burden, sensitivity, and relevance of the question. However, there is no recommended threshold to assess non-response rates against. Non-response rates to both versions of the impairment questions were low suggesting no major problems being able answer the question. For the harmonised impairment version, 0.4% of participants asked the question responded with ‘Don’t know’ or ‘Prefer not to answer’. For the social model aligned version of the question, the equivalent was 0.1%.

Understanding individual responses to different versions of the impairment questions

The analysis also examined consistencies in the answers provided by individual participants. Table 7 shows the proportion of participants who answered both questions consistently. Selection of the same category by the same participant indicated category equivalence. The categories of ‘Mental health’, ‘Hearing’, and ‘Mobility’ or ‘Moving around’ had the highest proportion of participants selecting these in both versions of the question. The categories with the lowest selection rates in both questions by the same participant were ‘Learning, understanding or concentrating’ and ‘Learning new things’, and ‘Vision’ and ‘Seeing’.

There are several factors to consider when interpreting these findings, not least that caution should be taken when interpreting differences between small samples. In addition, the 2 question versions measured impairment in different ways and it is therefore expected that participants may answer each question in a different way.

The wording of the question stem and response categories also differ, though some categories are more similarly worded than others, for example ‘Hearing’ and ‘Mental health’ were used in both versions. Similarly, the change in wording of the ‘Learning, understanding or concentrating’ to ‘Learning new things’ and ‘Memory’ to ‘Remembering or focusing’ may have resulted in differences in how participants answered each version.

Differences in the examples provided for each response category may also have influenced how participants answered the 2 questions. For instance, the GSS

harmonised impairment question used examples such as ‘blindness or partial sight’ for the ‘Vision’ category, while the social model version referred to ‘getting around unfamiliar places’ or ‘reading, even with glasses or contact lenses’. Some categories in the GSS harmonised impairment question such as ‘Learning or understanding or concentrating’, ‘Memory’, ‘Mental health’, and ‘Stamina or breathing or fatigue’, included no examples at all.

It is also worth noting that question order may have impacted participant responses. Although randomisation was used to minimise the effect of the first question influencing interpretation of subsequent questions, some measurement error may have remained.

Table 7: Comparison of participant responses to the GSS harmonised impairment version of the question and social model impairment question

Impairment type (GSS harmonised description / social model aligned description)	Only selected at harmonised impairment question (%)	Selected 'same' category at both questions (%) [note 1]	Only selected at social model question (%)	Unweighted base (number)
Vision / Seeing	20	37	43	162
Hearing	6	61	34	296
Mobility / Moving around	21	70	9	484
Dexterity / Using hands or fingers	35	40	24	297
Learning or understanding or concentrating / Learning new things	33	35	32	185
Memory / Remembering or focusing	12	46	43	347
Mental health	14	74	13	390
Stamina or breathing or fatigue / Managing energy levels or breathing	21	55	24	511

Table description: The table shows that some participants recorded an impairment at the ‘same’ response option on both versions of the question. Some recorded an impairment at the harmonised standard version but did not record this at the equivalent social model aligned version, and vice versa.

[Note 1] ‘Same’ means the functional equivalent.

5.3.2 Understanding barriers

Following the cognitive testing undertaken in work package 5, it was decided that 2 questions on barriers would be taken forward to the panel test, each measuring a different concept. The first was designed to capture data on the barriers experienced in different life domains, while the second intended to collect data on the different types of barriers that can be experienced.

The Welsh Government requested that all participants be given the opportunity to answer the questions on barriers, irrespective of whether they reported having an impairment or not. Neither question included the word ‘barriers’ in the question stem, instead participants were asked to state whether they personally had experienced any of the things listed in the previous 12 months. Both sat within the ‘social model set’ and were preceded by the social model version of the impairments question. Each had an ‘Other (write in)’ response and a ‘None of these’ option, while ‘Don’t know’ and ‘Prefer not to answer’ were listed or read out for a random half of the sample and hidden for the remaining half. For the latter half, these options could be selected if a participant tried to proceed past the question without answering or if mentioned spontaneously to the telephone interviewer. The order in which the 2 questions were asked was randomised to minimise question order effects.

5.3.2.1 Experience of barriers in different life domains

Distribution of responses

Exploring the distribution of responses to a survey question can help identify potential issues, understand the characteristics of the target population, and offer an insight into the variability and range of responses. Table 8 shows how often participants reported unmet needs (‘barriers’) across different areas of life, over the previous 12 months. Results are presented separately for all participants, and for those with one or more impairments, as recorded by the social model impairment question. The list of 9 life domains was randomised to mitigate against the primacy or recent effects that can occur with long lists.

For all participants, 62% had not experienced barriers in any of the listed life domains in the previous year. The equivalent figure for those with one or more impairments was 48%. Participants with one or more impairment consistently reported more experience of barriers in all life domains compared to other participants. The most commonly reported was barriers in ‘Health care’ (26%). The next most common life domains in which to experience barriers were: ‘Public spaces

and facilities' (18%), 'Transport and travel' (15%), and 'Financial services and benefits' (15%).

Table 8: Percentage reporting experience of barriers in different life domains for all participants and participants with one or more impairments (social model aligned)

Life domain	All participants (%) [note 1]	One or more impairment (social model aligned) (%)
Health care that does not support my needs	18	26
Employment and job opportunities that do not support my needs	9	12
Education and training that does not support my needs	5	7
Transport and travel that does not support my needs	10	15
Housing and independent living arrangements that do not support my needs	6	9
Community and social activities do not support my needs	5	8
Public spaces and facilities that do not support my needs	11	18
Financial services and benefits that do not support my needs	9	15
Voting and opportunities to get involved in politics that do not support my needs	3	5
Other	1	1
None of these	62	48
Don't know [note 2]	1.2	1.2
Prefer not to answer	1.6	2.3
Weighted base (number)	**2,507**	**1,418**

Table description: Overall, the table shows that participants with impairments have consistently experience more barriers than all participants in the last 12 months.

[Note 1] Column totals sum to more than 100% because participants can report more than one impairment.

[Note 2] ‘Don’t know’ and ‘Prefer not to answer’ were hidden response options for half the sample and unhidden for the remaining half.

One in 5 participants with an impairment (19%) experienced barriers in only one life domain in the past 12 months, while a similar proportion (20%) reported experiencing barriers in either 2 or 3 life domains (Table 9). The average number of life domains to experience barriers in was 1.2 for those with an impairment, compared to 0.8 for all participants.

Table 9: Number of life domains experienced barriers in for all participants and participants with one or more impairments (social model aligned)

Number of barriers	All participants (%)	Participants with one or more impairment (social model aligned) (%)
0 [note 1]	65	52
1	16	19
2 or 3	13	20
4 or more	6	9
Weighted base (number)	**2,507**	**1,418**

Table description: This table shows that participants with an impairment were more likely than all participants to have experienced one or more barrier types.

[Note 1] Participants who responded ‘Don’t know’ or ‘Prefer not to answer’ were assigned to the ‘0’ category in this analysis.

Experience of barriers in ‘Other’ life domains

In addition to the 9 life domains listed, participants were also able to select ‘Other’, with the option of describing this in their own words. Use of the ‘Other’ response option can provide evidence on whether all possible responses to a question are captured, and how effectively. A high proportion of ‘Other’ responses can suggest that a list does not adequately capture the range of possible answers. Reviewing the written descriptions can help verify this and highlight potential issues with interpretation of listed responses.

Just 1% of participants selected the ‘Other’ response for this question. Write-in responses were reviewed, with no evidence that any main domain of life was missing from the list. The 28 verbatim responses were varied, and around half (15) could be reassigned to one of the predefined categories. For example, “difficulty with a postal

vote needing a digital signature" was reassigned under option 9: 'Voting and opportunities to get involved in public life'. Other examples included "restriction in job opportunities due to limited ability to drive in dark" which was reassigned under response option 2: 'Employment and job opportunities'; and "increased cost of supported accommodation e.g. sheltered housing accommodation" which was reassigned to response option 5: 'Housing and independent living arrangements'.

Among responses that were unable to be reassigned to an existing category was "Lack of support from the Police", which was also raised during BSL cognitive testing. Generally, however, the 'Other' responses that could not be reassigned tended to fall under 3 groups:

- responses reflecting on general experiences of life rather than specific life domains for example, "public attitudes, more negative" and "rising costs"
- responses that were too specific and not framed in a way that was able to be captured by the question; for example, "Unable to see the tiny and various coloured nutritional info on food packets, which is essential to manage my T1 diabetes"
- responses detailing barriers experienced by someone else; for example, a family member

Non-response

Non-response for the full participating sample was relatively low, at 2.7% (Table 10). Since choosing not to answer can be indicative of potential issues with a question, further analysis of the non-responding group was explored. It is particularly important to understand this group since this question is used to produce social model aligned disability prevalence estimates.

Non-responders almost exclusively comprised of sample members presented with the 'Don't know' and 'Prefer not to answer' options upfront. This supports the theory that, when non-response options are readily available, participants may be more likely to choose them.[19] This could be either because they genuinely do not know the answer, or they prefer not to disclose their response.

[19] Krosnick, J. A., Holbrook, A. L., Brent, M.K., et al. (2002). The impact of "No Opinion" response options on data quality: non-attitude reduction or an invitation to satisfice? Public Opinion Quarterly. 66 (3); 371-403.

Table 10: Proportion of non-responses for barriers in areas of life, by approach to presentation - where the options were hidden or unhidden

Response option	Hidden option (%)	Unhidden option (%)	All (%)
Don't know	0.1	3.2	1.1
Prefer not to answer	0.1	2.2	1.6
Total non-response ('Don't know' and 'Prefer not to answer' combined)	0.2	5.4	2.7
Unweighted Base (number)	**1,262**	**1,245**	**2,507**

Table description: This table shows that non-response was lower when 'Don't know' and 'Prefer not to answer' were hidden and higher when they were visible alongside other responses.

The age profile of non-responders was similar to the profile of the full participating sample indicating that no particular age group was more likely to answer with 'Don't know' or 'Prefer not to answer'. The 'Prefer not to answer' group was disproportionately made up of those who reported no educational qualifications. Educational attainment can sometimes be considered as a useful proxy for comprehension, which in turn, can be related to non-response. Difficulty understanding a question can affect the likelihood to not respond.

The non-response group was also disproportionately made up of those who received the GSS harmonised impairment set of questions first, followed by the social model set. This is potentially an indication of fatigue, which may increase the likelihood of taking a cognitive short-cut by choosing not to answer. It could also be a product of the testing and being asked the same questions twice. However, this was not the case when the social model set was asked first.

Experience of barriers in different life domains by impairment type

Table 21 in Annex H highlights that barriers are experienced across all domains of life, irrespective of impairment. Across all impairment types, 'Health care' was the most common domain of life in which barriers were experienced. Other domains of life that were relatively common across all impairment types were: 'Public spaces and facilities', 'Financial services and benefits', and 'Transport and travel'. While barriers to 'Voting and opportunities to get involved in politics' were relatively low, 12% of those with an impairment related to 'Seeing' or 'Learning new things' reported experiencing barriers in this domain, as well as 11% of those with impairments related to 'Sensory processing'.

While those with a ‘Hearing’ impairment were most likely to report not experiencing barriers in any of the life domains listed (52%), they still experienced barriers in an average of 1.2 life domains. Experience of barriers was most common in ‘Health care’ (27%), ‘Transport and travel’ (17%), and ‘Public spaces and facilities’ (17%).

As discussed in Section 4.8, earlier BSL cognitive testing found that participant identity, as well as social, cultural, and language context, appeared to impact responses to the social model impairment question, and this should be considered alongside these findings. During cognitive testing, viewing deafness as a linguistic and cultural identity, and not an impairment, impacted upon how participants decided whether to tick any of the other impairment categories listed. It may also be the case that participants are reading and interpreting the barriers question through a similar lens, potentially thinking about barriers that impede communication.

5.3.2.2 Experience of different types of barriers

Distribution of responses

The frequency distribution for the second barriers question, which asked about the different types of barriers experienced in the last 12 months, is presented separately for all adults and those with an impairment, in Table 11. Each response option was aligned to one of the four categories of barrier commonly referred to under the social model as follows:

- attitudinal barriers: ‘Views and behaviour from others that are not supportive’
- institutional barriers: ‘Rules, policies, and practices that do not support my needs’
- communication barriers: ‘Information and communication that is not accessible’
- environmental barriers: ‘Buildings and spaces that are not suitable’

A ‘None of these’ option was included and an ‘Other’ (write in) option was also listed, enabling participants to describe any other barrier types they faced, in their own words. Since there were fewer response options to choose from, the list was not randomised. Participants could select multiple responses, if applicable.

Attitudinal barriers were the most common type reported, at 30% of those with an impairment (social model aligned) reporting having experienced unsupportive ‘Views and behaviour from others’ in the previous 12 months. Institutional barriers were the next most commonly experienced type of barrier (23%), followed by environmental barriers (19%). While communication barriers were least likely to be reported, they were still experienced by around 1 in 6 of those with an impairment (15%).

Table 11: Percentage reporting experience of different types of barriers for all participants and participants with one or more impairments (social model aligned)

Barrier type	All participants (%) [note 1]	Participants with one or more impairment (social model aligned) (%)
Information and communication that is not accessible	10	15
Buildings and spaces that are not suitable	13	19
Views and behaviour from others that are not supportive	20	30
Rules, policies, and practices that do not support my needs	16	23
Other (please give details)	2	2
None of these	63	47
Don’t know [note 2]	1.0	0.8
Prefer not to answer	2.0	2.6
Weighted base (number)	**2,507**	**1,418**

Table description: Overall, the table shows that participants with impairments consistently had more experience of different barrier types in the last 12 months than all participants.

[Note 1] Column totals sum to more than 100% because participants can report more than one impairment.

[Note 2] ‘Don’t know’ and ‘Prefer not to answer’ were hidden response options for half the sample and unhidden for the remaining half.

In the previous 12 months, 26% of those with an impairment experienced one type of barrier only, while 10% experienced 3 or 4 types of barriers, as shown in Table 12. The average number of barrier types experienced by those with an impairment was 0.9.

Table 12: Number of barrier types experienced for all participants and participants with one or more impairments (social model aligned)

Number of barriers	All participants (%)	Participants with one or more impairment (social model aligned) (%)
0	65	50
1	19	26
2	9	13
3	5	8
4	2	2
Weighted base (number)	**2,507**	**1,418**

Table description: The table shows the percentage of participants with an impairment experiencing one or more types of barriers was higher than the percentage for all participants.

'Other' types of barriers experienced

All participants had the opportunity to select 'Other' and give details of any additional types of barriers experienced, along with any of the 4 barrier types listed to choose from. This option was selected by 1.5% of all participants and 1.6% of those with an impairment. There was a higher number of write-in responses here (44) than for the question on barriers in different domains of life (28). Write-in responses were reviewed and, while there was no evidence to suggest an important type of barrier had been missed off the list, some themes were mentioned more than once.

Around half (26) of the written answers described barriers that could be reassigned to one of the predefined categories. For example, "rudeness and selfish behaviour" describes an attitudinal barrier that was reassigned under 'Views and behaviour from others that are not supportive'. Similarly, "No handrails at steps for those with mobility issues" is an environmental barrier that was reassigned under 'Buildings and spaces that are not suitable'.

The remaining responses after review and reassignment fell into 3 groups:

- responses framing experiences in terms of the areas of life they experienced barriers in, with it being unclear what the barrier types were
- responses providing a level of detail that the question was not designed to capture

- responses describing the experiences of someone else and not themselves personally

Non-response

At 2.6% for all participants and 3.4% among those with an impairment (social model aligned), non-response was higher for this question than for the alternative question on barriers in different domains of life (Table 13). ‘Prefer not to answer’ was the higher of the 2 non-response groups, with 2.6% of those with an impairment selecting this.

As with the life domains barriers question, the non-response group almost exclusively comprised of those presented with both options upfront, alongside all other responses. This suggests that the way these options are presented has a substantial impact upon the level of non-response. When non-response options are readily available, respondents may be more likely to choose them, either because they genuinely do not know the answer, or prefer not to disclose their response. Conversely, when these options are not presented upfront, participants may have felt more compelled to provide a valid answer, perhaps due to a perceived expectation to do so.

Table 13: Proportion of non-responses for types of barriers, by approach to presentation - where the options were hidden or unhidden

Response option	Hidden option (%)	Unhidden option (%)	All (%)
Don’t know	0.3	3.0	1.6
Prefer not to answer	w [note 1]	1.9	1.0
Total non-response (‘Don’t know’ and ‘Prefer not to answer’ combined)	0.3	4.9	2.6
Unweighted base (number)	**1,262**	**1,245**	**2,507**

Table description: This table shows that non-response was lower when ‘Don’t know’ and ‘Prefer not to answer’ were hidden and higher when they were visible alongside other responses.

[Note 1] ‘w’ denotes where no responses were recorded.

The age profile of the non-responding sample was similar to the profile of the full sample, while the proportion of non-responders with no educational qualifications was slightly higher than the equivalent in the full participating sample. The non-

response group was also made up of slightly more participants who received the GSS harmonised impairment set of questions first as opposed to second.

There was also a small difference according to the order the barriers questions were administered, with a higher proportion having received the question on experience of barriers in different life domains first. The question on barriers in life domains is much longer, and this finding could be evidence of fatigue or reduced attentiveness, potentially impacting the quality and accuracy of subsequent responses in some cases.

Types of barriers experienced by impairment type

Table 23 in Annex H highlights that while frequency varied, respondents in all impairment groups had experienced each of the barrier types listed over the last year. Across all impairment types, attitudinal barriers were most common, ranging from ‘Hearing’ at 27% to ‘Sensory processing’ at 61%. Similarly, communication barriers were least likely to have been experienced across all impairment types, ranging from 18% for ‘Hearing’ and ‘Being in pain or discomfort’, to 32% for ‘Learning new things’.

As observed with the life domain barriers question, experience of all barrier types was lowest among those with an impairment related to ‘Hearing’. The BSL cognitive testing indicated that identities, and social, cultural, and language contexts appeared to impact upon responses to the social model impairment question, which should be considered alongside these findings from the Panel. It is possible that this context, through which the questions are interpreted, impacted their responses for both questions on barriers.

5.3.2.3 Experience of barriers in different life domains by types of barriers experienced

The 2 different questions on barriers were designed to capture different dimensions. One explored the different domains of life in which people experience barriers and the other explored the different types of barriers that can be experienced in a broader sense. Results for both were cross tabulated to explore individual patterns of response.

Table 14 shows that around a quarter of participants (626 people) reported both experiencing barriers in one or more domains of life and experiencing one or more types of barriers over the last 12 months. There was a sizeable group who reported experiencing a barrier in one or more domains of life but did not report experiencing any particular type of barrier (244 participants). A similar sized group (241 participants) reported experiencing one or more types of barriers in the previous year but did not report experiencing barriers in any particular domain of life.

Table 14: Patterns in individual responses to both barriers' questions

Barriers question	Number of participants
Experienced barriers on both questions on barriers	626
Experienced barriers in life domains but did not experience any barrier type	244
Experienced barrier types but did not experience barriers in life domains	241

Table description: This table shows that some participants reported experiencing barriers on both survey questions about barriers, while others experienced barriers on one survey question but not the other.

A possible explanation for these response patterns is that the questions successfully captured different dimensions of barriers, and therefore participants' answers would not be expected to align perfectly. However, it is also possible that one or both questions did not effectively measure the intended constructs. Feedback from cognitive testing that they were cognitively demanding, particularly the life-domains question, lend support to this explanation.

5.3.3 Understanding the prevalence of disabled people

The survey questions asked in the Panel allowed 3 distinct prevalence estimates of disabled people to be produced. One estimate used current GSS harmonised standards questions and aligned with the Equality Act (2010) definition of disability. The remaining 2 estimates both aligned with the social model of disability. These estimates were produced using the social model question on impairments and either the question on barriers in domains of life or the question on different types of barriers experienced. Each participant was asked all questions, and the order of question sets randomised to assess any potential order effects.

Since there was no objective measure of whether a participant was disabled, analysis focused on exploring consistencies and differences in responses, and the non-response rates across the different approaches to measuring the prevalence of disabled participants.

5.3.3.1 Harmonised standard approach to measuring prevalence of disabled people

To measure 'disability' using the Equality Act (2010) definition, the current GSS harmonised standards on long-lasting health conditions and illness (LLHCI) and activity restriction were included in the Panel. Question wording and response options matched current wording exactly.

A participant was classified as ‘disabled (Equality Act aligned)’ if they responded ‘yes’ to the long-lasting health conditions and illness standard and either ‘yes, a little’ or ‘yes, a lot’ to the activity restriction question. According to this definition, 30.8% of the 2,507 participants were disabled, with 69% classified as ‘not disabled’. Non-response, defined in this analysis as answering ‘Don’t know’ or ‘Prefer not to answer’ to the requisite questions, was 0.1%.

As this estimate of 30.8% was based on responses to the harmonised questions, it was possible to externally validate it by comparing it with published estimates. Wide use of the harmonised standards meant multiple sources were available for comparison including Census 2021, the Family Resources Survey (FRS) and the Annual Population Survey (APS). Comparisons of estimates collected from different, or the same, populations in different ways should always be interpreted with caution, even when the questions used are identical.[20] That said, it was reasonable to anticipate that the Panel, based on random probability design, should produce broadly similar estimates to those published using the same standards.

The prevalence of disabled people, based on the Equality Act definition, was highest on the Panel, as show in Table 15. There are several potentially coinciding explanations as to why this might have been the case. Aside from methodological differences that may explain different estimates from different sources, these are the only data collected using a panel design. In addition, the Panel advance letter specifically mentioned that the survey would include “questions on disability”, potentially resulting in higher levels of motivation to take part among disabled people. It may also be that this higher prevalence was to be expected, given that published data points toward a trend of the number of disabled people increasing over time; a trend that is projected to continue.[21]

Table 15: Prevalence of disabled people (Equality Act definition) by data source [note 1]

Data source	Disabled people (%)
Census 2021 (England and Wales)	17.8
FRS 2023 to 2024 (UK)	25 .0
APS July 2024 to June 2025 (UK)	28.4

[20] Some published data on disability is age-standardised, while others is not and this should be considered when comparing data from across different sources. This is statistical method used to allow for fairer comparisons between populations that may have different age distributions.
[21] The employment of disabled people 2024 - GOV.UK; Watt, T., Raymond, A., Rachet-Jacquet, L., et al. (2023). Health in 2040: projected patterns of illness in England. The Health Foundation. https://doi.org/10.37829/HF-2023-RC03

Data source	Disabled people (%)
NatCen Panel 2025 (UK) [note 2]	30.6

Table description: This table shows that the percentage of disabled people is highest on the NatCen Panel. Over time, across these data sources the percentage of disabled people has increased.

[Note 1] Sources are as follows: Census 2021; FRS 2023-2024 (UK); APS 2024-2025.

[Note 2] The Panel figure presented here differs to those presented in Table 17. The figure here is based on those who provided valid responses at the requisite questions, with those responding ‘Don’t know’ or ‘Prefer not to answer’ excluded from analysis.

Further validation of the Panel’s Equality Act aligned estimate was possible by triangulating the observed patterns across population groups with published data. Published data on disabled people highlights that prevalence varies across society. It follows, that while estimates and patterns can vary depending on context and source of information, the patterns in prevalence observed in published data should have, to a greater or lesser extent, also been observed in the Panel data.

Wales versus elsewhere in the UK: 40% of participants in Wales were classified as disabled (Equality Act aligned), 10 percentage points higher than elsewhere in the UK (30%). This distinction, of higher prevalence in Wales, was in line with published data. The equivalent figures on the Census 2021 for England and Wales were 21.1% and 17.7%, respectively. More recently, APS data estimated 32.0% of the population in Wales met the Equality Act definition of disabled, compared with 28.2% of those living elsewhere in the UK.

Figure 1: Prevalence of the sex and age of disabled people based on the Equality Act definition [note 1]

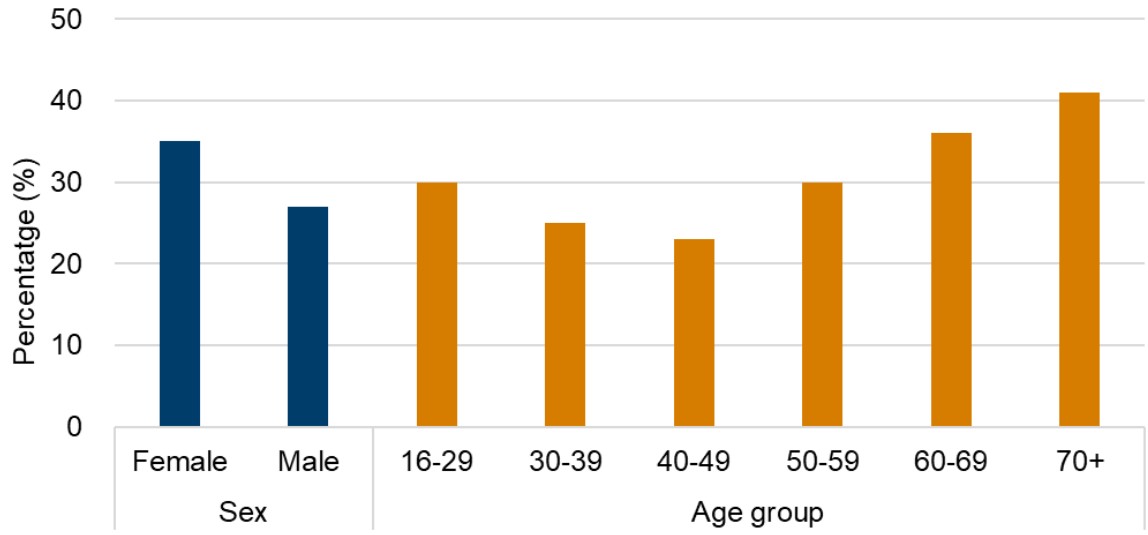

Figure description: More females than males were identified as disabled and participants aged 70 and over were more likely to be disabled, according to the Equality Act definition.

[Note 1] Unweighted bases: Female = 1,280; Male = 1,221. Age: 16 to 29 = 150; 30 to 39 = 334; 40 to 49 = 441; 50 to 59 = 483; 60 to 69 = 479; 70 and above = 647.

Sex and age: In Wales, and elsewhere in the UK, published data by the Office for National Statistics (ONS) indicates a higher proportion of disabled people are female, and that prevalence broadly increases in line with age. Figure 1 shows these patterns were also observed in the Panel data, with 35% of females and 27% of males classified as disabled (Equality Act aligned). While less pronounced on the Panel, there was a pattern by age group with the prevalence of disabled people highest in the oldest age group (41%).

Figure 2: Prevalence of disabled people (Equality Act definition) and monthly income [note 1] [note 2]

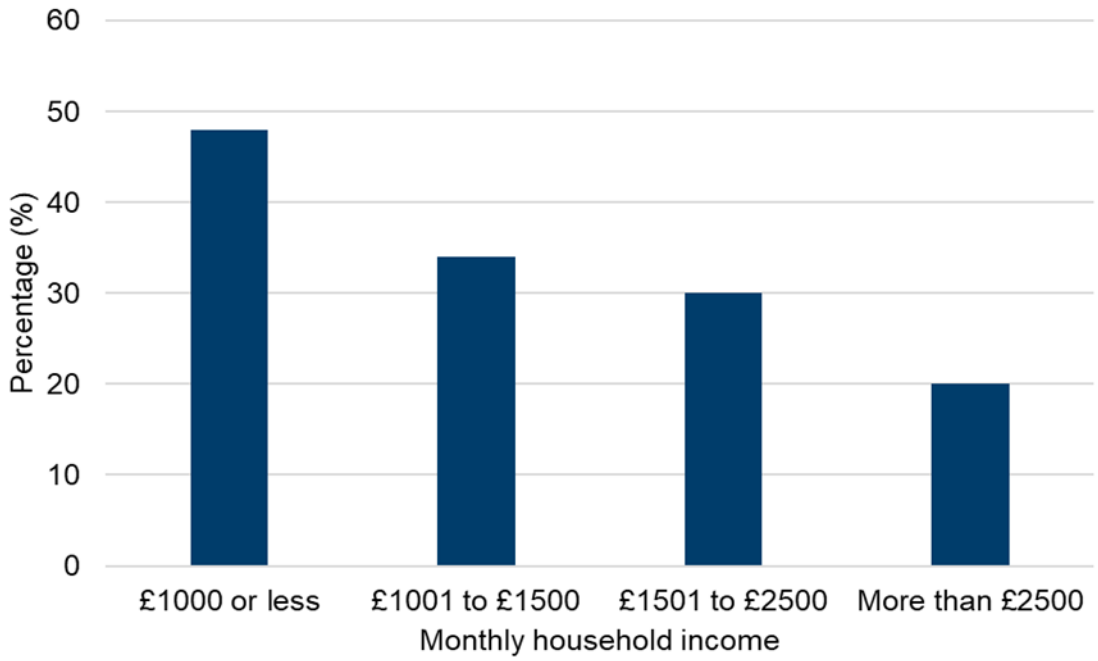

Figure description: Generally, the prevalence of disabled people as defined by the Equality Act reduced as monthly household income increased.

[Note 1] Monthly household income is latest equivalised monthly household income (2025).

[Note 2] Unweighted bases: £1000 or less = 382; £1001 to £1500 = 403; £1501 to 2500 = 746; More than £2500 = 860.

Income and educational classification: In line with published pay gaps data from ONS, the prevalence of disabled people was associated with household income (equivalised). Figure 2 shows that in the lowest household income group, 48% of participants were classified as disabled (Equality Act definition), decreasing to 20% for those with the highest household incomes, a statistically significant difference of 28 percentage points. Prevalence was lowest among those educated to at least degree level or equivalent (25%), and highest among participants reporting no educational qualifications (43%) (Figure 3).These findings also aligned with published equalities data.

Figure 3: Prevalence of disabled people (Equality Act definition) and highest level of formal qualification [note 1] [note 2]

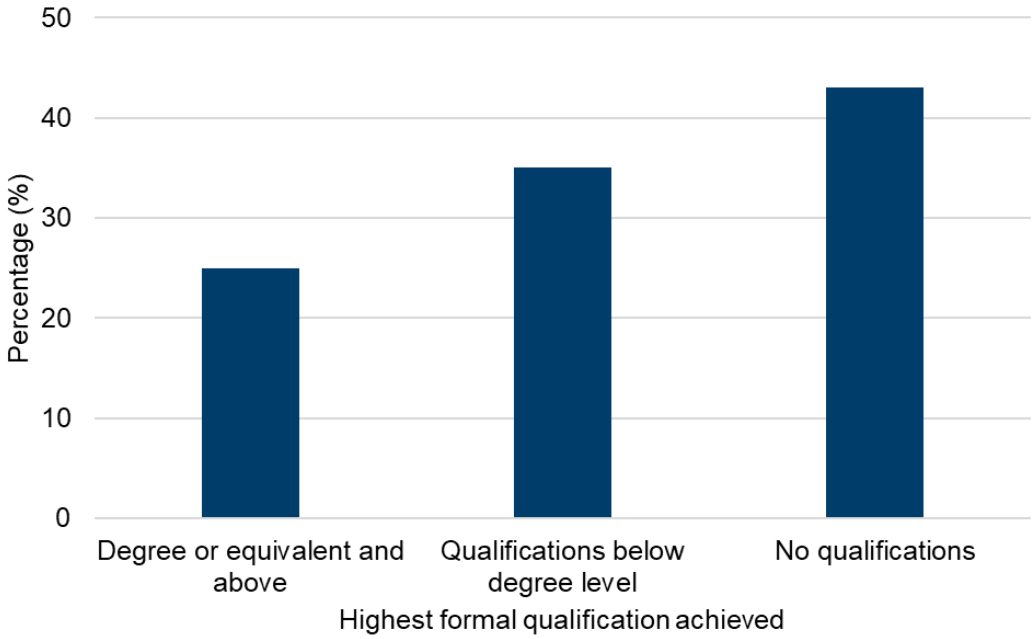

Figure description: The prevalence of disabled people tends to decrease with higher levels of formal qualifications.

[Note 1] Educational attainment is latest highest formal qualification achieved. Degree level or above includes qualifications equivalent to degree level.

[Note 2] Unweighted bases: Degree or equivalent or above = 1,190; Qualifications below degree level = 1,082; No qualifications = 225.

5.3.3.2 A social model of disability approach to measuring prevalence of disabled people

The review of existing survey questions, conducted as part of work package 2 during the discovery phase, highlighted that few attempts had been made internationally to measure the prevalence of disabled people in a way that is aligned with the social model. Where a more social model-aligned approach had been undertaken, questions tended to ask participants specifically about the domains of life they experience barriers in; or ask about a mix of life domains and types of barriers within a given question. Section 3.3 discussed the Welsh Government's desire to design and test 2 different ways of collecting data on the barriers experienced by people with a long-term condition or impairment. Measuring both dimensions of barriers, along with a revised social model aligned version of the harmonised standard on impairments, meant it was possible to produce and explore 2 separate social model aligned prevalence estimates for disabled people.

For the first of these estimates, referred to hereafter as social model 1 (SMD1), a participant was classified as disabled if they reported having one or more impairments, using the social model impairment question; and reported experiencing a barrier in one or more ‘domains of life’ options.

According to this definition, 27.4% of participants were disabled, 69.8% were not. There were 1.6% who responded ‘Don’t know’ to one or both of the questions, and 1.2% preferred not to answer one or both questions, as shown in Table 16.

For the second estimate, referred to hereafter as social model 2 (SMD2), a participant was classified as disabled if they reported having one or more impairments, using the social model impairment question, and reported experiencing one or more barriers under the ‘types of barriers’ question.

According to this approach, 28.2% of participants were classified as disabled and 68.8% were not disabled. A further 2.0% responded ‘Don’t know’ to one or both questions, and 1.0% chose not to answer one or both questions.

Table 16: Prevalence of disabled people using the 2 different social model aligned approaches

	Social model (SMD1) disabled (%)	**Social model (SMD2) disabled (%)**
Disabled	27.4	28.2
Not disabled	69.8	68.8
Don’t know [note 1]	1.6	2.0
Prefer not to answer	1.2	1.0
Weighted base (number)	**2,507**	**2,507**

Table description: This table shows a broadly similar proportion of participants classified as disabled for both of the social model-based approaches, 27.4% for SMD1 and 28.2% for SMD2.

[Note 1] ‘Don’t know’ and ‘Prefer not to answer’ were hidden response options for half the sample and unhidden for the remaining half.

Analysis of patterns in prevalence of disabled people using the Equality Act approach confirmed what was already known in previously published data. Nothing was known about the expected patterns when a social model aligned approach is employed.

Wales versus elsewhere in the UK: On the first social model aligned estimate (SMD1), 32% of participants in Wales were classified as disabled, compared with 28% elsewhere in the UK. This difference of 4 percentage points is smaller than the

difference of 10 percentage points observed when using the Equality Act approach. There was a very small difference between Wales and elsewhere in the UK on the second of the 2 approaches (SMD2), with 30% and 29%, respectively.

Figure 4: Prevalence of disabled people by sex, using for the 2 social model measures [note 1]

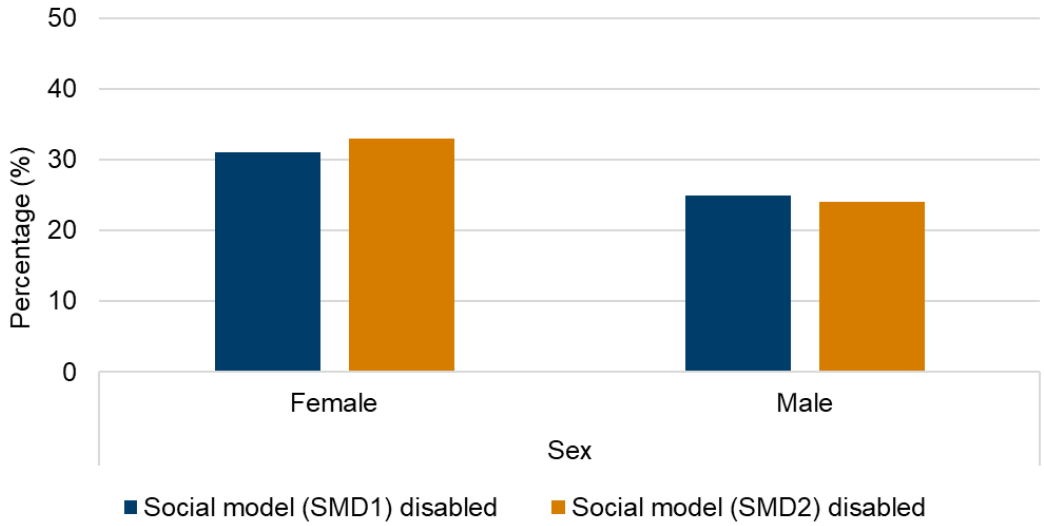

Figure description: Prevalence of disabled people was higher amongst females for both social model definitions.

[Note 1] Unweighted bases: SMD1 Female = 1,246; SMD1 Male = 1188. SMD2 Female = 1,242; SMD2 Male = 1,196.

Sex: On both social model estimates, and in line with the Equality Act estimate and published data, the prevalence of disabled people was highest among females. For SMD1, 31% of females were classified as disabled, compared to 25% of males. For SMD2, 33% of females and 24% of males were classified as disabled (Figure 4). The magnitude of the difference between female and male prevalence was similar across all approaches.

Figure 5: Prevalence of disabled people using for the 2 social model measures, in different age groups [note 1]

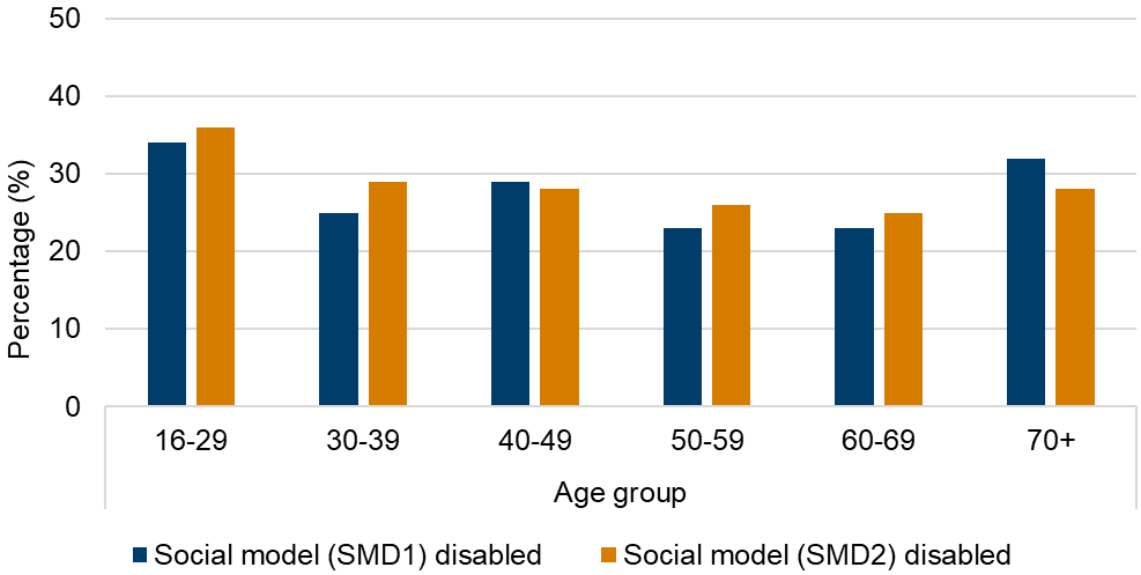

Figure description: The pattern of disabled people for both social model definitions was varied. For most age ranges, apart from aged 40 to 49, and aged 70 and over, SMD1 had a higher prevalence of disabled people.

[Note 1] Unweighted bases: SMD1 Age 16 to 29 = 149; 30 to 39 = 319; 40 to 49 = 399; 50 to 59 = 468; 60 to 69 = 469; 70 and above = 633. SMD2 Age 16 to 29 = 146; 30 to 39 = 321; 40 to 49 = 399; 50 to 59 = 470; 60 to 69 = 468; 70 and above = 637.

Age: The nature of the pattern in the prevalence of disabled people across age groups differed across both social model-aligned measures, as shown in Figure 5. For SMD1, prevalence was highest among the youngest and oldest age groups (34% and 32%, respectively). For SMD2 it was the youngest age group (those aged 16 to 29) that had the highest percentage of participants classified as disabled, at 36%. This was followed by those aged 30 to 39, with 29% classified as disabled.

Figure 6: Prevalence of disabled people using for the 2 social model measures, in monthly income levels [note 1] [note 2]

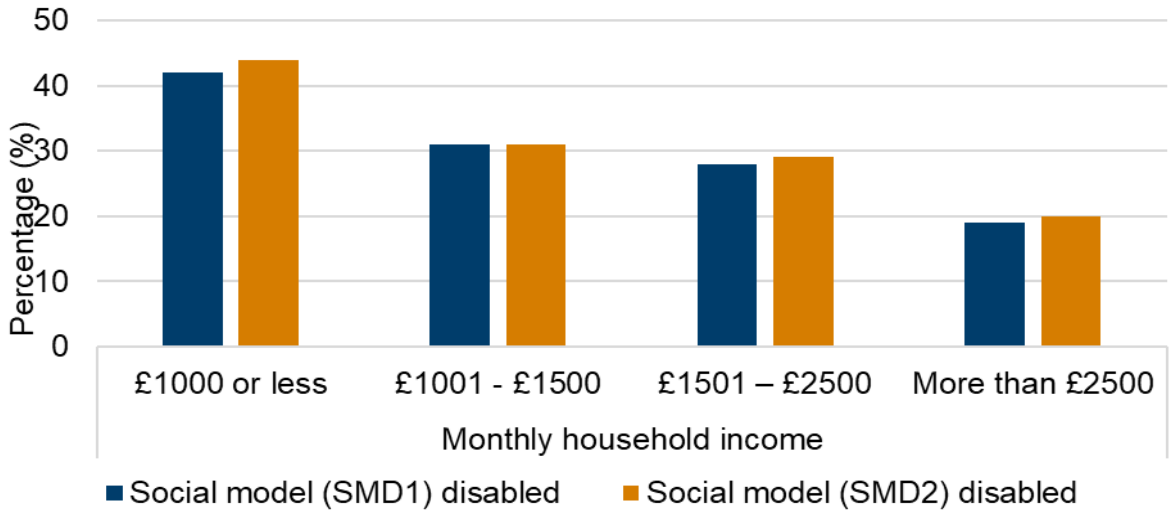

Figure description: The proportion of disabled people using both social model definitions reduced as monthly household income increased.

[Note 1] Monthly household income is latest equivalised monthly household income (2025).

[Note 2] Unweighted bases: SMD1 £1000 or less = 356; £1001 to £1500 = 390; £1501 to £2500 = 736; More than £2501 = 847. SMD2 £1000 or less = 362; £1001 to £1500 = 391; £1501 to £2500 = 736; More than £2500 = 847.

Income: The association with household income was similar for both social model-aligned estimates. Figure 6 shows the prevalence of disabled people decreased as equivalised household income increased. For example, 20% of those in the highest household income group were disabled (SMD2), increasing to 44% among those with the lowest household incomes. Additionally, the difference in the percentage of disabled individuals between the lowest and highest income groups was similar across both social model-aligned estimates. This pattern with income was in line with the patterns observed using the harmonised standard aligned approach.

Educational attainment: As observed with the Equality Act based estimates, the prevalence of disabled people was related to educational attainment. For SMD1, the prevalence of disabled people was highest among those with no qualifications, at 38%. However, in SMD2, 26% of participants with no qualifications were classified as disabled, compared to 32% of those with a highest qualification below degree level (Figure 7).

Figure 7: Prevalence of disabled people using for the 2 social model measures, in highest level of formal qualification [note 1] [note 2]

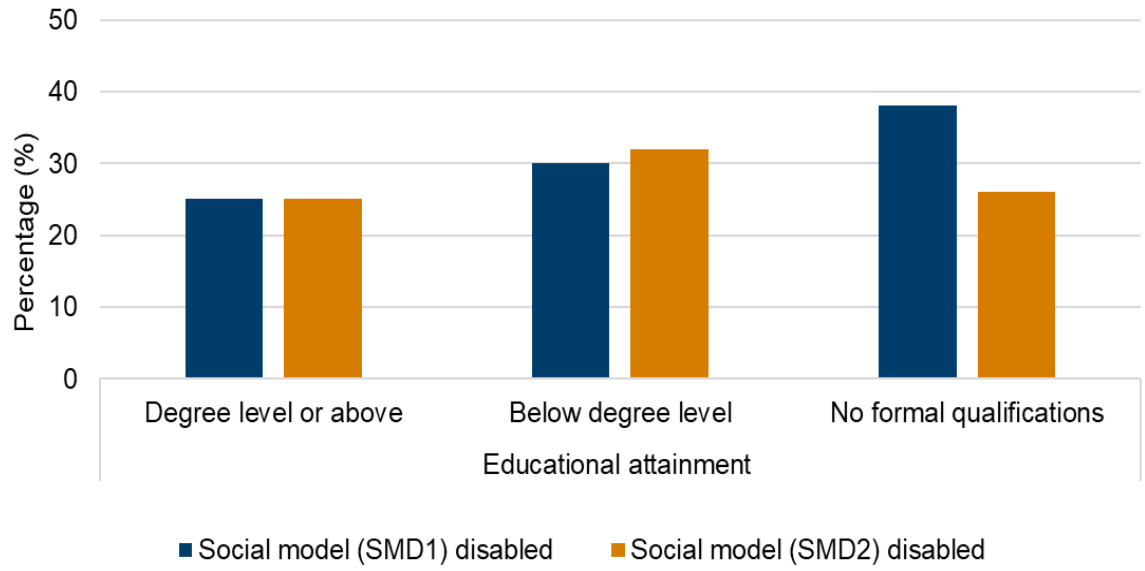

Figure description: For SMD1, the proportion of disabled people decreased with higher formal qualifications. SMD2 mostly followed this pattern, except for participants with no formal qualifications.

[Note 1] Educational attainment is latest highest formal qualification achieved. Degree level or above includes qualifications equivalent to degree level.

[Note 2] Unweighted bases: SMD1 Degree or equivalent or above = 1,175; Qualifications below degree level = 1,057; No qualifications = 199. SMD2 Degree or equivalent or above = 1,172; Qualifications below degree level = 1,053; No qualifications = 210.

5.3.3.3 Comparing prevalence estimates of disabled people

Comparison between the Equality Act definition and social model approaches focused on understanding the similarities and differences of the 3 approaches. Analytical considerations when interpreting findings include the handling of non-response and whether analysis used a restricted sample of participants. There are also different approaches to handling non-response in analysis and reporting of social survey data.

Two sets of estimates were produced to help understand the impact of non-response on estimates, here defined as responding ‘Don’t know’ or ‘Prefer not to answer’ to a question. The estimates presented in Table 17 are based on all participants, including those who responded with ‘Don’t know’ or ‘Prefer not to answer’, while both these categories were excluded from the estimates presented in Table 19.

Confidence intervals, the range within which the ‘true’ value of an estimate for the population is likely to fall, are described as follows:[22]

- confidence intervals around the prevalence of disabled people using the Equality Act estimate (30.8%) and SMD1 estimate (27.4%) overlap at the 99% confidence level, which means they were not significantly different; however, they were significantly different at a 95% level
- for the Equality Act estimate and SMD2, confidence intervals overlap at both 99% and 95% confidence, meaning the difference was not statistically significant in either case
- confidence intervals for SMD1 and SMD2 had large overlaps at both 95% and 99%, meaning there was no significant difference at either level, between the 2 social model aligned approaches to measuring the prevalence of disabled people

Table 17: Prevalence of disabled people (including ‘Don’t know’ and ‘Prefer not to answer’), based on the Equality Act and social model definitions

	Equality Act definition (%)	Social model definition - SMD1 (%)	Social model definition - SMD2 (%)
Disabled	30.8	27.4	28.2
Not disabled	69	69.8	68.8
Don’t know [note 1]	0.0	1.6	2.0
Prefer not to answer	0.1	1.2	1.0
Weighted base (number)	**2,507**	**2,507**	**2,507**

Table description: This table shows that ‘disability’ is broadly similar across the different ways of estimating it. Non-response is higher on the social model aligned approaches.

[22] For a 95% confidence interval, there is a 5% chance that the estimate does not contain the true value for the estimate. For a 99% confidence interval, there is a 1% chance that the estimate does not contain the true value of the estimate. The wider the confidence interval, the less precise an estimate is, and higher confidence levels produce wider intervals around the same estimate, meaning the 99% interval would be used when greater certainty is required. If the confidence intervals of estimates overlap, then it can be assumed that there is no statistically significant difference between them. If they do not overlap, then there is likely to be a statistically significant difference.

[Note 1] For the Equality Act definition questions, ‘Don’t know’ and ‘Prefer not to answer’ were hidden. For the social model definitions questions, these were hidden for half the sample and unhidden for the remaining half.

Further statistical testing was carried out to account for the fact that measures are related and that they were collected from the same responding sample. However, these tests excluded participants who responded ‘Don’t know’ or ‘Prefer not to answer’ on both measures being tested.

Using pairwise McNemar’s tests, the findings were similar to the confidence intervals. There were no significant differences found between the SMD2 estimate and the SMD1 or Equality Act estimates at the 5% or 1% significance levels. There were significant differences found between SMD1 and the Equality Act estimates at 5% significance but not 1%. An unweighted Cochran’s Q test was also carried out and identified significant differences between all 3 measures. These differences will mostly be due to differences in the definition of ‘disability’ used by the 2 measures.

A useful indicator of whether there are potential issues with a question is the proportion of non-responses it has. A high proportion of people choosing not to answer a question can suggest issues with a question, such as clarity, burden, sensitivity, and relevance of the question. However, there is no recommended threshold against which to assess non-response rates.

Directly comparing non-response rates between the Equality Act based approach and social model approaches is complex. 'Don't know' and 'Prefer not to answer' were hidden response options in the questions used to generate the Equality Act estimates. In the social model estimates, half of the sample was randomly assigned to have 'Don't know' and 'Prefer not to answer' options upfront and alongside the rest of the response options. These options were hidden for the other half of participants and only became available if they attempted to proceed to the next question without answering.

For this reason, the Equality Act non-response estimate of 0.1% is best compared with the social model non-response rate for the half of the sample that had hidden ‘Don’t know’ and ‘Prefer not to answer’ options. Based on this approach, non-response rates were similar for the medical model (0.1%) and SMD1 (0.2%) approach, as shown in Table 18. SMD2 had a higher non-response rate of 0.9%. These SMD2 non-response rates were mostly driven by ‘Prefer not to answer’ responses to questions on experience of barrier types rather than the impairment question. The figures in Table 18 show that where the response options of ‘Prefer not to answer’ and ‘Don’t know’ were not hidden, non-response rates were substantially higher. Having these response options available (i.e., unhidden) resulted in an overall higher level of non-response rates for the social model aligned prevalence estimates.

Table 18: Non-response rates, by approach to presenting 'Don't know' and 'Prefer not to answer' responses

Response option	Equality Act: Hidden (%)	SMD1: Hidden (%)	SMD1: Unhidden (%)	SMD2: Hidden (%)	SMD2: Unhidden (%)
Don't know	0.0	0.1	2.4	0.0	2.1
Prefer not to answer	0.1	0.1	3.2	0.9	3.0
Total non-response ('Don't know' and 'Prefer not to answer' combined)	0.1	0.2	5.6	0.9	5.1

Table description: This table shows that 'Don't know' and 'Prefer not to answer' responses were higher when these options were unhidden.

It is not uncommon for social survey outputs to exclude non-responders from analysis and sometimes it is not always clear how 'Don't know' and 'Prefer not to answer' responses have been handled in underlying analysis. For this reason, prevalence estimates were reproduced to only include participants who provided a valid response to the relevant measure (i.e., did not answer with 'Don't know' or 'Prefer not to answer').

Producing estimates this way resulted in higher prevalence on the social model aligned estimates. As outlined in Table 19, prevalence for SMD1 was 28.2% (27.4% with non-response) and for SMD2 was 29.0% (28.2% with non-response). This reduced the gap between the Equality Act definition of disabled and the social model estimates. Using pairwise McNemar's tests, the findings were similar to the confidence intervals. There were no significant differences found between the SMD2 estimate and the SMD1 or Equality Act aligned estimates at either the 5% or 1% significance levels (two-tailed). There were significant differences found between the SMD1 and the Equality Act aligned estimates at 5% significance but not 1% (also two-tailed).[23]

[23] An unweighted Cochran's Q test was carried out and identified significant differences between all 3 measures. This will mostly be due to differences between the Equality Act and social model measures. The pairwise McNemar's tests were carried out using only participants who gave a valid answer to questions from all 3 models (unweighted sample size 2,372). The results of those tests were the same, no significant differences between the SMD2 and the SMD1 or Equality Act measures, and significant differences were found between the SMD1 and the Equality Act measures, but only at the 5% significance level.

Table 19: Prevalence of disabled people where 'Don't know' and 'Prefer not to answer' were excluded, based on the Equality Act and social model definitions

	Equality Act definition (%)	Social model definition - SMD1 (%)	Social model definition - SMD2 (%)
Disabled	30.9	28.2	29.0
Not disabled	69.1	71.8	71.0
Weighted base (number)	**2,504**	**2,435**	**2,432**

Table description: This table shows that the different approaches to estimating disability are broadly similar when non-responders are excluded.

Understanding patterns in the prevalence of disabled participants

While the prevalence estimates for the Equality Act and social model approaches could be described as broadly similar, it is also important to understand responses to the underlying questions at the individual level. This allows consistency across questions to be explored. While inconsistency can indicate misunderstanding or ambiguity in the questions, or variability in individual perceptions, this is not necessarily always the case. It could also be because the social model aligned survey questions are new, and the methodological approach to estimating prevalence is novel, and therefore differences should be expected. Alternatively, a combination of reasons may explain inconsistencies and only further testing would help fully understand any observed differences.

Asking all participants all of the questions meant it was possible to explore the extent to which an individual was consistently classified across the different approaches to measuring it. Groups of particular interest were:

- those who were classified as disabled according to the Equality Act definition but not according to either social model aligned estimates
- those classified as disabled on both social model-aligned estimates but not according to the Equality Act definition of disabled

Table 20 highlights that 374 participants were disabled according to the Equality Act definition and both social model definitions. There were 247 participants classified as disabled using the Equality Act, but not with either social model definition. In contrast, 161 participants were classified as disabled according to both social model estimates but not the Equality Act definition. It was possible to explore the demographic profile of those classified as disabled using one approach but not the other.

Table 20: Comparison of participant categorisation according to the Equality Act definition and social model approaches

Definition	Number of participants
Disabled according to all 3 approaches (Equality Act and social model)	374
Disabled according to Equality Act approach only	247
Disabled according to social model approaches only	161

Table description: This table shows that there were some participants who were categorised as disabled on the 3 different approaches.

Disabled according to the Equality Act definition but not the social model of disability

The 247 participants in the group classified as disabled according to the Equality Act definition but not the social model definition disproportionately:

- were aged between 40 to 59, or 70 and above
- held a highest formal qualification below degree level

The potential impact of order effects was examined. It was hypothesised that the participants who received the shorter set of Equality Act aligned questions followed by the longer social model set might experience fatigue or view the questions as repetitive or overlapping in content. This can lead to a decreased level of engagement or attentiveness, potentially affecting the quality of their response. However, this was not the case in these data, suggesting order effect did not influence responses for these participants.

Disabled according to the social model but not the Equality Act definition

The 162 participants that were disabled according to both social model classifications but not the Equality Act disproportionately:

- were under the age of 60
- held a highest formal qualification at degree level and equivalent or above

For this group of participants, there was some evidence to suggest potential order effects. The hypothesis was that receiving the social model questions first might impact the responses to the Equality Act aligned questions that followed. These data suggested that this was the case. Most participants who were classified as disabled according to the social model, but not the Equality Act definition, received the social model aligned questions first.

5.3.4 Summary of findings

5.3.4.1 Impairments

In line with published data, for the harmonised impairments question, ‘Mobility’, ‘Mental health’ and ‘Stamina or breathing or fatigue’ were the most common impairment types reported by disabled participants.

Using a social model aligned approach to measuring impairments, the most frequently reported impairment types by disabled participants were ‘Mental health’ (50% for SMD1, and 53% for SMD2) and ‘Being in pain or discomfort’ (with 49% for SMD1, and 52% for SMD2).

Where there were functional equivalents across both versions of the question, prevalence tended to be highest on the social model aligned approach.

The social model version had the lowest proportion of participants selecting ‘Other’, suggesting it better captured the range of possible options that disabled people wanted to provide.

5.3.4.2 Experience of barriers in different life domains

Across all impairment types, the most common domains of life that disabled participants reported experiencing barriers in were ‘Health care’ and ‘Public spaces and facilities’. One in ten reported experiencing barriers across at least 4 life domains.

The low percentage of participants selecting ‘Other’, along with the descriptions provided under this response, suggest that the predefined response options effectively captured the broad range of life domains that barriers can be experienced in.

Non-response was relatively low and how it was presented impacted on selection. It was highest when the ‘Don’t know’ and ‘Prefer not to answer’ options were visible alongside all other responses.

Those with a ‘Hearing’ impairment were most likely to report not experiencing barriers in any of the life domains listed.

5.3.4.3 Experience of different types of barriers

The most commonly reported type of barrier experienced in the previous 12 months was attitudinal. Three in 10 of those with an impairment reported experiencing unsupportive ‘Views and behaviour from others’.

More than one type of barrier was experienced by 23% of those with at least one type of impairment.

Few participants selected the ‘Other’ response option suggesting the question effectively captured the range of barrier types it is possible to experience.

Non-response, largely driven by the ‘Prefer not to answer’ option, was higher among those with an impairment. Having the ‘Don’t know’ and ‘Prefer not to answer’ options hidden reduced the non-response rate.

5.3.4.4 Measuring the prevalence of disabled people

Using the Equality Act approach to measuring prevalence, around 3 in 10 participants were disabled. This was significantly higher than the first of the social model aligned estimates (SMD1), but not the second (SMD2).

Excluding non-responders from analysis reduced the gap between the Equality Act and social model aligned estimates.

The patterns observed across different groups of people when a social model aligned approach to measuring prevalence was used were similar to those observed when the Equality Act approach was applied.

There were participants categorised as disabled according to the Equality Act but not the social model definitions, and vice versa.

6. Recommendations

This section summarises the findings from the quantitative testing of the impairment and barriers questions. It draws on outcomes of the cognitive testing to interpret these findings and to inform recommendations. Recommendations are made for the impairment question and both barriers questions. In addition, some general recommendations that apply to all the questions are made.

Only the adult version of the questions was tested on the Panel, in English and Welsh. The formality of some of the language used in cognitive testing was addressed in advance of quantitative field testing. The Panel interview was completed in Welsh by 10 participants, with no issues relating to the translation raised.

6.1 Impairments

A new social model-aligned impairment question was developed, which used as its starting point the GSS impairment harmonised standard. Building on the feedback from disabled people who participated in the discovery phase, the number and description of response categories was amended. The question stem was also changed, referring to areas affected by long-term conditions or impairments. The question was refined further, following cognitive testing with disabled people, and tested on the Panel. This large-scale quantitative test demonstrated that survey participants are willing and able to answer it.

6.1.1 Interpretation of alpha phase findings

6.1.1.1 Prevalence of impairments

Both the GSS harmonised impairment standard and the new social model-aligned impairment questions were run on the Panel. Comparing estimates from both measures, the social model-aligned version provided a higher estimate of impairment among the UK population to the GSS harmonised impairment standard (35% compared to 57%). This suggests that the 2 questions measured the concept of impairment in different ways. They also produced different estimates of prevalence for specific types of impairment. These differences are to be expected given the 2 questions are worded differently and describe impairments in different ways. These differences should be kept in mind when interpreting results.

6.1.1.2 Comprehensiveness of response categories

Evidence from the quantitative field testing shows the question captures a wider range of impairments than the GSS harmonised impairment standard, resulting in a much lower rate of ‘Other’ answers. There is evidence that this low rate of ‘Other’ responses is due to the inclusion of additional response categories and the use of descriptions that better reflect participants lived experiences.

6.1.1.3 Acceptability

The question was acceptable to the public. Cognitive testing found participants were willing to provide responses to an impairment question with a ‘Select all that apply’ response format. This finding was confirmed in the quantitative testing, with very low levels of non-response (‘Don’t know’ and ‘Prefer not to answer’) found for the social model question.

6.1.1.4 Recommendations

General recommendations

The social model impairment question tested in work package 6 should be taken forward and used in a wider range of surveys and data collection contexts. Future users of these questions are encouraged to compare estimates from the social model aligned question with the GSS harmonised impairment standard, to understand how the 2 may differ. Users should be encouraged to publish results using the question, detailing the mode(s) of data collection used, and the placement of question within the questionnaire or form. The Welsh Government should review these findings, to build an evidence base on use of the question and the stability of estimates it produces. This evidence could inform whether further development work is needed and where it should be focused.

Specific recommendations

Easy read: The cognitive testing of the easy read English and Welsh versions of the impairment question highlighted the importance of images being clear and accurately conveying the meaning of the response category without participants having to read the text. It is recommended that images are cognitively tested with easy read users to ensure this.

British Sign Language (BSL): The social model-aligned impairment question that was run on the Panel was cognitively tested with 4 deaf BSL signers. Findings from this test highlighted issues with the current format of the impairment question, discussed later in this section, and specifically with the ‘Hearing’ answer option. Some participants did not select this category because it referred to hearing rather than being deaf. In the quantitative test, it was not possible to determine whether deaf participants selected the ‘Hearing’ category or not. It is recommended that the Welsh Government undertake further work with Deaf people to determine how the wording of the category can be improved.

Parents: Cognitive testing highlighted that the parent version needs an instruction on what parents should do if they have more than one child with an impairment. An additional question may need to be included in the questionnaire that identifies the number of children in the household and their ages, with answers used to determine which child the parent answers about. Any instructions or routing would need to be tested.

6.2 Barriers

6.2.1 Interpretation of alpha phase findings

6.2.1.1 Understanding and interpretation

Evidence from the quantitative field test indicated that people could answer both questions and they both appear to capture what they were designed to measure – experience of different types of barriers and in various life domains. In line with the cognitive testing findings, there was evidence of potential issues with comprehension and interpretation among some participants that should be kept in mind when interpreting data.

Although the non-response rates were low enough to be considered unproblematic, they could suggest some difficulty with understanding the questions, particularly among those with lower or no formal qualifications. Similarly, the relationship between the 2 questions at the individual level may be expected given the different aspects of barriers they aim to capture. However, it could also be evidence of comprehension issues with one or both questions for a small group of people. Further research would help to examine the relationship and interaction between the 2 questions.

6.2.1.2 Comprehensiveness of response categories

The Panel field test confirmed findings from the cognitive interviews that the response options on both barriers' questions were comprehensive. There was no evidence that any major domains of life or types of barriers were missed, or any irrelevant options included. The low percentage of 'Other' responses, along with a review of accompanying responses, confirmed that the response options were well-defined and appropriate. Some small refinements to the response examples are discussed in the recommendations section that follows.

6.2.1.3 Acceptability

Both questions were acceptable to the general public. Cognitive interviewing showed that neither was considered intrusive or overly personal, and the Panel data confirmed a general willingness to answer them. After cognitive testing, refinements were made to both questions, addressing concerns about the length and complexity of the question, and response burden. For both questions, the non-response group was mostly participants with lower formal qualifications. This could be evidence that the complexity of the questions resulted in increased cognitive load which led to non-response for some participants. There was also a higher non-response rate among those who received the social model set of questions second. This could be evidence of participant fatigue, or as a result of the testing process. Further research would allow the reasons for non-response to be fully explored.

British Sign Language (BSL)

A specific issue identified in cognitive testing was the unique interpretation of the question by deaf BSL signers. This finding underscores the need to explore cultural and linguistic adaptations to ensure that the question is inclusive and accurately interpreted by all participants.

6.2.1.4 Recommendations

General recommendations

A social model aligned approach to capturing people's experience of barriers across life in a survey is novel in Wales, and the wider UK context. Evidence from this research indicates that the final versions provided should now be taken forward and used in a wider range of surveys and different data collection contexts. As both return similar prevalence estimates for disabled people (when used in combination with the new impairment question), the Welsh Government should consider how each may be applied depending on the purpose and nature of the wider context in which they are used.

Future users should bear in mind the cognitive testing findings that question length can cause challenges for some disabled people. There is also potential for further experimentation, exploring whether changing the format of the questions reduces non-response, particularly for the question asking about barriers in different areas of life. One option, for example, could be to split the question into 2, using the same question stem but with 2 shorter lists. Alternatively, the question could be transformed from a multicode, 'select all that apply' format into a series of separate yes or no questions, each addressing one life domain. This could reduce cognitive load by allowing participants to focus on one area at a time. Both approaches would result in more survey questions, taking up space, and potentially time on data collection instruments. This may impact on adoption of these new questions and should be tested.

Users are encouraged to publish additional data generated to provide a growing body of evidence on how well the questions perform, and if there are any measurement issues. These data should inform decision making around whether any further development work is needed and where it should be focused.

Specific recommendations

All versions: The Welsh Government should consider whether 'needs not being supported by the Police' should be introduced either as a new response option or as an example for an existing option. Any change would need to be balanced alongside the general finding that the question is already cognitively demanding.

Easy read: On both questions on barriers:

- the question stem wording should make it explicit that the examples provided for each response option are not intended to be an exhaustive list; this recommendation should be cognitively tested
- the ‘Something else’ response option should be revised to make it clear that providing an accompanying written response is optional

For the question on experience of barriers in different life domains, the images for the following response options should be revised and cognitively tested to assess if they are clear and help people to correctly understand what the category is.

- **Health care:** The image should be replaced with one of a doctor, nurse, or someone at a doctor’s surgery.
- **Your local area:** Replace the image and examples with types of local buildings.
- **Activities and events:** Replace the image with one of an activity, sport, or a combination of events.

For the question on experience of different types of barriers, the images for the following response options should be revised and cognitively tested to assess if they are clear and help people to correctly understand what the category is.

- **Rules that do not support your needs:** The image should encourage participants to think more broadly about rules. The current image led some participants to focus on employment when answering.
- **Being treated differently:** A new image is needed that more clearly and consistently shows the meaning of this category to participants.
- **Spaces or buildings that are hard to use:** The image should be replaced with a picture of an accessible entrance to a building.

British Sign Language (BSL)

The social model questions on barriers that were run on the Panel were cognitively tested with 4 deaf BSL signers. Findings from this test highlighted issues with the current format of both questions, discussed later in this section. It is recommended that the Welsh Government undertake further work with deaf BSL signers to determine how the wording of the category can be improved.

Parents: For both barriers’ questions, it is recommended that the question stem be cognitively tested further to ensure parents are clear that they are being asked to answer about their child.

A parent with more than one child needs to be clear which child to answer these questions about. Guidance accompanying the survey questions should make this clear and outline some possible approaches for users. Any approach that includes instructions or routing for parents would need to be tested.

6.2.2 Overarching recommendations that apply to both the impairments and barriers questions

6.2.2.1 Parent version

It was not possible to quantitatively test the parent versions of the questions for various reasons. Therefore, parent versions of the questions are proposed based on the principles adopted in work package 4, findings from the cognitive testing of parent and adult questions (work package 5), and quantitative testing (work package 6) of the adult questions. It is recommended that further cognitive testing of these questions is undertaken prior to use. Where these questions are used, data should be published and reviewed by the Welsh Government to determine what, if any, further development and amendment may be needed.

6.2.2.2 Child version

A child version of the question should be developed and cognitively tested with disabled children, so that data can be collected directly from older children, rather than parents.

6.2.2.3 Easy read version

The images and wording of the easy read version should be subject to further cognitive testing, to ensure that they are consistently understood in the way intended.

6.2.2.4 BSL version

Further consultation with Deaf people should be carried out to explain and expand on the BSL cognitive test findings, and to inform further refinements. An exploration into the impact of different question structures and formats on the cognitive load for deaf BSL signers could suggest improvements to data collection in a visual language. It should also further explore the terminology issues highlighted in the BSL cognitive testing relating to the English source questionnaire.

6.2.2.5 Mode of data collection

The quantitative field test involved web and telephone modes of data collection but not face to face. However, it did not assess the extent to which the mode of data collection and how questions are presented to participants impacted answers to them. Based on findings from previous methodological studies, a lack of a visual reminder of the question and the answer options in the telephone mode may impact

responses[24]. To check this properly and see how big the effect is, it is recommended to further test the impact of having a reminder of the question and response options. The results of this test should be published and guidance provided on what, if any, actions data producers should take to deal with any mode effects given.

6.3 Question guidance

When using the new set of questions, the following guidance should be followed.

6.3.1 Question administration

Data collection must be undertaken in an inclusive way. Welsh language, BSL, and easy read versions of the questions should be offered to participants. The Government Social Research Profession Guide to Inclusive Social Research Practices provides useful guidance.

The questions include instructions, which must be communicated to participants.

If data are collected by face-to-face interview, the question stem and response options should be provided to the participant on a show card.

When administering questions in multiple modes, there should be consistent presentation of response options across modes. This will allow for order effect to be assessed.

The questions use a 'select all that apply' response format. Note that 'None of these', 'Don't know', and 'Prefer not to say' are mutually exclusive codes.

Users should consider whether they want to provide participants with 'Don't know' and 'Prefer not to say' response options up-front or not. If not, these response options should not be offered initially. The interviewer should code them if spontaneously mentioned. If online-self completion is used, then these options should be hidden and only become visible if the participant tries to move on without providing an answer. Note that the up-front inclusion of 'Don't know' and 'Prefer not to say' will result in higher non-response.

For the 'life domains' barriers question, the response option 'Employment and job opportunities that do not support my child's needs' can be excluded if not relevant to the child (based on their age) or there is no interest in collecting data on indirect barriers a disabled child might experience.

[24] Tomova, G. D., Silverwood, R. J., and Wright, L. (2025). Mode effects on survey item measurement: a systematic review of the experimental evidence, Survey Futures Working Paper number 12. Colchester, UK: University of Essex.

6.3.2 Data processing

The questions include an ‘Other’ category. Ideally, where resources allow, this should include a write-in option so participants can record answers that do not fit into the predefined response options.

Answers recorded for ‘Other’ should be reviewed and backcoded to existing response options where possible.

6.3.3 Data analysis

Two separate social model-aligned measures of the prevalence of disabled people can be produced based on responses to the impairment and barriers questions. These are:

- **social model 1 (SMD1):** A participant is categorised as disabled if they record the presence of one or more impairments (codes 1 to 13) and have experienced barriers in one or more ‘domains of life’ options (codes 1 to 10)
- **social model 2 (SMD2):** A participant is categorised as disabled if they record the presence of one or more impairments (codes 1 to 13) and have experienced one or more types of barriers (codes 1 to 5)

6.4 Recommended new questions

This section details the English version of the new recommended question set of an impairment question and 2 different barriers questions. There are separate versions designed for adults, and for parents. The adult question set has been produced separately in Welsh, easy read (English and Welsh), and BSL.

The parent question set has been produced in Welsh and easy read (English and Welsh). The BSL parent question was only cognitively tested by one participant and the adult version identified issues with the question structure. It is therefore recommended that deaf BSL signers are consulted and the BSL adult version is tested further. From additional testing, the findings can be applied more widely and the parent version developed further.

6.4.1 Impairment question

6.4.1.1 Adult version

In which, if any, of the following areas are you affected by long-term conditions or impairments? Include those that may come and go, or vary over time.

Please select all that apply.

1. **Seeing** – for example, getting around unfamiliar places, reading, even with glasses or contact lenses

2. **Hearing** – for example, following conversations in noisy places, hearing sounds
3. **Moving around** – for example, walking, getting up or down stairs without support
4. **Using your hands or fingers** – for example, dressing, using a keyboard
5. **Learning new things** – for example, reading, following instructions, or organising your thoughts on paper
6. **Remembering or focusing** - for example, recalling names or dates, staying focused on tasks
7. **Mental health** – for example, managing emotions or thoughts, experiencing hallucinations
8. **Managing energy levels or breathing** – for example, sleeping well, having the energy to complete daily activities
9. **Interacting with other people** – for example, expressing yourself, feeling overwhelmed by social situations
10. **Being in pain or discomfort** – for example, experiencing chronic pain or irritation that affects your mood, sleep, or concentration
11. **Sensory processing** – for example, being more or less sensitive to light, touch, or temperature
12. **Having an over or under active immune system** – for example, being prone to infection or inflammation
13. **Other** (please specify)
14. **None of the above**

    Don’t know

    Prefer not to say

6.4.1.2 Parent version

In which, if any, of the following areas is [Name of child / your child] affected by long-term conditions or impairments? Include those that may come and go, or vary over time.

Please select all that apply.

1. **Seeing** – for example, getting around unfamiliar places, reading, even with glasses or contact lenses

2. **Hearing** – for example, following conversations in noisy places, hearing sounds
3. **Moving around** – for example, walking, getting up or down stairs without support
4. **Using your hands or fingers** – for example, dressing themselves, using a keyboard, picking up a toy
5. **Learning new things** – for example, reading, following instructions, or organising their thoughts on paper
6. **Remembering or focusing** - for example, recalling names or dates, staying focused on tasks
7. **Mental health** – for example, managing their emotions or thoughts, experiencing hallucinations
8. **Managing energy levels or breathing** – for example, sleeping well, having the energy to complete daily activities or play
9. **Interacting with other people** – for example, expressing themselves, feeling overwhelmed by social situations
10. **Being in pain or discomfort** – for example, experiencing chronic pain or irritation that affects their mood, sleep, or concentration
11. **Sensory processing** – for example, being more or less sensitive to light, touch, or temperature
12. **Having an over or under active immune system** – for example, being prone to infection or inflammation
13. **Other** (please specify)
14. **None of the above**

Don’t know

Prefer not to say

6.4.2 Experience of barriers in different life domains

6.4.2.1 Adult version

Which, if any, of the following have you experienced in the last 12 months?

Please select all that apply.

1. **Health care that does not support my needs**

   For example, being treated unfairly by staff, difficult to use booking systems, waiting areas that are hard to move around

2. **Employment and job opportunities that do not support my needs**

   For example, being left out of social activities, inflexible recruitment or workplace adjustments, workplaces that are hard to get in and around

3. **Education and training that does not support my needs**

   For example, assumptions being made about my abilities, learning materials not in format I need, rooms that are hard to access or too noisy

4. **Transport and travel that does not support my needs**

   For example, staff not treating me with dignity, difficult to use booking systems, lack of accessible seating

5. **Housing and independent living arrangements that do not support my needs**

   For example, people assuming I cannot live alone, long waiting lists for accessible housing, lack of adaptations to existing home

6. **Community and social activities do not support my needs**

   For example, people assuming I cannot take part in events, information on venues not in accessible formats, shops and businesses with unsuitable parking

7. **Public spaces and facilities that do not support my needs**

   For example, feedback on accessibility not taken seriously, limited opening hours, lack of accessible toilets and public facilities

8. **Financial services and benefits that do not support my needs**

   For example, people assuming I cannot look after my own money, welfare payments do not cover living costs, hard-to-access banking services

9. **Voting and opportunities to get involved in politics that do not support my needs**

   For example, people thinking I do not understand political issues, limited support to join in public life, not able to vote privately at polling station

10. **Other** (please give details)

11. **None of these**

Don’t know

Prefer not to say

6.4.2.2 Parent version

Which, if any, of the following has [Name of child / your child] experienced in the last 12 months? Please answer about your child.

Please select all that apply.

1. **Health care that does not support your child’s needs**

   For example, being treated unfairly by staff, difficult to use booking systems, waiting areas that are hard for them to move around

2. **Education and training that does not support your child’s needs**

   For example, assumptions being made about their abilities, learning materials not in format they need, rooms that are hard to access or too noisy

3. **Employment and job opportunities that do not support your child’s needs ***

   For example, working hours that are not flexible, no quiet area to make calls to doctors or school

4. **Transport and travel that does not support your child’s needs**

   For example, staff not treating them with dignity, difficult to use booking systems, lack of accessible seating

5. **Housing and independent living arrangements that do not support your child’s needs**

   For example, people assuming they know what my child can do, long waiting lists for accessible housing, lack of adaptations to existing home

6. **Community and social activities do not support your child’s needs**

   For example, people assuming they cannot take part in events, information on venues not in accessible formats, shops and businesses with unsuitable parking

7. **Public spaces and facilities that do not support your child’s needs**

   For example, feedback on accessibility not taken seriously, limited opening hours, lack of accessible toilets and public facilities

8. **Financial services and benefits that do not support your child's needs**

   For example, welfare payments do not cover living costs, hard-to-access banking services

9. **Other** (please give details)

10. **None of these**

    Don't know

    Prefer not to say

***** The response option 'employment and job opportunities that do not support my child's needs' can be excluded if not relevant to the child (based on their age) or there is no interest in collecting data on indirect barriers a disabled child might experience.

6.4.3 Experience of different types of barriers

6.4.3.1 Adult version

Which, if any, of the following have you experienced in the last 12 months?

Please select all that apply.

1. **Information and communication that is not accessible**

   For example, health information not in a format I need, not having enough time to process information, booking systems that are hard to use

2. **Buildings and spaces that are not suitable**

   For example, public buildings that are too noisy or bright, workplaces with no ramps or lifts, accessible toilets that are not suitable

3. **Views and behaviour from others that are not supportive**

   For example, health staff making assumptions about me, co-workers using offensive language towards me or leaving me out, my views not taken being taken seriously

4. **Rules, policies, and practices that do not support my needs**

   For example, health staff not adequately trained to support my needs, lack of adjustments by employers, not enough money or support to live independently

5. **Other** (please give details)

6. **None of these**

   Don’t know

   Prefer not to say

6.4.3.2 Parent version

Which, if any, of the following has [Name of child / your child] experienced in the last 12 months? Please answer about your child.

Please select all that apply.

1. **Information and communication that is not accessible**

   For example, health information not in a format they need, not having enough time to process information, travel booking systems that are hard to use

2. **Buildings and spaces that are not suitable**

   For example, buildings that are too noisy or bright, public spaces with no ramps or lifts, accessible toilets that are not suitable

3. **Views and behaviour from others that are not supportive**

   For example, health staff making assumptions about them, people using offensive language towards them or leaving them out, their views not taken being taken seriously

4. **Rules, policies, and practices that do not support my needs**

   For example, health staff not adequately trained to support their needs, lack of adjustments at school or nursery, not enough money or support to live independently

5. **Other** (please give details)

6. **None of these**

   Don’t know

   Prefer not to say

Annex A: Government Statistical Service (GSS) harmonised standards

The GSS harmonised standards are updated periodically. The versions listed below were the most up to date available when the research was carried out.

Current guidance from the GSS harmonised standards team states that the long-lasting health conditions and illnesses (LLHCI) standard and activity restriction standard are combined to determine if an individual would be identified as disabled.

This is to align with the definition of disability as provided under the Equality Act (2010): that a person is considered to be disabled if they have a 'physical or mental impairment' and that impairment has a 'substantial' and 'long-term' adverse effect on their ability to carry out normal day-to-day activities.

Long lasting health conditions and illnesses (LLHCI) standard

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

1. Yes
2. No
3. Don't know (spontaneous only)
4. Refusal (spontaneous only)

Activity restriction standard

'Does your condition or illness / do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?'

1. Yes, a lot
2. Yes, a little
3. Not at all

According to this approach, a person is considered to be disabled if they answer 'yes' to the first question and 'yes, a little' or 'yes, a lot' to the second.

Impairment standard

In addition to the two core questions outlined above, the impairment standard provides an optional third question, which may be used to collect more granular information on impairment type:

'Do any of these conditions or illnesses affect you in any of the following areas?'

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting and carrying objects, using a keyboard)
5. Learning or understanding or concentrating
6. Memory
7. Mental health
8. Stamina or breathing or fatigue
9. Socially or behaviourally (for example associated with autism spectrum disorder (ASD) which includes Asperger's, or attention deficit hyperactivity disorder (ADHD))
10. Other (please specify)
11. None of the above (spontaneous only)
12. Refusal (spontaneous only)

Annex B: Work package 4 – impairment questions

Work package 4 aimed to develop the first iteration of new social model aligned questions. This Annex lists the impairment questions that resulted from the question design process. These were tested through a series of cognitive interviews in work package 5 and refined further based on the findings.

It was proposed that 2 alternative versions of an impairment question would be tested:

- version 1 was to be aligned closely with the current impairment standard question but amended to reflect social model language
- version 2 was to be a new question, more loosely based on the impairment standard but making more extensive changes in line with social model principles to measure the concept of ‘impairment’

Both versions were tested with adults, and with parents about their children.

Version 1

This question was more aligned to the existing GSS harmonised impairment standard and had less alterations than version 2. The main considerations for version 1 of the impairment question were as follows:

- question stem included the phrase ‘long term’ without a definition, and referred to the condition
- question stem did not explicitly include a statement on fluctuating conditions
- question stem used the terms ‘impairments’ and ‘conditions’
- answer categories were based on the harmonised impairment categories, but amended to use social model language
- ‘prefer not to say’ response was not included
- participants were asked to tick all responses that apply
- mode of administration: self-completion

Adult question

[Version 1 of the impairment question, designed to be asked of adult participants]

In which, if any, of the following areas are you affected by long-term impairments or conditions?

Please select all that apply.

Vision – for example, blindness, partial sight

Hearing – for example, deafness, partial hearing

Mobility or strength – for example, moving independently or carrying heavy things

Dexterity – for example, performing careful tasks with your hands

Learning – for example, understanding new ideas, reading and writing or using numbers

Memory or concentration – for example, remembering information, maintaining focus

Mental health – for example, managing moods, emotions or thoughts, making sense of the word around you

Stamina, breathing or energy – for example, managing energy levels, regular sleep

Social interaction or communication – for example, expressing yourself, maintaining relationships

Pain or discomfort – for example chronic pain or irritation

Sensory processing - for example over or under stimulation with sound, light, taste, or touch

Immune system regulation – for example, over or under active immune system

Other (please specify)

None of the above

Parent and child question

[Version 1 of the impairment question, designed to be asked of parents about their child]

In which, if any, of the following areas is [child name/your child] affected by long-term impairments or conditions?

Please select all that apply.

Vision – for example, blindness, partial sight

Hearing – for example, deafness, partial hearing

Mobility or strength – for example, moving independently or carrying heavy things

Dexterity – for example, doing careful tasks with their hands

Learning – for example, understanding new ideas, reading and writing, or using numbers

Memory or concentration– for example, remembering information, maintaining focus

Mental health – for example, managing their moods, emotions or thoughts, making sense of the word around them

Stamina, breathing or energy – for example, managing energy levels, regular sleep

Social interaction or communication – for example, expressing themselves, maintaining relationships

Pain or discomfort – for example chronic pain or irritation

Sensory processing - for example over or under stimulation with sound, light, taste or touch

Immune system regulation – for example, over or under active immune system

Other (please specify)

None of the above

Version 2

This question made more extensive changes, in line with the social model of disability. The main considerations for version 2 of the impairment question were as follows:

- question stem did not include phrase ‘long term’ or a defined time period

- question stem explicitly included a statement on including conditions that may fluctuate
- question stem asked if participants ‘experience issues or differences’
- answer categories were a more radical revision of the harmonised standard response options, based on social model language
- ‘prefer not to say’ response was included
- participants were asked to respond with yes or no
- mode of administration: interviewer

Adult question

[Version 2 of the impairment question, designed to be asked of adult participants]

Do you experience issues or differences with any of the following?

Please include anything that may come and go or vary over time.

Seeing - for example, getting around unfamiliar places, reading, watching TV, even with glasses or contact lenses

Hearing - for example, following conversations in noisy places, hearing sounds, communicating with people

Moving around - for example, walking, getting up or down stairs, getting in or out of a chair, moving without support

Using your hands or fingers - for example, dressing, writing, or using a keyboard

Learning new things - for example, reading, counting, following instructions, organising your thoughts on paper

Remembering or focusing - for example, remembering recent events, recalling names or dates, staying focused on tasks

Mental wellbeing - for example, feelings about yourself and others, managing emotions, seeing or hearing things that other people do not

Energy levels or breathing - for example, sleeping well or having energy to get up, wash, cook or watch a film

Interacting with other people - for example, understanding what others are thinking or feeling, making friends, listening

Being in pain or discomfort – for example regularly feeling pain or irritation that affects your mood, sleep, or concentration

Experiencing the world – for example, more or less sensitive to light or sound, food textures, touch or temperature

Immune responses – for example, eating whatever they like, going out in sunlight, fighting infections

Yes

No

Prefer not to say

Parent and child question

[Version 2 of the impairment question, designed to be asked of parents about their child]

Does [name child/your child] experience issues or differences with any of the following?

Please include anything that may come and go or vary over time.

Seeing - for example, getting around unfamiliar places, reading, watching TV, even with glasses or contact lenses

Hearing - for example, hearing sounds, communicating with people

Moving around - for example, walking, getting up or down stairs, getting in or out of a chair, playing without support

Using your hands or fingers - for example, dressing themselves, holding a pencil, picking up a toy, using a keyboard

Learning new things - for example, reading, counting, following instructions, organising their thoughts on paper

Remembering or focusing - for example, remembering what they did at school, recalling names or dates, staying focused on tasks

Mental wellbeing - for example, feelings about themselves and others, managing their emotions, seeing or hearing things that other people do not

Energy levels or breathing - for example, sleeping well or having the energy to get up, play, watch a film

Interacting with other people - for example, understanding what others are thinking or feeling, making friends, listening

Being in pain or discomfort – for example regularly feeling pain or irritation that affects their mood, sleep, or concentration

Experiencing the world – for example, more or less sensitive to light or sound, food textures, touch or temperature

Immune responses – for example, eating whatever they like, going out in sunlight, fighting infections

Yes

No

Prefer not to say

Annex C: Work package 4 – barriers questions

Work package 4 aimed to develop the first iteration of new social model aligned questions. This Annex lists the barriers questions that resulted from this. These were tested through a series of cognitive interviews in work package 5 and refined further based on the findings.

As with the impairment question, it was proposed that 2 alternative versions of the barriers question would be tested. Both follow the social model principles:

- version 1 aligned with policy areas (or ‘life domains’)
- version 2 aligned with broader categories, as outlined in social model literature

An option for adults and an option for parents was designed.

Version 1

The main considerations for version 1 of the barriers question were:

- response options were framed around policy domains - each response option broadly represented a policy area or domain
- question stem explicitly linked barriers to impairment(s) or conditions
- examples covered the 4 main types of barriers e.g. environmental, communication
- it did not function as a standalone question
- the question asked ‘do you’ experience
- question response options of ‘tick all that apply’
- did not include a ‘Prefer not to say’ option

Adult question

[Version 1 of the barriers question, designed to be asked of adult participants]

Thinking about (this/these) long term impairment(s) or condition(s) which, if any, of the following barriers do you experience?

Please select all that apply.

1. **Health care and support that does not support my needs**

   For example, waiting areas are hard to move around, appointments that do not work for me, health information not in a format I need, healthcare staff treating me differently

2. **Education and training that does not support my needs**

   For example, learning materials not in a format I need, inflexible teaching methods, classrooms that are hard to access or too noisy, tutors not understanding my needs

3. **Employment and job opportunities that do not support my needs**

   For example, not enough adjustments to help me do my job, application processes that are not accessible, workplaces that are hard to get in and around, being left out of social activities

4. **Transport and travel that does not support my needs**

   For example, lack of facilities or equipment on public transport, timetables not in a format I can use, staff thinking they know what I can manage, booking processes that are not accessible

5. **Housing and independent living arrangements that do not support my needs**

   For example, hard-to-access housing, not enough adaptations to existing home, not enough support for living independently, people thinking I cannot live by myself

6. **Opportunities to take part in community and social activities do not support my needs**

   For example, activities held in spaces I cannot access, events starting too early or late, not enough information on what to expect at events, people assuming I cannot take part

7. **Public spaces and facilities that do not support my needs**

   For example, community spaces that are hard to use, no accessible toilets, assistive technology not available, my feedback on accessibility not being taken seriously

8. **Financial support and services that do not support my needs**

   For example, hard-to-access banking services, no help with managing my money, welfare that does not cover my living costs, people assuming I cannot earn and manage my money

9. **Voting and political participation opportunities that do not support of my needs**

   For example, information about candidates not in a format I can use, not able to vote privately, lack of support to take part in public life, people think I cannot understand political issues

10. **Other** (please give details)

11. **None of these**

Parent and child question

[Version 1 of the barriers question, designed to be asked of parents about their child]

Thinking about (this/these) long term impairment(s) or condition(s) which, if any, of the following barriers does [child name/your child] experience?

Please select all that apply.

1. **Health care and support that does not support your child's needs**

   For example, waiting areas are hard for my child to move around, appointments that do not work for them, health information not in the format needed, healthcare staff treating my child differently

2. **Education and training that does not support your child's needs**

   For example, learning materials not in a format my child needs, not enough support in the classroom, rooms that are hard to access or too noisy, school staff not understanding my child's needs

3. **Employment and job opportunities that do not enable me to support my child's needs**

   For example, no quiet area to make calls to doctors or school, working hours that are not flexible, no clear information on policies and support available to me, bosses assuming that I am less committed because I have a disabled child

4. **Transport and travel that does not support your child's needs**

   For example, transport to school or nursery that is not suitable, announcements and signs my child cannot use, staff thinking they know what my child can manage, not enough assistance available on public transport

5. **Housing and independent living arrangements that do not support your child's needs**

   For example, hard-to-access housing, not enough adaptations to existing home to allow my child to move around or do tasks independently, not enough support for living independently, others thinking they know what my child can and cannot do

6. **Opportunities to take part in community and social activities do not support your child's needs**

   For example, activities held in spaces my child cannot access, few opportunities to take part in things like sports, arts and play, no visual images to help my child understand, people assuming my child cannot take part

7. **Public spaces and facilities that do not support your child's needs**

   For example, no suitable play parks, accessible toilets or changing spaces not available, no assistive technology available, people assuming my child needs constant help

8. **Financial services and benefits that do not support your child's needs**

   For example, hard-to-access financial support, no help with managing my child's expenses, welfare that does not cover my child's needs, people thinking that I use my child's needs to get extra money

9. **Other** (please give details)

10. **None of these**

Version 2

The main considerations for version 2 of the barriers question were:

- response options were framed around social model barrier types - each response heading represented one of the 4 main barriers
- question stem did not explicitly link barriers to impairments or conditions
- examples provided were purposefully quite broad
- functioned as a standalone question
- the question asked 'have you' experienced
- question response options of 'tick all that apply'
- included a 'Prefer not to say' option

Adult question

[Version 2 of the barriers question, designed to be asked of adult participants]

Which, if any, of the following have you experienced?

Please select all that apply.

1. **Buildings and indoor and outdoor spaces that are not suitable**

   For example, places that are not designed for me to get in and around, that cause me sensory discomfort, or that do not have the facilities I need

2. **Information and communication that is not accessible**

   For example, information not available in a format I need (like British Sign Language or large print), websites that are hard to use, signs I cannot see or understand, not being given enough time to process information

3. **Rules, policies, and practices that are not supportive**

   For example, things being done in a way that means I am treated unfairly, no or unsuitable support available, rules that are not flexible, staff that are not trained to understand my needs

4. **Views and behaviour from others that are not supportive**

   For example, people thinking they know what I can and cannot do, holding negative views about me, treating me differently or using offensive language

5. **Other** (please give details if you wish)

6. **None of these**

7. **Prefer not to say**

Parent and child question

[Version 2 of the barriers question, designed to be asked of parents about their child]

Which, if any, of the following has [child name/your child] experienced?

Please select all that apply.

1. **Buildings and indoor and outdoor spaces that are not suitable**

   For example, places that are not designed for my child to get in and around, that cause them sensory discomfort, or that do not have the facilities my child needs

2. **Information and communication that is not accessible**

   For example, information not available in a format my child needs (like British Sign Language, large print) websites that are hard to use, crowded or cluttered signs or leaflets, my child not being given enough time to process information

3. **Rules, policies, and practices that are not supportive**

   For example, things being done in a way that means my child is treated unfairly, no or unsuitable support available, rules that are not flexible, staff that are not trained to understand my child's needs

4. **Views and behaviour from others that are not supportive**

   For example, people thinking they know what my child can and cannot do, holding negative views about them, treating my child differently or using offensive language towards them

5. **Other** (please write in if you wish)

6. **None of these**

7. **Prefer not to say**

Annex D: Work package 5 – cognitive testing recruitment specification

Background to the research

The National Centre for Social Research (NatCen) is an independent, not-for-profit research organisation. This project is being conducted on behalf of the Welsh Government (WG) who are responsible for a range of public services in Wales, including health, education, and local councils. They develop policies, laws, and services to help improve the lives of people in Wales. WG have committed to embracing the social model of disability (SMD) in their work. This model emphasises that ‘disability’ is caused by the way society is organised, rather than by a person's impairment or difference. It advocates for the removal of barriers that restrict life choices for disabled people, ensuring they have the same opportunities and access to services as everyone else. By focusing on changing attitudes, policies, and environments, the SMD aims to create a more inclusive society.

This project aims to find out the best way to ask survey questions about people’s impairments or conditions, and any barriers they might face in daily life. We want to make sure that future survey questions better reflect the lived experiences of disabled people and capture the issues they face in everyday life.

Taking part will involve a one-to-one interview with a researcher or interviewer from Shift Insight. It will take up to an hour, at a day and time that works for participants. The interview will take place either:

- online, using Zoom or Microsoft Teams
- on the telephone
- or face-to-face at a location of the participants choosing

At the start of the interview, permission will be sought to video (online) or audio (online, telephone and face to face) record the discussion. This is so that we have an accurate record of what is said. Participants are welcome to have their camera off if they wish. If a participant really did not want the interview audio recorded, we would honour this.

In the discussion, participants will be asked to answer some survey questions which have been developed by NatCen and the Welsh Government. These questions are centred on types of impairment or conditions people might have and barriers that disabled people may face in their day-to-day life. The researcher will then ask some follow up questions (probes). These follow-up questions will be to gather feedback on the questions and may include things such as whether they think the survey questions are clear, if they ask the right things, what they thought the question was asking about and if they are easy to understand.

Participants will get a £40 Love 2 Shop voucher as a thank you for taking part in the interview. This will be sent by NatCen directly to participants via email after the interview.

This document describes the details of the type of people we would like you to recruit for this cognitive testing exercise.

Quotas

For this testing, we would like you to recruit for, and conduct, 52 cognitive interviews. We require 30 interviews with adults (aged 18 and over), 16 with parents or carers of children (aged 0 to 15), and 4 with adults and 2 with parents to take part in interviews testing easy read versions of the questions.

Interviews would be provided in the first instance via Zoom or Teams, but face to face and telephone can be booked for those persons who may require one, and the screening questionnaire guides you through this.

The separate ‘quotas’ file provides quotas on the range of demographic characteristics and experience we would like to be represented in the sample.

Additional guidance on recruiting easy read participants

The survey questions we are showing people have also been translated into easy read. Easy read is an accessible way of communicating written information using simple words, short sentences, and pictures. Some people find it a more accessible way of receiving complex information that might be difficult to understand. We want to check how well these questions work in easy read by doing some interviews with people likely to find easy read beneficial.

People with a learning disability, those with memory issues, and sometimes those who have trouble reading or writing are known to find easy read beneficial. It is people with these types of impairments or conditions that we would like to recruit for the 6 easy read interviews we need to carry out.

Recruitment questionnaires

We have provided screening questionnaires recruiters should follow when inviting people to take part. Details collected on screening will be double-checked at the start of each interview.

Recruitment materials

Materials provided for recruitment are:

- this recruitment specification
- quotas

- recruitment screening questionnaire for adults
- recruitment screening questionnaire for parents
- recruitment screening questionnaire for easy read interviews
- participant information sheet (English, Welsh, easy read English, and easy read Welsh)
- privacy notice (English, Welsh, easy read English, and easy read Welsh)

At the end of the screening questionnaires, participants are asked for their preferred way to receive the information sheet and privacy notice. After recruitment these should be emailed to participants in their preferred format.

Asking about support when arranging appointments

Whoever is contacting participants after recruitment to arrange an appointment time, should re-ask questions 5 and 15 from the screening questionnaires. This is in line with our ethical application which states that we will ask participants at multiple points what would support them to take part.

We have provided the questions to be asked in a standalone document called ‘Accessibility questions for appointment making’.

FAQs about interviews

What will the interviews be like?

Interviews will be conducted on Zoom or Teams and last for up to 60 minutes. During the interview, participants will be asked some survey questions. After each question or a set of questions researchers will talk to participants about how they found answering them and if any improvements could be made.

Will the information I give be shared with anyone else?

Participants should be assured that the feedback they give will only be used for research purposes and all their personal details will be held securely within NatCen. If participants agree, the interviews will be recorded on Zoom or Teams, telephone, or in person (at a quiet place of the participants choosing). This recording will be summarised and used to make improvements to the questions.

Will I be paid for taking part?

Participants will be given a £40 Love2Shop voucher for taking part in the interview, as a thank you for their time and feedback. This will be emailed to participants by NatCen following the interview.

Incentives

Each interview will last around 60 minutes. Everyone who takes part will receive a £40 Love2Shop voucher to thank them for their time. Incentives will be distributed by NatCen.

Updates and data security

Fieldwork is scheduled to take place between 8 September 2025 and 3 October 2025.

We would like updates about how recruitment and interviewing is progressing every 3 working days.

Any participant confidential information can be passed on via the NatCen secure FTP site. We will provide you with log in details for this.

As with all NatCen projects, personal data about participants (including names, contact details) should be stored securely by Acumen, Shift Insight, and NatCen. NatCen will delete any personal details of recruits after the final report has been written. People recruited by Acumen or Shift Insight will not knowingly be approached by NatCen to take part in any further studies. Please ensure that Acumen and Shift Insight shred any paper screening questionnaires after the fieldwork process and securely deletes any emails which contain data relating to recruitment.

Please contact the project team if you have any queries in relation to our data security policies.

Annex E: Work package 5 – recruitment quotas

For this work package, it was recommended that 52 cognitive interviews should be carried out with people living Wales. Draft quotas are included below.

Sampling criteria non-easy read adult interviews (total of 30)

Hard quotas

A minimum of 10 interviews in Welsh.

A minimum of 8 interviews in each of the following age groups: 18 to 29, 30 to 64, 65 and over.

A minimum of 4 interviews with participants who answer ‘no’ to both of the following questions:

- Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?
- We are also looking to talk to people who might face barriers in daily life but do not consider themselves disabled, for example, BSL speakers or neurodivergent people. Does this apply to you?

Broad impairment grouping minimum quotas:

- 5 interviews: Your vision, hearing or another of your senses is affected
- 5 interviews: You are affected physically, for example, perhaps your mobility or coordination is affected. Or your energy levels are affected, and you feel tired all the time. Other ways you might be affected physically include your breathing being affected, or you are experiencing pain. Or perhaps you are affected in some other way physically
- 5 interviews: Your memory, or how well you can learn, understand, or concentrate, is affected
- 5 interviews: Your mental health is affected, some examples include depression, anxiety, eating disorders, and psychosis
- 5 interviews: How your brain thinks and processes information is affected
- 3 interviews: Affects you in another way, not mentioned yet
- 2 interviews: Does not affect me in any way

Soft quotas

A minimum of:

- 12 females and 12 males
- 8 participants in (or waiting to take up) work, training or education
- 8 participants unable to work or took early retirement because of a longstanding illness or health condition
- 6 retired participants
- 6 participants living in a rural area
- 5 participants who are not ‘White, White Welsh or White British’
- 8 participants with no qualifications or qualifications below A-levels (such as GCSEs/O-Levels)
- 8 participants in receipt of means tested benefits

Sampling criteria non-easy read parent interviews (total of 16)

Hard quotas

A minimum of 3 interviews with parents who answer ‘no’ to both of the following questions:

- Does your child or young person have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?
- We are also looking to talk to people whose child or young person might face barriers in daily life but do not consider themselves disabled, for example, BSL speakers or neurodivergent people. Does this apply to you?

A minimum of 5 interviews where the language of the parent is Welsh.

A minimum of 4 interviews with a parent a child in each of the following age groups: 0 to 8, 9 to 11, and 12 to 15.

A minimum of 6 interviews with parents of a child with additional learning needs.

A minimum of 2 interviews with parents of a child with an Individual Development Plan.

Broad impairment group of the child, minimum quotas:

- 2 interviews: Affects one or more of their senses

- 2 interviews: Affects them physically, for example it impacts on mobility, coordination, stamina, breathing or causes me fatigue or pain, or affects them in some other way physically
- 2 interviews: Affects their ability to learn understand or concentrate
- 2 interviews: Affects how their brain thinks and processes information
- 2 interviews: Affects their speech language and/or communication
- 2 interviews: Affects them in another way not listed here or does not affect their child in any way

Soft quotas

A minimum of:

- 7 male children and 7 female children
- 3 children living in a rural area
- 4 children where their family's ethnicity is not 'White, White Welsh or White British'
- 4 children where the educational attainment of parent or carer is 'no qualifications or qualifications below A-levels (such as GCSEs/O-Levels)'

Annex F: Work package 5 – testing protocol

A version of this testing protocol was used for adults, parents of disabled children, participants receiving the easy read questions, and BSL questions. The adult testing protocol is included below; the other protocol versions are available upon request.

Adult protocol: participants were split into 2 groups based on their individual serial numbers - adult group A (odd numbers) and adult group B (even numbers). All participants received the same introductory information. Adult group A received the impairment questions first; adult group B received the barriers questions first.

Introducing the interview

Interviewer instructions: The aim of this section is to introduce the interview to the participant and gain their informed consent to take part. You should use the prompts as a guide as well as answering any questions the participant has.

Introduce the study

Read aloud: Hello, my name is [your name]. I work for Shift-Insight, a specialist research agency. We are working with the National Centre for Social Research (NatCen) between now and November 2025 on research for the Welsh Government.

The aim of this research is to come up with new survey questions that better reflect the lived experiences of disabled people and the barriers they face in everyday life. These new questions should provide the Welsh Government with better information about disabled people to help make more inclusive policies and services.

As part of this research, we are trying out these new questions with members of the public. Your feedback is very important to us and will help us to finalise the questions.

Taking part

Read aloud: Taking part will involve talking with me for around an hour. Around halfway through, I'll check if you would like a break. If, at any other time, you feel like you need a break please let me know or type me a message in the chat.

Before we go any further, is there anything else I can do to support you taking part? [E.g. volume, screen background, noise]

You do not need any special knowledge to take part and there are no right or wrong answers. I am interested in your thoughts and experiences.

As we talk, I will show or ask you an example survey question and ask you to try to answer it. I will then ask you some follow up questions to find out more about what you thought about the survey question, how you went about trying to answer it and how you would improve it.

You will get a £40 Love 2 Shop voucher as a thank you for taking part in the interview. This will be emailed out from the National Centre for Social Research after the interview.

Confidentiality and data use

Read aloud: I would now like to take a few moments to talk you through our confidentiality procedures.

Taking part is voluntary. You do not have to take part if you do not want to. If you decide to go ahead, you can stop at any time and withdraw your agreement up to 2 weeks after this interview without giving a reason and without any consequences. You do not have to answer the questions I ask you if you do not want to. However, I may ask you about why you did not want to answer a survey question, but you don't have to tell me if you don't want to.

To accurately capture what you say, with your agreement, this conversation will be recorded.

Your personal information will be stored securely. Only members of the research team at Shift Insight and NatCen will have access to it. It will only be used for the purposes of this research. The information you tell us will be used to help NatCen researchers analyse the results.

Shift Insight will securely share the interview recordings, transcripts, and summaries with the NatCen research team. Separately, Shift Insight will provide National Centre for Social Research (NatCen) with your name and contact details so that they can send you your Love2Shop voucher.

NatCen will use the information they collect and analyse to write a report for the Welsh Government. The Welsh Government will publish this report on their website in 2026. Your name and contact details will not be included in the report. The report may include some of the things you have said but nobody will know that you said them.

Once the project is finished, all information held by Shift Insight and NatCen about you will be securely deleted.

You can find more information about how NatCen will use your data during this research in the privacy notice that you were emailed.

Participant agreement

Interviewer read aloud: Have you received and had a chance to read and understand the information leaflet you were emailed?

- Do you have any questions?

- Are you happy to proceed and take part?

Interviewer instructions:

- Yes – Proceed
- No – Thank and close

Interviewer read aloud: Are you happy for us to record the discussion today?

Interviewer instructions:

- Yes – proceed
- No – go to ‘Think aloud’ section and continue. Do not record.

Interviewer instructions (if yes – proceed):

Select ‘Record’ on Zoom / Teams.

Once recording has started, ask participants again to confirm that they are happy to take part and for interview to be recorded (so that this is captured on record).

State interview serial number for recording. (e.g. ‘for our purposes this is interview serial number RB01’).

Think aloud

Interviewer instructions: The aim of this section is to encourage the participant to think aloud whilst completing the questions.

Read aloud: Let me explain a little bit more about the rest of the session. I am going to ask you to tell me what you are thinking about while you are reading and answering the questions.

I want you to tell me whatever comes into your mind as you are working out how to answer: if the question is what you expect or not, whether you like it or not, any words you do not understand or find odd, or any changes that you think should be made, and so on. This is called ‘thinking out loud’.

To give you an example, if I was asked the question ‘how many rooms do I have in my home?’ then in answering the question I might think ‘I have 2 bedrooms, 1 sitting room, 1 kitchen so that is 4 rooms in total’. Some people find thinking easier than others. I will prompt you to do so.

Testing the questions

Read aloud: We will now start going through the survey questions. After every question we will pause, and I will ask you some more specific things about how you found using the questions.

Interviewer instructions: Share word document (show screens) with participant and work through the relevant sections in the probe sheet. Pause to probe at points highlighted in the probe sheet.

Observations to be noted when charting:

- did respondent ask for help or clarification?
- did the respondent hesitate at any questions?
- did the respondent change their response at any questions?

Impairment questions

[Participants in Group A were asked these questions first; participants in Group B were asked these second.]

Impairment question, version 1

Read aloud: I am now going to show you a survey question that I would like you to answer.

Give participants Showcard C with version 1: impairment question and response options (as displayed in Annex B).

Priority probes

- Can you tell me, in your own words, what you think this question is asking about?
- How did you feel about being asked this question?
    - Explore what it was about the question that made the participant feel that way:
        - terminology used – ‘long term impairments or conditions’
        - having to tick all that apply
        - mode - being asked in a self-completion questionnaire compared to being asked by an interviewer
- How did you go about answering this question? Talk me through what, if anything you read and thought about when attempting to answer this question.
    - Get participant to talk through what they did e.g. read, considered, when deciding on which response options to endorse.
- How easy or difficult was it to answer this question? Why?

- Explore if any descriptions were unclear, or if the participant was unsure which options to select.

- The question asked about ‘long term impairments or conditions’. What did you understand by these terms: long term impairments; long term conditions?
  - Please provide examples of long-term impairments and long-term conditions.
  - Was the participant clear in their mind about which, if any, of the categories applied to them?
    - Which categories were they uncertain about and why?
    - What did the participant understand the response option ‘Dexterity’ to cover?

- **If answered** None of these: Please talk me through why you selected this option.

- What changes, if any, would you make to this question?
  - Explore alternatives:
    - terms – ‘condition’, ‘impairment’, ‘affected by’
    - response option descriptions
    - response option examples

Supplementary probes, if time allows

- How did you feel about the use of the phrase ‘partial sight’?
  - Explore if would prefer use of a different term, such as sight impaired. e.g. what do you think about using the phrase ‘sight impaired’ instead?

- What did you understand by the term ‘managing energy levels’?

- What did you understand by the term ‘social interaction’?

- The mental health response option included the example ‘making sense of the world around you’. What did you understand by this? Please ask for examples.

- The pain and discomfort response option included the example ‘chronic pain’. How would you describe chronic pain?

Impairment question, version 2

Read aloud: I am now going to ask you a survey question and would like you to answer.

Interviewer to only read question stem aloud.

Read aloud: Do you experience issues or differences with any of the following? Please include anything that may come and go or vary over time.

Do not read out the 3 possible answer options:

- Yes
- No
- Prefer not to say

Give participants Showcard D with version 2: impairment question response categories (as displayed in Annex B).

Priority probes

- In your own words, what do you think this question is asking about?
- How did you feel about being asked this question?
    - Explore what it was about the question that made the participant feel that way:
        - terminology used
        - answering yes or no rather than having to state which issues or differences apply
        - mode – being asked by an interviewer compared to filling in a questionnaire yourself
- How did you go about answering this question? Talk me through what, if anything you read and thought about when attempting to answer this question.
    - Get participant to talk through what they did e.g. read, considered when deciding on which response options to endorse.
- How easy or difficult was it to answer this question? Why?
    - Explore any descriptions that are unclear.

- The question asked about if you experience any ‘issues or differences’. What did you understand by this? What did you think was meant by ‘issues or differences’?
    - Please ask for examples.
- The question also asked people to ‘include anything that may come and go or vary over time’ - what did you understand by this/ what did you think this meant?
    - Please give me examples of things that may come or go or vary or over time that you might include for this question.
    - What things would you not include?
        - Why would you include or exclude these examples?
    - Would you have answered this question differently if it had not included the phrase ‘include anything that may come and go or vary over time’?
        - Explore how answer would be different.
- What changes, if any, would you make to this question?
    - Explore alternatives and reasons for changes:
        - to terms ‘issues or differences’
        - term ‘experience’
        - response option descriptions (the emboldened text)
        - examples
- Comparing this question with version 1, which version do you prefer?
    - Explore reasons for preference:
        - question wording – ‘areas are you affected by long-term impairments or conditions’ compared to ‘experience issues or differences with any of the following … including anything that may come and go or vary over time’
        - response options – ‘tick all that apply’ compared to ‘yes or no’
    - If doesn’t prefer either, how would they suggest this question is worded?
- Having now seen these questions about impairment and conditions, would you change any of your answers to the early questions you answered on barriers you experience, or would you not? Probe for detail.

Supplementary probes, if time allows

- Mental wellbeing included the example ‘managing emotions’. What did you understand by this phrase? Ask for an example.
- What did you understand by the phrase ‘interacting with other people’? Please provide examples.
- Interacting with other people included the example ‘listening’. What did you think this was referring to?
- What did you understand by the phrase ‘experiencing the world’? Please provide examples.
- Under ‘Immune responses’ was the example, ‘going out in sunlight’. What did you think this was referring to?

Interviewer instruction: at this stage, pause and ask participant if they would like to take a short break.

Barriers questions

Participants in Group A were asked these questions second; participants in Group B were asked these first.

Barriers question 1 (version 2)

Interviewer to only read question stem aloud

Read aloud: Which, if any, of the following have you experienced? Please select all that apply.

Give participants Showcard A with version 2: barriers response categories (as displayed in Annex C).

Priority probes

- Can you tell me, in your own words, what you think the question is asking about?
- How did you feel about answering this question?
    - Explore what it was about the question that made the participant feel that way:
        - sensitivities with question and providing an answer (especially if chose ‘prefer not to say’)
        - terminology used

        - how the question and response options were phrased e.g. positively or negatively
        - having to tick all that apply
        - mode – being asked by an interviewer rather than answering questions myself
- Can you talk me through how you went about answering the question?
    - What did you read?
    - What did you consider?
- How easy or difficult was this question to answer? What makes you say that do you say that?
    - Wording of response options and examples
    - Anything else
- The question asked you which of the things listed you ‘have experienced’? What types of things were you thinking about here? Why do you think you’ve experienced the things you’ve told me about or are you not sure?
- What time period were you thinking about when answering this question? If you had been asked if you had experienced these things in the last 12 months, would you have answered the same, or differently?
- **If answered** None of these – Please talk me through why you selected this option.
- **If answered** Prefer not to answer - Please talk me through why you selected this option.
- What, if any, changes would you make to this question?
    - Explore alternatives and reasons for changes
        - terms used (alternatives to ’not suitable’, ‘not accessible’ and ‘not supportive’)
        - response option descriptions (the emboldened text)
        - examples given (different examples, more or less)

Supplementary probes, if time allows

- What areas of your life were you thinking about when you were answering this question? [If necessary, prompt for work, home life, leisure, your health, getting around.]
- Can you tell me in your own words what the term ‘rules, policies and practices’ means to you?
- Response option 2 refers to ‘communication that is not accessible’, what did that make you think of? Can you think of any better ways to say that which we could use?

Barriers question 2 (version 1)

Read aloud: I am now going to show you another survey question that I would like you to answer.

Give participants Showcard B with version 1: barriers question and response categories (as displayed in Annex C).

Priority probes

- In your own words, what do you think this question is asking about?
- How did you feel about answering this question?
    - Explore what it was about the question that made the participant feel that way:
        - the terminology used
        - having to tick all that apply
        - sensitive
        - mode - being asked in a self-completion questionnaire compared to being asked by an interviewer
- Tell me how you went about answering the question?
    - Get participant to talk through what they did e.g. read it, considered which response options to endorse.
- How easy or difficult was this question to answer? Why was that?
    - Explore if any descriptions were unclear, or participant was unsure which option(s) to select, how well they felt the answer options applied to them.

- The question asked about ‘barriers’ you experience. What did you understand by the term ‘barriers’ here?
    - Was the participant thinking about specific impairments when they selected the barriers option(s)?
    - Was the participant clear in their mind about which, if any, of the categories applied to them?
    - Which categories were they uncertain about and why?
- What time period where you thinking about when answering this question? [Probe for detail]
    - If the question had asked you if you had experienced any of these barriers in the last 12 months, would you have answered the same, or differently? [Probe for detail]
- **If answered** None of these – Please talk me through why you selected this option.
- What changes, if any, would you make to this question?
    - Explore alternatives:
        - terms - ‘issues’ instead of barriers, a different word (or remove entirely?)
        - number of response options (more or less?) – anything we missed?
        - response option descriptions
        - more, less, or better examples given
- Comparing this question with the previous question (question 1: barriers version 2), which version do you prefer?
    - Explore reasons for preference:
        - question wording – do they prefer question that specifically mentions **‘**barriers’ over one that does not? or ‘do you experience’ compared to ‘have you experienced’?
        - response options – listed by ‘areas of life’ compared to listed by ‘type of barrier experienced’
        - number and type of examples given – version 1 has lots of detailed examples, compared to version 2 with broader and fewer examples
        - linking to impairment in version 1 compared to not linking to impairment in question 1: barriers version 2)

- If doesn't prefer either, how would they suggest this question is worded?

Supplementary probes, if time allows

- What, in your own words, does the term 'does not support my needs' mean to you?
- [If not already covered] What long-term impairment(s) or condition(s) were you thinking about when answering this question?
- A few of the examples mention information not being available in a 'format you need' e.g. timetables not in a format you need. What did the term 'format' mean to you?
- Option 3 was 'transport and travel that does not support my needs'. What did you understand by this? Please give examples.
- Option 7 was 'public spaces and facilities that do not support my needs'. Can you tell me the kinds of things you were thinking about here?
- Option 8 referred to 'financial services and benefits that do not support my needs'. Can you tell me, in your own words, what you this term means to you? Probe for examples of financial services support thought about, and of benefits considered.
- What about option 9, what do you understand by the term 'political participation opportunities' mean? And what about 'take part in public life'?

Close

The aims of this section are to get participants' general views on the survey questions and how they found completing the survey.

These questions are asked after participants have completed the questionnaire.

General

- How easy or difficult was it to understand what the questions were asking in the survey?
- How did you find answering the questions in the survey?
- How did you find the length of each of the questions? Did you feel that the amount of text to read through for some questions caused any difficulties or not really?
- Do you have any other comments on the questions?

- Is there anything else about the survey questions you would like to see changed, or not?

Interviewer: thank the participant and go to screening questions.

Screening questions

The aim of this section is to check participants have been screened in correctly.

Read aloud: The last thing I need to do is check that the information we hold for you is correct. These are the things the recruiter would have asked you when you were first contacted to take part. This is not about proving who you are at all, this is just to check that we are talking to the right groups of people for this study.

1. Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more, or do you identify as disabled?

Yes – Proceed to 3

No – Proceed to 2b

[Ask if Q3='No']

2b. We are also looking to talk to people who might face barriers in daily life but do not consider themselves disabled, for example, BSL speakers or neurodivergent people. Does this apply to you?

Yes – Proceed to 3

No – Continue if still require participants for no health condition quota and go to question 4, otherwise screen out

3. I am now going to read out a list of some of the ways long-standing illnesses and health conditions can affect people. For each of the options I read out, please say 'yes' if you are affected in this way or 'no' if you are not.

Interviewer: If 'yes' tick the box. If the participant is unsure, please do not tick.

Your vision, hearing or another of your senses is affected

You are affected physically, for example, perhaps your mobility or coordination is affected. Or your energy levels are affected, and you feel tired all the time

Other ways you might be affected physically include your breathing being affected, or you are experiencing pain

Or perhaps you are affected in some other way physically

Your memory, or how well you can learn, understand, or concentrate, is affected

Your mental health is affected, some examples include depression, anxiety, eating disorders, and psychosis

How your brain thinks and processes information is affected

Affects you in another way, not mentioned yet [**Interviewer**: ask and either back code or assign to 'other way' category]

Does not affect me in any way

4. How old are you?

18 to 29

30 to 64

65 and above

5. What is your sex?

Male

Female

Prefer not to say

6. What is your current working status?

In (or waiting to take up) work, training

Unable to work or took early retirement because of a longstanding illness or health condition

Retired

Doing something else

7. Do you live in an urban or a rural area?

Interviewer: To read out if needed.

Urban: An urban area usually includes cities, towns, and suburbs. Urban areas tend to have more people than rural areas.

Rural: A rural area usually includes farms, small towns, and villages. Rural areas tend to have less people than urban areas.

Urban

Rural

Prefer not to say

8. What is your ethnic group? (Please choose one option that best describes your ethnic group or background)

White, White Welsh, or White British

(also includes Gypsy or Irish Traveller; Roma; Any other White background)

Asian, Asian Welsh, or Asian British

Black, Black Welsh, Black British, Caribbean, or African

Mixed or Multiple ethnic groups

Other ethnic groups

9. What is your highest level of educational attainment?

Interviewer: if necessary, say: By which I mean which is the highest exams or qualifications you have gained.

Up to GCSE level or equivalent

A-Levels or equivalent or above

10. Do you currently receive any means-tested benefits (these are benefits based on your income or savings, like Universal Credit, Income Support, or Housing Benefit)?

Yes

No

Read aloud: Thank you for answering those screening questions. That is now the end of today's interview.

Read aloud: Do you have any other comments before I stop the recording?

Interviewer instruction: (When ready) stop the recording.

Housekeeping and interview close

Interviewer: Ask the participant if they have any further questions.

Explain we will send them a £40 Love 2 Shop incentive code and instructions. Explain this may take up to 10 days to arrive and that they will come from a NatCen email address. The exact address will be: NatCen@comms.natcen.ac.uk

We will also send a leaflet of useful contacts. This will include links to organisations relevant to the topics discussed in the interview.

Annex G: Work package 6 – NatCen Opinion Panel technical information

Introduction

In November 2025, NatCen conducted a survey amongst its Opinion Panel members on behalf of the Welsh Government to collect data on people's experiences of disability in line with the social model of disability. This document provides details on the variables included, questionnaire wording, sample design, fieldwork approach, and the weighting methodology.

Sampling

The NatCen Opinion Panel is based on a random probability design, with panel members originally selected at random and considerable effort put in to maximise participation and to minimise the risk of bias.

Members of the NatCen Opinion Panel are recruited through probability-based surveys, that use the Postcode Address File (PAF) as the sampling frame. Participants are selected at random, and substantial effort is made to secure interviews to ensure high quality, representative data.

For this survey, all panel members aged 16 and over recruited from the British Social Attitudes (BSA) 2015 onward and the Consumer Detriment Study (CDS) Wales, who had not subsequently left the panel or become 'inactive', were eligible to be invited. From this pool, a random sub-sample of 4,383 cases was selected, maintaining the probability-based design. This included a boost of 750 panel members who lived in Wales at the time they took the survey, to a total of 896 panel members in Wales selected to take part.

Selection probabilities were adjusted by sampling in proportion to weights reflecting the extent to which panel members characteristics (age, sex, region, household structure, income, education, economic activity, ethnicity, tenure, social class, interest in politics and party support) were over- or under-represented in the eligible panel. The procedure enhances the representativeness of the issued sample as much as possible.

Fieldwork design

Mode

Fieldwork followed a sequential mixed-mode design. Panel members were initially invited to participate in the research online, and sent multiple reminders by post, email and/or text message. If they had not completed the interview within two weeks, and if telephone numbers were available, they were then contacted by NatCen's Telephone Unit (TU) to encourage online completion or offer an interview over the

phone. This approach allows us to include individuals who were unable or unwilling to complete the survey online.

Communication strategy

Issued panel members are contacted multiple times, and via multiple modes to provide them with the required information and encourage them to take part in the live survey. Multiple modes of contact (letter, email, and SMS), diverse messages (social impact, reward upon completion, urgency) and different days of the week are used to maximise the chances of reaching different groups. These are spread across the first 2 weeks of fieldwork to maximise the number of people completing the questionnaire online before the outstanding sample is issued to the NatCen's Telephone Unit for contact. A final set of reminders are sent 3 weeks into fieldwork to those that have not completed the questionnaire and for whom we do not have a contact phone number, as these panel members will not be contacted by the Telephone Unit during the last few weeks of fieldwork.

Fieldwork period

The fieldwork period lasted for one month. Web fieldwork ran from 13 November 2025 to 14 December 2025 and telephone fieldwork ran from 20 November 2025 to 14 December 2025. Although most participants completed the survey within the first week, the one-month timeframe ensured that all individuals had the opportunity to participate, rather than only those who were immediately available.

Completes by language and country

All panel members were given the option to complete the survey in Welsh or English, regardless of which country they resided in at the time the survey was completed. Those living in Wales received an invitation letter in Welsh and in English. In total, 10 panel members completed the survey in Welsh, with 9 living in Wales and 1 living in England.

Incentive

Participants received a £5 or £10 Love2Shop voucher (either digital or physical) as a thank you for their time.

Targeted approach

To improve sample quality, fieldwork resources were redirected from individuals who are typically over-represented in the sample and participate regularly, towards those who are under-represented and participate less frequently. For instance, under-represented individuals were eligible for a higher incentive, received more reminders, and/or were contacted more frequently by our interviewers (up to 8 calls).

Response rates

This survey achieved a 57% overall response rate among those panel members invited to participate.[25]

Weighting

Non-response to NatCen Opinion Panel surveys can occur at various points: the recruitment survey, the invitation to join the panel (at the end of the recruitment interview), subsequent attrition from the Panel, and the survey of panel members itself. The recruitment surveys are already weighted to adjust for non-response. Further weights are computed to adjust for non-response at the subsequent stages. The final survey weight is the product of these weights. This multi-stage approach is ideal because the correlates of non-response can be different at each stage.

Non-response

The final delivered weight is the product of the recruitment survey weight, the sample selection weight, and the panel non-response weight.

Recruitment survey weight: The weights from the recruitment surveys followed similar designs: selection weights to adjust for uneven selection probabilities; non-response weights computed via logistic regression models of response (at address level) to adjust for differential non-response; and calibration to population estimates[26].

Sampling weight: This weight adjusts for selection probabilities used in the sampling process and all non-response or attrition that occurs after the recruitment surveys but prior to sampling.

First, a logistic regression model was created to derive non-response weights to adjust for non-response that occurred prior to sampling, i.e. at the panel recruitment stage plus any subsequent attrition. The following variables were used as predictors in the model: age and sex groups, region, household type, household income, education level, ethnicity, tenure, social class group, economic activity, political party identification, and interest in politics. The non-response weight was the inverse of the probability of joining or remaining in the panel.

A random subsample of panel members was selected for this survey, with boosts applied for some populations. Weights were used to adjust the probabilities of

[25] This response rate does not account for non-response as a result of people not taking part in the recruitment survey, not joining the panel, or attrition from the panel. However, since much of this bias is mitigated through our weighted sampling approach, we believe that this response rate is a better indication of the risk of bias.
[26] More details on the BSA weight can be found at bsa.natcen.ac.uk/

selection, therefore a ‘sample selection’ weight was computed to account for these differential selection probabilities (equal to the inverse of the probability of being selected for the sample). The final ‘sampling weight’ is the product of the recruitment survey weight, the panel non-response weight and the sample selection weight.

Survey weight: This weight is used to adjust for non-response to this panel survey.

Logistic regression models were used to estimate the probability of response for each panel member issued to the survey. The panel survey weight was equal to the inverse of the probabilities of response. This weight adjusts for non-response using the same variables as used for the panel recruitment weight above i.e. age and sex groups, region, household type etc.

Two different models were used, one for the face-to-face surveys and one the push-to-web surveys. In each case, the resulting survey weight was multiplied by the sampling weight to create the pre-calibration weights. Finally, calibration weighting was used to adjust the profile of the responding sample so that it matched the UK population profile.

Design effect and effective sample size

Design Effect (Deff) measures the efficiency of a sampling design compared to simple random sampling. It indicates how much larger the sample size must be to achieve the same precision as a simple random sample assuming 100% response rate. A Deff greater than 1 means the design is less efficient, requiring a larger sample size; conversely a Deff less than 1 means the design is more efficient. For this project, the Deff is 1.70.

Design effect is particularly important in complex stratified or clustered sampling designs, such as those used in the NatCen Panel, where the correlation within clusters or strata can affect the precision of the estimates.

The effective sample size represents the number of independent observations contributing to the analysis. It accounts for the reduction in sample diversity caused by the design effect. It is calculated by adjusting the total sample size based on the Deff. For this project, the effective sample size is 1,478.

Survey dataset

Sampling variables

The sample design for the British Social Attitudes (BSA) survey and Consumer Detriment Survey (CDS) – and therefore the NatCen Opinion Panel which is recruited through these surveys – involves stratification and clustering. These design features affect standard errors and should be accounted for in the analysis. Variables are provided to allow for this:

- Primary Sampling Unit from which the panel members were recruited during their recruitment survey; it refers either to the household from which our push-to-web recruitment sample was recruited (since 2020) or to recruitment point for the face-to-face sample (prior to 2019)

- the sampling stratum from which the panel members were selected, with each code representing a different region; it takes into account Index of Multiple Deprivation (IMD) quintiles

Non-response weight variable

Survey estimates from random probability samples are affected by non-response; if this is not addressed it can cause estimates to be biased. To ensure the achieved sample of respondents is representative of the population, a set of non-response weights has been computed to account for non-response to the recruitment surveys, refusal to the join the panel, and non-response in the survey of panel members itself.

Survey paradata information

Two pieces of survey paradata are included in the survey dataset: the date on which the survey was completed and the mode in which the survey was completed (online or telephone).

Fed-forward data

As NatCen Opinion Panel members are interviewed regularly, we possess a wealth of background information on our panel members which can be used in analysis.

Question order

Social model of disability or harmonised standard set first: Respondents were either shown the harmonised impairment standard (HS) questions first or the social model measures (SMD) first. Variable “sampsplit3_qtypeorder” shows the order, with 1 meaning HS were shown first and SMD second, while 2 means SMD question set were shown first and HS second.

Barriers question 1 or 2 shown first: Respondents were shown either ASMDBar1 (barriers question 1) or ASMDBar2 (barriers question 2) first. The variable “sampsplit4_smdbarorder” indicates the order in which the questions were shown: a value of 1 indicates that ASMDBar1 was shown first and ASMDBar2 second, while a value of 2 indicates that ASMDBar2 was shown first and ASMDBar1 second.

Derived variables: hidden or upfront ‘Don’t know’ and ‘Prefer not to say’

At questions ASMDBar1 and ASMDBar2, ‘Don’t know’ and ‘Prefer not to say’ responses were shown up front to around half the sample and hidden for around half the sample. Whether ‘Don’t know’ and ‘Prefer not to say’ were hidden or shown

upfront was determined by the variable “sampsplit5_dkpnta” in which 1 means hidden and 2 means displayed up front.

If ‘Don’t know’ and ‘Prefer not to say’ were hidden and respondents tried to skip this question, these hidden responses would appear on screen and could be selected. This is how ‘Don’t know’ and ‘Prefer not to say’ appear as standard for questions asked on NatCen’s Opinion Panel.

The derived variables listed below show all ‘Don’t know’ and ‘Prefer not to say’ responses (whether hidden or displayed up front):

- ASMDBar1_PNTA_DV
- ASMDBar1_DK_DV
- ASMDBar2_PNTA_DV
- ASMDBar2_DK_DV

Additional derived variables have also been computed based on the survey data and included in the dataset. To facilitate analysis, a set of socio-demographic variables with categories grouped to meet specific analysis needs.

Backcoding ‘Other’ responses

Participants were given the option to select ‘Other’ and provide verbatim responses for the following questions:

- AHSImp – Do any of these conditions or illnesses affect you in any of the following areas?
- ASMDImp – In which, if any, of the following areas are you affected by long-term conditions or impairments?
- ASMDBar1 - Which, if any, of the following have you experienced in the last 12 months?
- ASMDBar2 - Which, if any, of the following have you experienced in the last 12 months?
- DebQ1 - We asked you to tell us about any barriers you have experienced in the last 12 months. When answering these questions, which, if any of the following did you think about?

‘Other’ responses provided at questions AHSImp and ASMDImp were backcoded. To facilitate consistent backcoding, duplicate backcoding variables were created for each parent response option (for example, AHSImp01BkC, AHSImp02BkC, and equivalent variables for ASMDImp).

All verbatim responses provided under the ‘Other (please specify)’ option were reviewed manually. Where a respondent’s description clearly corresponded to an existing response category, the verbatim response was recoded into the relevant parent category using the corresponding backcoding variable. Where verbatim responses did not clearly fit any existing response option, they were left coded as ‘Other’ and not reassigned. For example, if a respondent selected ‘Other’ and reported a condition such as “asthma” this response was backcoded to the relevant variable at ASMDImp specifically which is the category of ‘Managing energy levels or breathing’.

This approach ensured that responses originally captured under ‘Other’ were incorporated into existing categories only where conceptually appropriate, while preserving genuinely uncategorisable responses in the ‘Other’ category.

Quality assurance

At the analysis stage, analysis was run for the full participating sample and separately for those living in Wales versus elsewhere in the UK. This was a quality check to ensure participants in Wales were not answering the questions significantly differently to people in the rest of Britain. Some differences, for example higher prevalence of disabled people in Wales compared with England, were observed and in line with published data.

Questionnaire specification

A unimodal questionnaire design approach was adopted for the development of the survey instrument. This means that differences between the web and telephone survey have been actively minimised. Differences between the 2 modes, when unavoidable, are marked in the questionnaire specification presented below.

Colour legend:

Instructions for programmers

Start and end of section-specific filters and/or specifications

Annotations:

	Bolding starts
	Bolding ends
	Italic starts
	Italic ends
HL	Helplink: appears next to answer categories

HS Helplink: appears after a question stem, or for FAQ-style purposes underneath a question stem

Start survey

Language selection

{ASK IF CATI}

WGIntro: The next questions are about people's conditions, and the barriers disabled people experience in daily life.

{ASK IF WEB}

Lang: The next set of questions is about people's conditions, and the barriers disabled people experience in daily life.

Which language would you prefer to complete this section in?

1. Welsh
2. English

Main survey: English

START FILTER: IF (MODE =WEB AND Lang=1) OR MODE=CATI

PROGRAMMING: RANDOMISE ORDER OF SET1A and SET2A

IF Nov25SampSplit3=1 THEN HARMONISED FIRST AND SMD SECOND

IF Nov25SampSplit3=2 THEN SMD FIRST AND HARMONISED SECOND

Harmonised standard (SET 1A)

{ASK ALL}

AHSLLHC

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

1. Yes
2. No

{IF AHSLLHC=1}

AHSActR

Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?

Interviewer: Probe if yes: “Is that a little or a lot?”

1. Yes, a lot
2. Yes, a little
3. Not at all

{IF AHSLLHC=1}

AHSImp [MULTICODE] [items fixed order, not randomised]

Do any of these conditions or illnesses affect you in any of the following areas?

G_Multi_II1

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting and carrying objects, using a keyboard)
5. Learning or understanding or concentrating
6. Memory
7. Mental health
8. Stamina or breathing or fatigue
9. Socially or behaviourally (for example associated with autism spectrum disorder (ASD) which includes Asperger’s, or attention deficit hyperactivity disorder (ADHD))
10. Other (please specify)

PROGRAMMING: ALONGISDE THE USUAL NON-REPONSE HIDDEN OPTIONS, ADD “None of the above”. POSITION: AFTER PNTA.

SMD measures (SET 2A)

{ASK ALL}

ASMDImp **[MULTICODE – RANDOMISE 1..12]**

In which, if any, of the following areas are you affected by long-term conditions or impairments?

Include those that may come and go, or vary over time.

G_Multi_II1

1. **Seeing** – for example, getting around unfamiliar places, reading, even with glasses or contact lenses
2. **Hearing** – for example, following conversations in noisy places, hearing sounds
3. **Moving around** – for example, walking or getting up or down stairs without support
4. **Using your hands or fingers** – for example, dressing, using a keyboard
5. **Learning new things** – for example, reading, following instructions, or organising your thoughts on paper
6. **Remembering or focusing** – for example, recalling names or dates, staying focused on tasks
7. **Mental health** – for example, managing emotions or thoughts, experiencing hallucinations
8. **Managing energy levels or breathing** – for example, sleeping well, having the energy to complete daily activities
9. **Interacting with other people** – for example, expressing yourself, feeling overwhelmed by social situations
10. **Being in pain or discomfort** – for example, experiencing chronic pain or irritation that affects your mood, sleep, or concentration
11. **Sensory processing** – for example, being more or less sensitive to light, touch or temperature
12. **Having an over or under active immune system** – for example, being prone to infection or inflammation
13. **Other** (please specify)
14. **None of the above**

PROGRAMMING: RANDOMISE ORDER OF ASMDBar1 AND ASMDBar2

IF Nov25SampSplit4=1 THEN ASMDBar1 FIRST AND ASMDBar2 SECOND

IF Nov25SampSplit4=2 THEN ASMDBar2 FIRST AND ASMDBar1 SECOND

{ASK ALL}

ASMDBar1 **[MULTICODE – RANDOMISE 1..9]**

Which, if any, of the following have you experienced in the last 12 months?

G_Multi_II1

1. **Health care that does not support my needs**

   For example, being treated unfairly by staff, inaccessible appointment booking systems, waiting areas that are hard to move around

2. **Employment and job opportunities that do not support my needs**

   For example, being left out of social activities, inflexible recruitment or workplace adjustments, workplaces that are hard to get in and around

3. **Education and training that does not support my needs**

   For example, assumptions being made about my abilities, learning materials not in format I need, rooms that are hard to access or too noisy

4. **Transport and travel that does not support my needs**

   For example, staff not treating me with dignity, inaccessible booking systems, lack of accessible seating

5. **Housing and independent living arrangements that do not support my needs**

   For example, people assuming I cannot live alone, long waiting lists for accessible housing, lack of adaptations to existing home

6. **Community and social activities do not support my needs**

   For example, people assuming I cannot take part in events, information on venue facilities not available in accessible formats, shops and businesses that are inaccessible

7. **Public spaces and facilities that do not support my needs**

   For example, feedback on accessibility not taken seriously, limited opening hours, lack of accessible toilets and public facilities

8. **Financial services and benefits that do not support my needs**

   For example, people assuming I cannot look after my own money, welfare payments do not cover living costs, hard-to-access banking services

9. **Voting and opportunities to get involved in politics that do not support my needs**

   For example, people thinking I do not understand political issues, limited support to join in public life, not able to vote privately at polling station

10. **Other** (please give details)

11. **None of these**

PROGRAMMING: DK & PNTA OPTIONS

IF Nov25SampSplit5=1 THEN DK & PNTA HIDDEN AND TRIGGERED (Panel standard)

IF Nov25SampSplit5=2 THEN DK & PNTA DISPLAYED UPFRONT

{ASK ALL}

ASMDBar2 **[MULTICODE]**

Which, if any, of the following have you experienced in the last 12 months?

G_Multi_II1

1. **Information and communication that is not accessible**

   For example: health information not in a format I need, not having enough time to process information, travel booking systems that are hard to use

2. **Buildings and spaces that are not suitable**

   For example: public buildings that are too noisy or bright, workplaces with no ramps or lifts, accessible toilets that are not suitable

3. **Views and behaviour from others that are not supportive**

   For example: health staff making assumptions about me, co-workers using offensive language towards me or leaving me out, my views not taken being taken seriously

4. **Rules, policies, and practices that do not support my needs**

   For example: health staff not adequately trained to support my needs, lack of adjustments by employers, not enough money or support to live independently

5. **Other** (please give details)

6. **None of these**

PROGRAMMING: DK & PNTA OPTIONS

IF Nov25SampSplit5=1 THEN DK & PNTA HIDDEN (Panel standard)

IF Nov25SampSplit5=2 THEN DK & PNTA SHOW UPFRONT

Feedback question

{ASK ALL}

DebQ1 [MULTICODE]

We asked you to tell us about any barriers you have experienced in the last 12 months. When answering these questions, which, if any of the following did you think about?

G_Multi_II1

1. Long-term conditions or impairments
2. Things like age, sex, gender identity, ethnicity, religion, or sexual orientation
3. Other things (please give details)
4. I was unsure what I was meant to think about when answering [EXCLUSIVE]

END FILTER: IF (MODE=WEB AND Lang=1) OR MODE=CATI

Annex H: Work package 6 – experience of barriers by impairment type

Table 21: Percentage of barriers in domains of life experienced by participants with different impairment types

	Seeing	Hearing	Moving around	Using hands or fingers	Learning new things	Remembering or focusing	Mental health	Energy levels or breathing	Interacting with other people	Pain or discomfort	Sensory processing	Immune system
Health care	31	27	36	38	41	35	36	38	38	34	48	37
Employment and job	16	12	15	22	29	19	22	20	25	14	31	20
Education and training	9	7	8	9	24	14	15	13	16	7	20	13
Transport and travel	19	17	25	27	27	20	19	22	19	21	25	25
Housing and independent living	13	10	16	20	23	14	17	15	17	11	23	23
Community and social activities	15	11	16	17	19	15	13	11	17	11	19	18

	Seeing	Hearing	Moving around	Using hands or fingers	Learning new things	Remembering or focusing	Mental health	Energy levels or breathing	Interacting with other people	Pain or discomfort	Sensory processing	Immune system
Public spaces and facilities	22	17	33	34	30	23	25	26	28	24	35	32
Financial services and benefits	22	16	23	28	35	25	27	22	28	17	29	28
Voting and politics	12	6	9	10	12	8	8	7	7	6	11	9
Other	1	2	1	2	1	1	1	1	2	1	1	1
None of these	45	52	33	33	29	36	34	34	30	40	25	29
Don’t know or Prefer not to answer	1	1	2	2	1	1	1	1	1	2	0	2

[Note 1] Unweighted bases: Seeing = 228; Hearing = 479; Moving around = 452; Using hands or fingers = 238; Learning new things = 191; Remembering or focusing = 469 Mental health = 462; Managing energy levels or breathing = 531; Interacting with other people = 362; Being in pain or discomfort = 680; Sensory processing = 196; Having an overactive or underactive immune system = 247.

Table 22: Average number of barriers in areas of life experienced by participants with different impairment types

Impairment type	Average number of life domains barriers
Seeing	1.6
Hearing	1.2
Moving around	1.8
Using hands or fingers	2
Learning new things	2.4
Remembering or focusing	1.7
Mental health	1.8
Energy levels or breathing	1.7
Interacting with other people	1.9
Pain or discomfort	1.4
Sensory processing	2.4
Immune system	2

[Note 1] Unweighted bases: Seeing = 228; Hearing = 479; Moving around = 452; Using hands or fingers = 238; Learning new things = 191; Remembering or focusing = 469; Mental health = 462; Managing energy levels or breathing = 531; Interacting with other people = 362; Being in pain or discomfort = 680; Sensory processing = 196; Having an overactive or underactive immune system = 247.

Table 23: Proportion of barrier types experienced by participants with different impairment types (percentage, %)

	Information and communication that is not accessible	Buildings and spaces that are not suitable	Views and behaviour from others that are not supportive	Rules, policies, and practices that do not support my needs	Other	None of these	Don't know or Prefer not to answer
Seeing	22	23	34	29	1	43	2
Hearing	18	20	27	23	2	51	2
Moving around	20	35	38	32	2	33	3
Using hands or fingers	26	36	41	38	3	30	1
Learning new things	32	39	51	43	1	20	3
Remembering or focusing	25	28	46	34	2	30	2
Mental health	20	27	50	34	1	30	3
Managing energy levels or breathing	19	30	44	34	2	33	2

	Information and communication that is not accessible	Buildings and spaces that are not suitable	Views and behaviour from others that are not supportive	Rules, policies, and practices that do not support my needs	Other	None of these	Don't know or Prefer not to answer
Interacting with other people	25	30	50	39	1	25	5
Being in pain or discomfort	18	29	37	29	2	36	3
Sensory processing	28	40	61	48	3	17	5
Having an over or under active immune system	24	32	42	39	1	30	3

[Note 1] Unweighted bases: Seeing = 228; Hearing = 479; Moving around = 452; Using hands or fingers = 238; Learning new things = 191; Remembering or focusing = 469; Mental health = 462; Managing energy levels or breathing = 531; Interacting with other people = 362; Being in pain or discomfort = 680; Sensory processing = 196; Having an overactive or underactive immune system = 247.

Table 24: The average number of barrier types experienced by participants with different impairment types

Impairment type	Average number of barrier types
Seeing	1.1
Hearing	0.9
Moving around	1.3
Using hands or fingers	1.4
Learning new things	1.7
Remembering or focusing	1.3
Mental health	1.3
Energy levels or breathing	1.3
Interacting with other people	1.5
Pain or discomfort	1.1
Sensory processing	1.8
Immune system	1.4

[Note 1] Unweighted bases: Seeing = 228; Hearing = 479; Moving around = 452; Using hands or fingers = 238; Learning new things = 191; Remembering or focusing = 469; Mental health = 462; Managing energy levels or breathing = 531; Interacting with other people = 362; Being in pain or discomfort = 680; Sensory processing = 196; Having an overactive or underactive immune system = 247.