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Social model of disability: discovery phase interim report

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1. Introduction and background

Historically, policy and legislation in the UK has been influenced by the medical model of disability. Review of medical model literature indicates that the model views an individual's impairment as the root cause of their disadvantages and focuses on curing or managing the impairment through medical interventions, with healthcare professionals as the experts (Crawford et al., 2012[1]; Cockburn et al., 2023[2]). This approach is also reflected in demographic survey questions used by the Welsh and UK Governments to collect data on disabled people, which were developed based on the Equality Act (2010) and by extension, the medical model.

In line with Government Statistical Service (GSS) guidance, government data collection has tended to use the long-lasting health conditions and illness (LLHCI) harmonised standard, and the activity restriction harmonised standards to ensure consistency in data collection and to align with the relevant legislation (Annex A). However, as also noted in the GSS guidance, these questions may not accurately capture the neurodivergent population; those receiving treatment or medication; those with 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; an alternative model which views disability as a result of societal barriers, not individual impairments. 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 has since identified that new survey questions are required to ensure 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 guidance. The questions need to capture disabled people’s experiences in line with the social model in a consistent and standardised way. The questions will also be suitable for use alongside indicators needed for legislative (for example, Equality Act, 2010) and policy monitoring purposes, and for planning for service demand.

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[1] 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 Disabled People – Canadian Case Study. Review of Disability Studies: An International Journal, 8(4).

[2] 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.

Upon completion, these questions will be shared with others including public bodies, the third sector, and other producers of statistics so they can be used more widely. The learning from this research will be shared with the GSS Harmonisation Team and other UK nations so that the questions can be adopted more broadly across government.

The research aims and objectives are listed below.

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 disabled people 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 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.

Research objectives

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

In keeping with the Respondent Centred Design Framework (RCDF), the research methodology included a ‘discovery’ phase, followed by an ‘alpha’ phase to design and test questions. The discovery phase was completed in April 2025, and this report synthesises findings from across all the discovery phase work packages. The alpha phase commenced in May 2025 and is scheduled for completion in March 2026.

The remainder of this section comprises of an overview of the discovery phase work packages and arrangements for oversight and scrutiny of the research. The aims, methods, and findings for each of the 3 discovery phase work packages are provided in Sections 2 to 4. Section 5 has a synthesis of discovery phase findings and insight into the next phase of the research.

1.1. Discovery phase overview

The discovery phase comprised of 3 consecutive, related, work packages:

- work package 1 (WP1): mapping data user needs and literature review
- work package 2 (WP2): review of existing survey questions
- work package 3 (WP3): deliberation workshops with disabled people

Findings from each work package informed subsequent phases of the research.

1.2. Project oversight

1.2.1. Project steering group

The Welsh Government established a steering group, comprising of policy officials, external experts, and people with lived experience, to oversee the research. Responsibilities of the steering group were to feedback on the main project documentation, provide expert input, and to advise on project management related issues including ethics, the 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 commented on the discovery phase proposed research design. Where feasible, recommendations from the group were incorporated into the design before progressing to the ethical review stage.

1.2.2. Ethical review

During the discovery phase research development process, the project underwent ethical scrutiny to ensure the proposed research processes and procedures in place were robust and ethical, and that the well-being of research participants was protected.

The Government Social Research (GSR) ethics checklist was completed for the discovery phase, to ensure the research was conducted in line with the 5 principles of the GSR Ethical Assurance for Social Research in Government.

The discovery phase of the project was also reviewed by the National Centre for Social Research's own Research Ethics Committee (REC). National Centre's REC procedures meet the requirements of the GSR Code.

All project staff received a copy of the Social Research Association ethical code and were bound by it. They 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 in the research 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.

1.2.3. Note on terminology

Not all evidence found during the discovery phase of this research used social model informed language. When summarising literature, it was important that article content was accurately reflected. This means some of the terminology used in this report may not correspond with social model language. This is used to avoid our misconstruing or misrepresenting the sources being summarised.

Similarly, it is acknowledged that when working with members of the public, people will vary in the extent to which they already use social model informed language in their day-to-day lives. Descriptions of how research participants responded to questions accurately reflect the language they used. So not to misconstrue evidence or misrepresent their 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. Work package 1: mapping data user needs

2.1. Aims

Work package 1 (WP1) comprised of 2 strands: a literature review and data user workshops.

The primary objective of the literature review was to synthesise academic and grey literature on different models of disability, and their reported advantages and disadvantages in relation to the design and delivery of survey research. Welsh Government have published the literature review as a separate, standalone, report.

To supplement the literature review findings, data user workshops were held with Welsh government employees; other government and public sector employees; and charity and third sector employees. The aim of these workshops was to gather the views of professionals who rely on, work with, or consult data and statistics about disabled people in Wales as part of their working lives. More specifically, the workshops aimed to understand which measures are used by different data users and for what purposes; what they appreciate about existing questions (particularly the GSS harmonised standards) and their limitations; and ultimately, if and how measures relating to impairment might be improved to better reflect the social model.

2.2. Literature review

2.2.1. Methodology

The evidence review adopted a literature review research design. The purpose of a literature review is to collate relevant studies within a limited timeframe to draw broad conclusions from an evidence base. There are several limitations to conducting literature reviews when compared to more systematic forms of synthesis, such as rapid evidence assessments. This includes potentially missing relevant texts, introducing bias into study selection, and not assessing the quality of studies included in the review. To mitigate these risks, the literature review approach was supplemented with additional steps indicative of a more systematic approach. This literature review methodology therefore consisted of:

- the identification of peer-reviewed research papers - searching academic databases using bespoke search strings and manual review of pre-identified journals
- the identification of grey literature - searching an online database using simplified search strings and a manual review of pre-identified websites
- the inclusion of evidence recommendations provided by a subject expert in survey measurement of various impairment types and the social model of disability

- backwards and forward tracking of important text citations

Details of the literature search strategy, the inclusion and exclusion critieria, search terms, and sources of both peer-reviewed academic and grey literature sources can all be found in the separate, standalone literature review publication.

The 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. Studies were selected to ensure coverage of research questions and to provide case studies of surveys and question sets. Once studies were shortlisted, a thematic framework was developed for data extraction, based on the Framework Method (Richie et al., 2014[3]). This Framework approach involved summarising the identified evidence in a matrix, with each row representing an individual evidence source, and the columns representing central themes and different models of disability. This approach ensured the review synthesised the most relevant evidence, and identified the central themes and evidence gaps.

2.2.2. Summary of main findings

Findings from the literature review outline how different models provide varying frameworks for understanding and addressing disability, substantially influencing survey design and societal approaches. The models include the medical, social, and biopsychosocial frameworks.

The medical model conceptualises being disabled primarily as resulting from a deficiency or impairment within the individual, and requiring medical intervention (Cappa et al., 2015[4]; Cockburn et al., 2023). The main advantage of this model cited within the literature is the clear diagnostic criteria. However, some disadvantages are noted, including limiting the focus to impairments with a medical diagnosis and overlooking any broader social determinants of health and wellbeing, for example access to healthcare (Loeb, et al., 2018[5]).

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[3] Ritchie, J., Lewis, J., Nichols, C. M., and Ormston, R. (2014). Qualitative Research in Practice. Second edition. Sage: London.

[4] 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.

[5] Loeb, M., Mont, D., Cappa, C., De Palma, E., Madans, J., and Crialesi, R. (2018). The development and testing of a module on child functioning for identifying children with disabilities on surveys. I: background. Disability and Health Journal, 11(4), 495-501.

The social model suggests that it is the societal barriers which disable people, rather than individual impairments (Burchardt, 2004[6]; Cockburn et al., 2023). This model highlights the need for societal change to remove barriers for disabled people and in doing so shifts the focus from peoples' impairments to the societal structures which restrict positive change for these individuals. However, criticisms of this model from the reviewed literature include the possible risk of downplaying the impact that impairments have on people's daily life, regardless of contextual factors, and interpretations that underestimate the intrinsic impacts and objective realities of impairments (Beaudry, 2016[7]; Crawford et al., 2012).

The biopsychosocial model seeks to integrate elements from both the medical and social models by recognising complex interactions between biological, psychological, and social factors (Norwich et al., 2016[8]). This approach is seen by some as providing a more nuanced understanding of being disabled that encompasses both individual impairments and environmental influences. It has, however, been criticised for its broadness and lack of clear guidelines for application (Roberts, 2023[9]).

Surveys and question set case studies identified by the literature review highlighted several important considerations.

- Many existing surveys fail to adequately capture environmental barriers for disabled people. Studies therefore recommended that surveys should integrate specific questions addressing accessibility, workplace inclusivity and societal attitudes (Loeb et al. 2018; Cappa et al., 2015; Lammons et al., 2024[10]).
- Many current measures use close-ended formats that restrict detailed insights into the lived experiences of disabled individuals. Some studies therefore recommend open-text responses, as well as avoiding the use of arbitrary

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

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

[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] Roberts, A., (2023). The biopsychosocial model: its use and abuse. Medicine, Health Care and Philosophy 26, 367-384.

[10] Lammons, A., Markham, S., and Saloniki, E.C. (2024). PPIE in a technical research study: using public involvement to refine the concept and understanding and move towards a multidimensional concept of disability. Health Expectations, 27(3), e14072.

scales that fail to capture the nuanced experiences of individuals (Beaudry, 2016; Crawford et al., 2012).

- Excessive survey length can deter participation and comprehensive data capture (Loeb et al., 2018). Balancing brevity with depth in survey design was essential to improve survey participation rates.

Some existing adult-centric standards are not appropriate or relevant for disabled children and young people. The literature review identified more appropriate ways of collecting data from children and young people, including the use of the Washington Group Child Functioning Measure (CFM) which assesses children's difficulties in areas such as vision, hearing, mobility, communication, and learning using a rating scale, and is suitable for population-based and national household surveys.

2.3. Data user workshops

2.3.1. Methodology

A series of 3 online workshops were held with users of disability survey data between June and October 2024. Each workshop was scheduled for 2 hours and included between 8 to 16 participants, with a total of 36 participants. 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.

A list of known data users was recommended by the Welsh Government, and each user's details were shared securely with NatCen, who issued invitations. Participants were allocated to one of the following 3 workshop groups, depending on their organisation:

- workshop 1: data users employed within the Welsh Government (8 participants)
- workshop 2: data users employed within UK government and other public sector bodies (12 participants from 9 different organisations)
- workshop 3: data users employed within third sector and community organisations (16 participants from 15 different organisations)

NatCen produced topic guides (Annex B) and a series of online interactive whiteboard activities to structure the data users' conversations. The workshops drew out participants' thoughts and suggestions on surveys that collect data on impairment. Participants were also asked to reflect on the benefits and drawbacks of the existing measures they used; the harmonised standards, including which of these should be retained or adapted; and the prospect of redrafting questions in accordance with the social model, including whether this would address the limitations of existing surveys. Participants were not encouraged to reach consensus positions.

At the end of each workshop, data users were asked to suggest priorities for the research, as well as preferred format for its outputs. Invitees who could not attend a scheduled workshop were given the opportunity to feedback via an email survey sent out after the workshops were held. NatCen researchers tabulated and analysed data from the online whiteboards, chat function, and the survey. The data were thematically coded, drawing on pre-set themes built into the whiteboard exercises, as well as the prevalence of data user responses. Participant numbers in small scale qualitative engagement like this are too low to establish quantitative thresholds for reportable themes. However, researchers were able to broadly identify the common or prevalent views, discussed below.

2.3.2. Summary of main findings

During the workshops, data users noted the small range of surveys used to collect data on people with impairments. Internal organisational surveys and governmental surveys at local, national, and international levels were the 2 most cited. Several themes emerged relating to how the measures are used.

All data user groups referred to using existing data to monitor and assess trends or evaluate and improve circumstances for disabled people. Some data users in workshops 1 and 2 (public sector organisations) referred to equality and diversity considerations for collecting data, including evaluating workforce diversity. Whereas those in workshop 3 (third sector and community organisations) use the data to further understand the needs of, and advocate for, communities they represent.

These uses are applied across several policy areas. Across each data user group, these include informing corporate or governmental policy or strategy decisions, the public policy context (for example, work and employment, health and social care, welfare), or the development of democratic services.

Existing and harmonised standards

Data users reflected on the benefits and limitations of the harmonised standards produced by the Government Statistical Service.

The current recommendation to collect disability-related data is to use the long-lasting health conditions and illness (LLHCI) harmonised standard along with the activity restriction harmonised standard together. Alternatively, the impairment harmonised standard looks at areas that are affected because of their health condition or illness (Annex A).

Advantages of the harmonised standards

Across the workshops, it was found that the standardisation provided by the harmonisation was one of the main advantages of using these questions. They comply with the 2010 Equality Act; include people with multiple impairments; and as they have been used over many years across all 4 nations of the UK, they are able to capture trends over time and provide a general sense of population needs. Some users described the questions as quick and easy, and others noted that as they do not refer to ‘disability’ directly, they can still be used to capture information about people who would not self-define using this term.

Disadvantages of the harmonised standards

Data users also reflected on 3 main limitations of the harmonised questions.

Firstly, conceptual limitations and an overreliance on the medical model were discussed. One data user said, “the impairment standard is not clearly connected to a clear concept.” Participants felt that the questions were unduly based on a “deficit model” and focused excessively on “limitations” caused by peoples’ impairments. They described the questions as “simplistic”, often conflating impairments with symptoms, and that the categories (for example, vision, mobility) are too broad and therefore not detailed enough to provide guidance for policymakers. It was suggested that there should be a clearer connection between the harmonised questions and the International Classification of Functioning (ICF) framework.

Linguistic limitations were also highlighted during workshops, including that the language used “sound negative [and] represent disability as negative”. Some users specifically objected to the way the harmonised questions offered a response option which referenced ‘autism spectrum disorder’: “the autistic community avoids this term as it has ‘disorder’ in it, and dislike being described as disordered”. Another concern was that the questions were too complex and difficult, which could prevent people from understanding or relating to them.

Finally, exclusionary features of the harmonised questions were noted in the workshops. For example, it was highlighted that the questions could exclude or create barriers to engagement for certain groups of people. Data users said that the wording does not account for fluctuating conditions or co-occurring impairments; it used dated or offensive language when referring to neurodivergence and learning disabilities which could be exclusionary; and that the questions would not work for some groups, including first-language British Sign Language (BSL) users.

Practical considerations for revising the standards

Data users also discussed the viability of the harmonised measures. Third sector users, who placed greater emphasis on the importance of self-identification and ensuring surveys capture data on those who may not “consider themselves” as disabled, said existing measures should be “re-written” in line with the social model.

Public sector and government data users noted that any adaption of the existing questions would need to be accompanied by “rigorous testing” to ensure new questions would yield the desired data, and work well for people with impairments and disabled people. This group also raised the possibility of re-drafting the questions to create a child-friendly version and reiterated the need to make new questions suitable for capturing data on neurodivergent people.

Across all 3 workshops, participants felt the questions should be redesigned with input from the people they are intended to serve, and not just organisations and professionals. Arguments were made for retaining the existing questions and supplementing them with new measures, as some users felt that discarding the harmonised measures entirely would reduce the ability to compare and track data over time.

Social model-informed questions

Data users engaged positively with the prospect of using social model-informed measures, with discussions in the workshops focusing on how they could avoid the gaps in the existing and harmonised questions, and any practical considerations for their development.

Advantages of social model-informed questions

A widely noted advantage of social model-informed measures among participants related to ‘conceptual reorientation’; the shift of focus away from viewing ‘disability’ as a problem with the individual, towards a focus on societal and environmental barriers (for example, inaccessible environments and exclusionary policies).

Data user workshops also identified a need for a ‘linguistic shift’, which participants felt could be achieved by adopting the social model, with evidence suggesting that adopting person-first language (for example, using ‘disabled person’ rather than ‘person with a disability’) can affirm identity and respect for individuals’ experience.

Data users said that the ability to use free-text response options in social model-aligned questions would allow respondents to define their own impairment, capture more in-depth information about varied experiences; provide the opportunity for people to use their own language to describe themselves; and enable individuals to articulate complicated or less classifiable circumstances. Surveys that gave more scope for respondent self-identification would enable more and better data to be captured on neurodivergent populations, those with fluctuating or recurrent health conditions, and children and young people. However, data users also noted practical limitations with a completely open approach, given the need for a classification system to generate statistics.

Disadvantages of the social model informed questions

Each cohort included in the data user workshops raised potential limitations of social model-informed measures.

Data users were concerned that the social model's provision for self-identification might risk data being less accurate and reliable if, for example, it becomes impossible to distinguish between respondents who have self-identified with (or self-diagnosed) a particular impairment, and those with a formal diagnosis. It was felt that this may be exacerbated by delays in the formal diagnosis of some neurodivergent conditions and could cause difficulties for implementing policy.

Third sector data users specifically emphasised that even if new measures were introduced in line with the social model, this would not change the reality that many people with impairments will continue to be disabled by societal barriers. As one third sector data user explained:

> "It doesn't matter how many accommodations society makes for them, they're still in pain / exhausted, and it's that that disables them – so we just need to bear that in mind and ensure that the questions are as inclusive and all-encompassing as possible".

Practical considerations for social model informed questions

Lastly, data users were aware of a range of practical considerations**.** As one participant put it:

> "If you're surveying disabled people only, then you need something tailored to the community more than the harmonised standards are. But if it [the survey] needs to be understood by the whole population, you'd need something more accessible for people who might be less familiar with the types of experiences or things relevant to disabled people."

Participants noted several factors to do with survey user-experience that the developers of social model-informed questions will need to engage with.

Data users from the Welsh government and across the public sector stressed the need for surveys to include guidance on the social model, so respondents understand the survey questions and could complete them without assistance. The trade-off was the prospect of lengthier survey questions, and a more taxing user experience. Additionally, they cautioned that having broader categories for impairment may lead to overly granular data, with the potential to complicate analysis and comparability.

Similarly, there were concerns that having to include guidance on the social model would increase the length of the surveys, which could pose difficulties for respondents and increase the drop-out rate. Most data users felt that having to “explain [the] social model of disability” to survey respondents might cause questionnaires to be too “lengthy”. Data users emphasised the need to strike a balance between survey usability and how much data could be captured.

Participants also noted that the format and mode of questionnaires may still be an exclusionary factor, which must be addressed. For example, data users noted that although online questionnaires were the default, there should be a range of modes used to cater for people without digital literacy and access to technology, and a range of ways to ask and answer the questions (for example, BSL, spoken, easy read). There were differing views on the importance of free-text responses among users, with some expressing concern that they might be too taxing for some respondents.

3. Work package 2: review of existing questions

3.1. Aims

Drawing on findings from WP1, the main aim of work package 2 (WP2) was to conduct a comprehensive systematic review of existing survey measures, from the UK and other countries, that capture information regarding disabled people and their impairments. The review 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 language of the social model of disability.

3.2. Overview of methods

The review started with the identification of relevant surveys aimed at collecting information on impairment and/or disabled people (Annex C). This included both disability-focused surveys and other surveys which contained disability-focused questions but were not the sole focus of the survey. The scope extended beyond the UK to international sources. This included private tools such as the Washington Group Enhanced Short Set or government sponsored surveys such as the Canadian Survey on Disability, and the European Health Interview Survey, to ensure a broad and representative list of measures.

A list of evaluation criteria (outlined in Annex D) was then agreed with the Welsh Government. To ensure thorough and consistent assessment of each of the selected survey instruments, the criteria were divided into 4 focus areas: descriptive and contextual information, concepts measured, meeting user needs, and administration features. Each area was then further sub-divided into more granular areas including the alignment of the survey with the social model of disability, the types of impairments measured, the availability of accessible variants, amongst other criteria (Annex D has a detailed list of measures). Compliance with the Equality Act (2010) and the ability to meet data user requirements that emerged from WP1 findings were also considered.

In total, question sets from 20 surveys were reviewed, these surveys are listed in Annex C. Each survey was coded against the set of evaluative criteria. The analysis then took the form of a report in which a brief overview was provided for each survey, alongside the relative advantages and disadvantages for each selected measure. The top-level findings from this analysis were written up and presented to the Welsh Government, along with a discussion on the main priorities that would inform work package 3 and subsequent questionnaire development.

3.3. Summary of findings

The findings from the review of existing survey measures are summarised below.

3.3.1. Models of disability

One of the main findings across the surveys reviewed was that ‘disability’ was largely conceptualised through the biopsychosocial model. One survey explicitly followed the medical model, and no single set of measures reflected the social model. The GSS harmonised standards, for example, assess ‘disability’ primarily through the presence of long-term health conditions and associated activity limitations, focusing on individuals’ impairments rather than barriers encountered. While this approach offers consistency and legislative alignment, it falls short in capturing the societal and environmental factors that can disable individuals.

In contrast, the Life Opportunities Survey offered an expanded model by asking respondents about barriers to education, employment, and participation in social activities. Similarly, the UK Disability Survey incorporated questions regarding societal attitudes, stigma, and accessibility barriers, aligned with the social model. However, such examples were relatively rare and where societal barriers were included, they were often secondary to questions about impairments and limitations, indicating a biopsychosocial approach.

While designed to capture functional limitations without necessarily attributing them to medical conditions, the Washington Group question sets still predominantly measure personal capacity rather than environmental or attitudinal barriers. These survey instruments are underpinned with a biopsychosocial orientation rather than a social model framing.

3.3.2. Coverage of impairments

The extent to which surveys captured the diversity of impairments experienced by disabled people varied. The impairment harmonised standard covers a broad but basic set of impairment domains such as vision, hearing, mobility, dexterity, learning, memory, and mental health. However, there are some notable gaps that these measures do not address yet. For instance, neurodivergence and fluctuating conditions are often poorly represented in these measures. The GSS impairment standard includes ‘socially or behaviourally’ as a category referencing ‘autism spectrum disorder’ and ADHD. However, use of such terms has been increasingly criticised by the neurodivergent community and disability-focused researchers for being vague, outdated, and pathologizing (for example, Bottema-Beutel et al., 2021[11]), and the category itself may be too narrow or imprecise to fully capture the experiences of neurodivergent individuals.

Similarly, there was limited consideration across most surveys of how fluctuating or progressive conditions (such as, multiple sclerosis or certain mental health conditions) affect people's daily lives. The Washington Group Short Set on Functioning Enhanced Questions was found to have made some attempt to address these limitations by including questions about affect (anxiety and depression) and dexterity, but questions about chronic fatigue, sensory sensitivity, or communication barriers were limited. The World Health Organization (WHO) Model Disability Survey offered a broader range of functional domains, including sleep and social participation, but at the cost of substantially greater length and complexity.

3.3.3. Measurement of barriers

Most of the reviewed surveys were limited in their ability to capture data on environmental and social barriers. Only 2 instruments from the ones that were reviewed, the Life Opportunities Survey and the UK Disability Survey, directly asked respondents about the barriers they faced in accessing services, engaging in employment, or participating in society.

The Life Opportunities Survey asked participants whether they experience difficulties in accessing health services and to assign causes such as unhelpful staff, inaccessible buildings, or lack of transport. Similarly, the UK Disability Survey asked about barriers to using public spaces, accessing products and services, and concerns about societal attitudes. These questions offer more detailed insights into the external factors that disabled individuals might encounter that is more consistent with the social model of disability. However, even in these cases, the measures tended to treat barriers as supplementary topics rather than integrating them fully into the primary conceptualisation of disability. This indicates a gap in survey design and the need to place greater emphasis on societal barriers as a central rather than peripheral component of understanding ‘disability’.

3.3.4. Linguistic framing

The review found that most surveys adopted either biopsychosocial or medical model language to discuss disabled people and impairments. Many surveys avoided using the word ‘disability’ directly and instead preferred to ask about ‘long-term health conditions’ or ‘activity limitations’. While this approach may reduce stigma and

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[11] Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: suggestions for autism researchers. Autism in adulthood: challenges and management, 3(1), 18–29.

encourage disclosure among those who do not self-identify as disabled, it also risks depersonalising the lived experiences of disabled people (Kafer, 2013[12]).

Some instruments used language that is now considered outdated or insensitive. For example, the English Longitudinal Study of Ageing referred to “infirmity”, a term likely to be seen as pejorative by disabled people’s advocacy groups for reinforcing ageist and medicalised stereotypes. Other surveys employed language that conflated impairments with medical symptoms which invariably reduces the focus on social participation and barriers. By contrast, the Washington Group question sets were designed to use simple, accessible language focusing on difficulty in functioning rather than diagnosis. However, even these instruments did not fully adopt the social model language as they emphasised individual difficulties without explicit reference to societal structures.

Therefore, there remains scope for developing survey questions that use affirming, inclusive language aligned with the social model, particularly by framing questions in ways that acknowledge the disabling effects of inaccessible environments and exclusionary attitudes.

3.3.5. Accessibility and mode of administration

The mode of survey administration and accessibility features varied across the survey instruments that were reviewed. Many surveys were originally designed for interviewer-administered face-to-face formats (examples include the GSS harmonised standards, and Life Opportunities Survey) and have only more recently been adapted for self-completion, telephone, or online administration.

It was found that surveys providing alternative accessible formats were rare. The UK Disability Survey and the Annual Disability and Activity Survey provided easy read versions and allowed completion in Welsh and BSL. Nonetheless, across many surveys, there was little evidence of systematic consideration of accessible formats beyond standard online or face-to-face completion. This presents a potential barrier to inclusivity, particularly for disabled people who may face communication, sensory, or cognitive challenges. Moreover, many surveys permitted proxy responses for children or individuals unable to complete the survey independently. While necessary in some ad hoc cases, there is uncertainty over the extent to which proxy reporting captures the subjective or lived experiences of disabled individuals, especially in relation to emotional well-being, autonomy, and perceived barriers.

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[12] Kafer, A. (2013). Feminist, Queer, Crip. Indiana University Press.

3.3.6. Children and young people

The experiences of disabled children and young people were only marginally addressed in many of the instruments reviewed. Most surveys relied on adult proxy responses to collect information about children's health conditions or impairments. The Washington Group-UNICEF Child Functioning Module stood out as a rare example of a tool specifically designed to capture children's functional difficulties through caregiver reporting. This addressed domains such as vision, hearing, mobility, communication, and social participation, and used scaled response options suitable for population-based household surveys.

The SEND Futures survey also represented a more inclusive approach, asking young people directly about the support they received in educational settings and their unmet needs. However, its education-specific focus limits its applicability to broader measures of 'disability' and participation outside the school environment. Overall, there remains a notable gap in survey instruments that meaningfully capture the perspectives and experiences of disabled children and young people across multiple domains of life.

3.3.7. Practical considerations

A further theme that emerged from the review relates to practical considerations of deploying reviewed measures within large-scale general population surveys, such as the National Survey for Wales. Short instruments, such as the GSS harmonised standards for measuring disability and the Global Activity Limitation Indicator (GALI), stood out for their brevity and ease of integration into existing surveys, although their conceptual limitations reduce their usefulness for measuring the full range of barriers experienced by disabled people.

Conversely, instruments such as the Life Opportunity Survey, WHO Model Disability Survey, and the Washington Group Extended Set offered more nuanced and richer data but at the cost of considerably greater length and respondent burden. These surveys are likely to take a substantial amount of time to complete, making them impractical for inclusion in general-purpose surveys in their current format.

The findings from WP2 suggest that while some existing measures partially align with the social model of disability, most would require substantial adaptation to fully reflect its principles and meet the needs of data users. Any future integration of social model-informed questions into mainstream surveys will need to consider conceptual alignment and how such measures can be practically implemented without compromising accessibility, clarity, or data quality.

4. Work package 3: deliberations with disabled people

4.1. Aims

Work package 3 (WP3) was led by NatCen's Centre for Deliberation (CfD). It focused on conducting deliberative research to understand disabled peoples' perspectives on how information about impairments should be collected and what type of questions should be asked in surveys. Specific aims were to:

- understand how disabled people in Wales think about the concepts of 'impairment' and 'disability', and the relevance of these ideas to their personal experiences
- share information about the medical model, social model, and how survey questions are used by the Welsh Government
- gather participants' views on the GSS disability harmonised standards, harmonised impairment question, and social model-aligned survey questions, and the trade-offs associated with each

4.2. Overview of methods

This stage of the research comprised 2 online deliberative workshops with disabled people from across Wales. To maximise accessibility, each workshop was divided into 2 half-day segments and all materials were made available in both BSL and easy read formats. Participants were also encouraged to attend alongside a companion to provide support during the event where needed, and encouraged to make known any additional support needs ahead of the workshop.

Deliberative research methods provide participants with the time, information, and conditions needed to engage in-depth with a topic. These processes typically take place over extended periods, although in this project, the same design principles were applied to shorter half-day segments. Materials on a given topic are provided to ensure that all participants have access to the same balanced information to inform their views (in this case, on the medical and social models of disability, and surveys). Trained facilitators support participants to discuss this information and form views on the topic. Deliberative research gives insights into people's considered views on complex, value-driven issues that often require trade-offs for resolution.

By using deliberative methods in this stage of the research, we were able to recruit a diverse range of disabled people, share complex and in some cases unfamiliar information (about disability models and surveys), and give them the time and space to reach considered conclusions. The workshops generated in-depth and reflective conversations, giving insight into participants' values and rationales that might not have been captured through other forms of engagement.

The CfD partnered with third party recruiters, who adopted a three-part recruitment drive: drawing on their extensive panel, working with local recruitment firms, and engaging with third sector organisations. Soft quotas were used to ensure people with different impairment types were represented (Annex E). A total of 40 participants took part in the deliberative research, with 20 people allocated to each workshop. Participants dropping out between sessions is common in deliberative research. However, only one participant from the day 1 session did not attend the day 2 session.

Participants alternated between plenary sessions (the whole group of 20 or 19 participants in one virtual room) and breakout rooms (smaller group discussions with 3 to 5 participants with a mix of impairments). The breakout rooms were moderated by CfD and freelance facilitators (who followed topic guides drafted by the CfD; Annex F). The workshops were not attended by members of the Welsh Government.

On day one, participants compared the concepts of 'impairment' and 'disability' and discussed the merits and drawbacks of the 2 'core' GSS harmonised standards for disability. On day 2, participants deliberated the GSS harmonised impairment question (Annex A) and an example social model-informed question drafted for use in the workshops (Annex G).

The findings summarised in the following section draw on data from facilitators' in-session notes and post-session reflections, as well as workshop audio recordings and transcripts. Using an online whiteboard programme, the CfD coded the findings deductively, using themes and headings from the workshop exercises; and inductively, through close analysis of the notes and transcripts. The small number of participants in deliberative research rules out quantitative or statistical analysis. Common or prevailing views and themes were identified, but the main findings are not explained quantitatively, or generalisable to the wider Welsh population. For the same reason, the views of particular individuals or groups (defined by impairment type or demographic characteristics) were not analysed for this report.

4.3. Summary of findings

Through the process outlined above, main findings were identified. These findings reflect the overall themes identified across the workshops as a whole.

- **Language:** participants expressed a range of views on the appropriateness of disability-related language, and how they relate to terms such as 'impairment,' and 'being disabled.' While there was no consensus on preferred terminology, some participants highlighted a preference for words like 'needs' or 'condition' over 'impairment' and 'being disabled'.
- **Comparability:** many participants struggled with the concept of data 'comparability,' often conflating it with the use of simple, clear and accessible language in survey questions. Similarly, the trade-offs posed in the workshops

between comparability and inclusive language were sometimes misinterpreted.

- **Inclusivity:** most participants judged inclusivity to be more important than comparability when designing survey questions. They defined inclusivity both as a linguistic quality relevant to the language used in survey questions, and as a conceptual category, ensuring survey questions captured a wide range of impairments and experiences.
- **‘Core’ harmonised standards:** participants identified numerous drawbacks and problems with the GSS ‘core’ harmonised standards (that measure long-lasting health conditions and illness, and activity restrictions). They highlighted that these could be difficult to answer, and exclusionary.
- **Impairment standards:** most participants preferred the harmonised impairment question over the 2 harmonised ‘core’ standards.
- **Social model sample question:** many participants responded positively to the idea of the sample question based on the social model but found the draft question too complicated and confusing. Most participants were in favour of the social model sample question being asked in conjunction with the harmonised impairment question.

These findings illustrate participants’ conceptual reflections on ideas like inclusivity and comparability, and their assessments of different survey questions, both existing (the harmonised standards and impairment question) and prospective (the social model informed question). More detailed findings are structured below, moving from more conceptual to more practical reflections.

4.3.1. Language

Throughout the workshops, participants shared their views on the language used to discuss impairments and the idea of being disabled. Researchers explored participants’ views by asking them directly about their understanding of terms such as ‘being disabled,’ ‘disability’, and ‘impairments,’ and by asking them to reflect on how specific survey questions were worded. Language featured in discussions in relation to how participants identified themselves, and how they perceived and understood various survey questions.

Participants expressed a range of views on how they liked to refer to their own ‘impairments’ or ‘disabilities’. In many cases, their understanding was aligned with the social model, as many participants described a distinction between being disabled and having impairments. However, some participants also expressed a preference for terms such as ‘needs,’ ‘difficulties,’ or ‘condition’ rather than impairment. One participant noted:

> "I would say I had a condition, and I think that's a far better word to use than disability, or impaired, which both have negative connotations".

Most participants held a negative view of the terms 'disability' and 'being disabled', associating these with restrictions and negative societal perceptions. One participant said they associated the term 'disabled' with "being spoken over" and gave the following example:

> "If I'm out with my husband and he says I'm disabled, they speak over me and speak to my husband, but they're asking me questions".

Some, however, preferred the term 'disabled' as they felt it highlighted the social aspects of disability, specifically the ways that society creates barriers.

> "Disability is more socially related for me…I would prefer to say I'm disabled rather than saying that I'm impaired. Because I feel like saying I'm impaired makes it sound like it's my fault, and it's sort of like me and my problem…whereas I feel like saying I'm disabled puts more of the responsibility on society and the barriers that they have [in] accessibility to accommodate for me."

Throughout the discussions, some participants used the term "mental impairment". For many, this term only had cognitive and learning associations, while for others, it had both mental health and cognitive associations.

Some participants offered reflections on how the wider populations' understanding of language might differ from the meaning or intentions of the social model. For example, while most participants indicated that they understood how the term 'barriers' was being used in the workshops, some suggested that the word was to abstract to be fully understood by the general public. They believed that older people in particular, would associate 'barriers' exclusively with physical barriers, and overlook the existence of attitudinal, environmental, and institutional barriers.

4.3.2. Comparability

Participants gave a range of views about the importance of comparability in designing survey questions. While some participants understood the value of having survey questions that generate comparable data, others struggled with the concept of data comparability, what it is used for, and what it can achieve. For example, many participants conflated 'comparability' with 'clarity'. When they discussed the importance of comparability, they tended to equate it with simple or clear questions. One participant stated that "if [a question is] written in a way that's simplified, it's easily comparable," while another said:

> "If you really want comparable data you need to firstly be using inclusive language because you're not going to reach everyone if you're not using

> language that’s easily accessible and that can be easily understood by all groups of people”.

Other participants equated ‘comparability’ with “getting accurate data”. These reflections indicate that the concept of comparability had slightly different meanings for participants than it does for policymakers.

When discussing the GSS ‘core’ harmonised standards and the social model sample question, many participants did not feel that comparing data over time to gauge changes in policy within Wales, or across the UK to compare policy implementation in different nations, was relevant. In some cases, this scepticism revealed further misapprehensions about the meaning and importance of data comparability. For example, some said they liked the idea of Wales doing something different from the rest of the UK, and that, because Welsh Government’s priority should be Welsh people, data comparability with the UK was not important. Others held the view that society is rapidly changing and so queried the importance of comparing data over time, as older information might not be relevant.

While many participants did value the benefits of having comparable data (defined in various, and in some cases erroneous, ways), some said that it was only worth comparing data on barriers (from a social model-aligned question). Similarly, others thought that comparing data on outdated measures (like the harmonised standards) was pointless.

Overall, participants offered mixed views on the importance of comparability. While some participants did find it to be an important consideration in developing survey questions, for many, the trade-off between comparability and inclusive language which facilitators asked about directly, was confusing.

4.3.3. Inclusivity

Most participants judged inclusivity to be more important than comparability when designing survey questions. However, ‘inclusivity’ was referred to in different ways and in different contexts. It was used to describe survey questions and response options that captured a range of impairments and disabling experiences. It was also shorthand for inclusive language.

For some participants, inclusivity was about ensuring different impairments or experiences of being disabled are captured in survey questions. They judged the ‘core’ harmonised standards as exclusionary because they did not capture the experiences of people with fluctuating impairments, neurodivergent people, those on medication, or people whose impairment had been impacting them for less than 12 months, as described below. As one participant noted when explaining why it would be difficult to select a response to these questions:

> "I'm neurodiverse. So where do I fit? It's not a mental health condition as far as I'm concerned, and I'm not ill…I experience lots of barriers, but…this is just part of who I am".

For other participants, inclusivity was about using inclusive language in the wording of specific survey questions. They felt that offensive or dated wording (for instance, the use of the term 'disorder') would make people reluctant to respond to questions. They felt that these terms had negative connotations – for example, that a person with a disorder may be violent or dangerous. As one participant said:

> "[I am] more likely to tick a box that doesn't say disorder, because I don't feel disordered. Autism is not a disorder…you hear somebody's got autism [and you think] they're automatically going to kill you".

Similarly, many participants objected to the way that the GSS harmonised impairment question linked the word 'behaviourally' with 'autism spectrum disorder,' stating that this would make them less likely to select this option. These participants worried that selecting a response option which suggested 'behavioural' problems could "limit opportunities" (especially regarding employment) or suggest that a respondent is "a bad person".

However, there were opposing views on the topic of inclusive language. A minority of participants felt that the idea of inclusive language was being taken too far - that accepted terminology was changing too rapidly, driven by younger generations, and that survey questions cannot accommodate everyone. For example, some participants did not realise that the term 'disorder' (used in the GSS harmonised impairment question in the context of 'autism spectrum disorder') was considered outdated by others, and they reacted with surprise when this was raised in the discussions. "Who says it's outdated?", asked one participant. While another said:

> "The fact they keep changing terminology that's acceptable on everything, it's getting ridiculous…you're fighting to open your mouth these days."

The sentiment that language was becoming too complex, and people were too easily offended was expressed by a minority of participants but was an important feature of the discussion in certain groups.

4.3.4. GSS 'core' harmonised standards

Participants were shown the GSS harmonised standards on long-lasting health condition and illness and day-to-day activities and were asked for their initial reflections. Initially, many participants said they would find these questions easy to answer. However, when these participants reflected on the questions and discussed them with others, many began to identify numerous drawbacks, concluding that they are difficult to answer and exclusionary.

Most participants thought that the questions and response options were too simplistic, and did not capture the complex experiences of being disabled. As the questions asks people to summarise the impacts of their impairments by responding to a ‘yes or no’ question, some participants felt they would be difficult to answer for people with fluctuating impairments, those taking medication, or those experiencing an impairment of uncertain duration. They said the questions did not capture the nuance and the changeability of their experience, and their answers to the questions might change, depending on how they felt on the day they answered.

For some participants, it was the exclusionary, negative, and subjective language that made the questions hard to answer. For example, participants pointed out that neurodivergent people might not categorise themselves as having a ‘mental health’ impairment or ‘illness’, which is the language used in both questions. Others felt the words ‘illness’ and ‘condition’ implied that an impairment is something to be cured.

The 12-month threshold was seen to disregard those who, for various reasons, may have had a ‘condition’ for less than 12 months. For the day-to-day activities question, participants said the subjective nature of the responses ‘a little’ or ‘a lot’ would leave people guessing their meaning. As one participant put it: “How do you measure a lot versus a little?”. For some, the interpretation and thinking required, and the risk of misjudging, made the question confusing, exhausting, and disabling.

Some participants said the overall framing of the ‘core’ standards, made them reflect on the effects of their impairments, in a way that was uncomfortable, even traumatising. A carer who was in attendance said that the person they support had “anxiety…[about] the questions”. According to another participant:

> “You spend your life trying to be well and being positive about it…and then you've got to [complete this] form…and it's all so negative.”

Some participants reacted adversely to the questions due to the stigma associated with being disabled, and their fear of judgment. One participant said:

> “I see it as a complete negative and I feel labelled by society by answering that question how they expect me to answer it.”

Conversely, some participants did not identify as disabled and opposed the questions on that basis.

4.3.5. GSS harmonised impairment question

Most participants reacted more positively to the GSS harmonised impairment question, calling it “gentler” than the ‘core’ harmonised standards. Participants said this question was easier to complete than the other standards and provided a more realistic understanding of how a person can be affected by an impairment. Some also felt it used more sensitive language than the other standards.

The question was viewed as easy to understand and answer because it included a broader range of responses than the other harmonised standards, and in some cases provided examples clarifying the meaning of the response options. The response options for the harmonised impairment question include ‘Other’, allowing people to self-identify with an impairment not captured by the other options. The harmonised impairment question also allows people to select ‘all the answers that apply’ rather than limiting them to one. Participants felt these features would enable the collection of in-depth and accurate data that reflects disabled people’s complex experiences, as opposed to the ‘core’ harmonised standards, which reduce responses to ‘yes’ or ‘no’. That said, for some participants, the greater level of detail, and a more open, less binary approach felt overwhelming and exhausting, and difficult to comprehend.

A few participants preferred the phrase ‘health conditions’ to ‘conditions’, saying that it seemed friendlier. However, most participants still felt the harmonised impairment question used outdated and offensive language with negative connotations. They thought terms like ‘health conditions’ and ‘illness’ were implicitly negative, and that coupling ‘health’ with ‘condition’ excluded people who do not think of their impairment as a health condition, for example, neurodivergent people. Most pointed out that the word ‘disorder’ in relation to ‘autism spectrum disorder’ is offensive and would need to be changed. As one participant put it:

> “I don't like the word, the term disorder, which includes Asperger's, which again is quite an outdated term”.

Participants had different views about how the language in the harmonised impairment question should be adapted. Some said they preferred words like ‘condition’ and ‘needs’ to ‘health conditions’ or ‘illness’. Others said the response option ‘Socially or behaviourally’ was stigmatising. In relation to ‘autism spectrum disorder’ in particular, these terms might suggest a lack of control or “something you attribute to a child”, which would likely cause offense and make a neurodivergent person reluctant to select this option.

> “I'm uncomfortable ticking something that suggests that I might have some behavioural problems, which might mean the other person reading this might think, I don’t want to be around this person because I might get attacked or behave in a strange way that might make me uncomfortable.”

Some participants also noted issues with the question format and structure. Some asked if it could be adapted to offer open text responses, or accommodate a longer list of impairments, noting that some impairments were not captured adequately in the response options, for example, colitis and communication impairments. It was also highlighted that some categories were vague and subjective, and needed to be defined so it was clearer what they encompassed. For example, some felt the ‘memory’ response option overlapped with the ‘learning’ response option.

When asked, most participants felt that the benefits of the impairment standard (the more inclusive language and more detailed response options) outweighed any drawbacks. However, their discussions reveal a more complicated set of considerations. In comparison to the ‘core’ harmonised questions, the impairment question was viewed positively as it displayed a better understanding of, and gathers in-depth data on, impairments. However, when considering the question in isolation, participants overwhelmingly felt that the drawbacks outweighed the positives. As one participant phrased it:

> “It's definitely an improvement on that [the harmonised standards]. But I think it still needs to be improved further”.

4.3.6. Social model sample question and trade-offs

Most participants reacted positively to the idea of a social model-inspired survey question, but found the draft question put to them by facilitators to be too complicated and wordy. Many participants approved of the fact that the sample social model question (Annex G) listed discrimination as a barrier, noting that experiences of discrimination were not touched on in any of the other questions they discussed in the workshops. Some participants said the question was “empowering” and would make them feel like the government “cared” for them by showing attention to the barriers people face.

While there was significant approval for this question’s attention to the barriers that people may encounter in the world, many participants said it was too lengthy, “confusing”, and required too much “brain power” to answer. This was due to what many perceived as the overly complex language in the question, which some described as not very “user friendly”. Other participants stated that “the people who need to answer it don’t understand it” and that “it’s not very plain language … not everybody will know what [terms in the social model question] mean”.

Some participants reflected on the content of the question and the information it could or could not capture. For example, some found the time parameter in the social model sample question relating to the past 12 months confusing, noting that the impacts of discrimination could be felt for longer than a year. Some participants said specific types of barriers were missing; they felt the question should include barriers people face inside their homes, as well as barriers relating to employment. Several participants also suggested that the question could be more “‘visual” using pictorial icons to highlight main points.

Most participants were in favour of the harmonised impairment question and a social model-style question being asked together, as this could help to link data on impairments with data on barriers and produce more actionable data. As one participant stated:

> “I think the intention is the right intention – about looking at barriers – because…to me that implies that they're going to do something with the information. If they want information about what barriers people are facing…they must be interested…they must want to do something and change it. But if they're not going to link it [data on barriers] to impairments or make the question more user friendly and more meaningful…, how are they going to do anything with the information?”.

Overall, participants tended to particularly appreciate the sample social model question’s focus on barriers, but raised several points about its complexity, useability for disabled people, and the necessity of linking it with the harmonised impairment question.

5. Synthesis of discovery phase findings

5.1. Main findings from discovery phase

The purpose of the discovery phase was to collect information to support the development of survey questions that measure ‘disability’, whilst aligning to the Welsh Government’s ongoing commitment to the social model. The discovery phase involved:

- a review of the existing literature on the relative strengths and weaknesses of different models of disability
- a review of requirements of different data users
- a review of what questions have been used to measure ‘disability’ in other surveys
- deliberative events, with disabled people from the general public, about their views on the appropriateness of disability-related language, and their views on different forms of question

Within the existing literature, the main advantage of the social model was found to be its focus on the societal barriers and the need to remove these barriers, to enable disabled people's full participation in society. In contrast, the main criticism is the potential for focusing on environmental and social factors of disability and interpretations that underestimate the intrinsic impacts and objective realities of impairments on daily life (Beaudry, 2016; Crawford et al., 2012).

In the literature review, some authors suggested the biopsychosocial model provided a more nuanced understanding of disability as being an intersection between an individual’s health condition, their impairments, and both environmental and societal influences. However, the main critiques evident from the literature related to its broadness and its potential lack of application in a policy setting. There were also concerns that, where the biopsychosocial model has been applied in practice, it had become impairment centred. For example, in the survey context, existing survey measures generally failed to capture much information on environmental barriers for disabled people, with their primary focus being on health conditions and/or impairments.

When it comes to current use, existing data users (professionals who use statistics about disabled people as part of their work) described using different sources of ‘disability’ data for a variety of purposes. Some use government funded general population survey data (for example, the National Survey for Wales), some use institutional survey data (for example, to evaluate their workforce or profile of their service users), and some use surveys of disabled people to find out about their lived experiences (for example, advocacy groups described conducting their own ‘quality of life’ surveys amongst the groups they represent).

Data users described collecting data about disabled people for similar motivations - to evaluate to what extent disabled people are excluded and to ultimately develop policies to improve their experiences. Despite this commonality, in practice the data from different sources have different, specific purposes. It was strongly stated by data users that the most appropriate questions to use when measuring impairment or disabled people should be informed by context and the aims of research.

- Some data users described the importance of being able to consistently monitor changes over time using the same standardised questions as they were interested in maintaining data compatibility without introducing a confounding factor by changing question wording. In contrast, other data users did not raise this as a consideration.

- Some data users stated the importance of wanting to use definitions of ‘disability’ that align with relevant legislation (such as the Equality Act, 2010), whereas others did not raise this as a consideration.

How detailed or specific questions need to be is dependent on context. As a practical example, questions used in routine equality, diversity, and inclusion (EDI) monitoring forms need to be kept relatively short and simple. ‘Disability’ is one of many characteristics measured in these forms which means questions need to be kept brief. In contrast, an entire survey that focuses on experiences and barriers encountered by disabled people collect higher levels of detail and can include more questions on different topics.

The aim of this project is to develop a set of questions that can be used to collect information relating to impairments and disabled people, that align with the social model. The questions would be used in Welsh Government surveys and could also be used more widely by other public bodies in Wales and in the UK. The data users consulted for this project described how they use current ‘disability’ questions for purposes such as monitoring diversity in service uptake and workforce characteristics. The target audience are members of the general population (both disabled people and non-disabled people) completing questionnaires on multiple topics. Data users stressed brevity as an important consideration and how questionnaire length needs to be kept to a minimum. It is beyond the scope of this project to design a standalone survey for disabled people that asks about all the barriers they face in different domains of their life.

The desk review of questions identified a broad range of surveys that measure ‘disability’, from the UK and internationally. This review did not identify any question sets that solely used the social model. A variety of questions were identified that measure impairments in different formats. None of the identified question sets were completely free from language which inferred that impairments affect activities, or limit function in some way. Most included some reference to health or health conditions. Of the examples found, even those that referred to themselves as being social model informed, questions seemed to align more closely with the biopsychosocial model.

During the deliberative workshops, participants discussed their views on the appropriateness of disability-related language, including how they themselves would prefer to be described. There was no consensus over preferred terminology. Some participants highlighted a preference for descriptions such as, having ‘needs’ and ‘conditions’ over ‘impairments’ or ‘being disabled.’ It should be noted that social model informed language (like the distinction between having an impairment and being a disabled person) did not consistently resonate with members of the public, with some saying they think both terms can sound negative. One advantage of the existing harmonised questions is that they measure disabled people and impairment without using either of these terms directly. This feature should be retained for any future questions used by Welsh Government.

Most disabled people who participated in the deliberative events felt that inclusivity should be considered more important than data comparability when deciding what questions should be used in future Welsh surveys. By inclusivity, participants were referring to using non-exclusionary language, that reflects the broadest range of possible impairments. Some participants felt that if the harmonised questions use “outdated” terms or language, or terms that are difficult to understand, the questions may not collect accurate information. These participants felt that the Welsh Government’s priority should be improving questions for Welsh people, rather than being tied to what has been before, or what is being used elsewhere in the UK. However, it should be noted that during the deliberations, participants were not familiar with what comparability meant in this context, and participants’ reflections were based on their views as ‘survey completers’ rather than end users of statistics.

During the deliberative events, participants showed more support for Welsh Government using the GSS harmonised impairment question over the harmonised ‘core’ questions (on long-lasting health conditions and activity restriction). However, some participants thought the harmonised impairment question still had specific wording issues and would benefit from being refined further.

Participants were positive about including a question on societal barriers to supplement an impairment question. They noted that the intention of including a barriers question seemed positive, and that this could help improve disabled people’s perceptions of the ‘disability question set’ as a whole. However, it was noted that if questions on barriers are added to Welsh Government surveys, this should be because the information collected is going to be used in policy formation rather than just to make existing questions appear social model aligned. Likewise, participants described that the sample barriers question (produced for the deliberative workshop) was long-winded, and that it would be difficult to formulate a simple “catch-all” question which measures the full spectrum of barriers that disabled people encounter.

5.1.1. Advantages and disadvantages of different approaches

No single question-set, that met the needs of all groups, was identified during the discovery phase. It is important to note that it is unlikely that such a question-set could be formulated in practice, given that the priorities of different stakeholder groups are conflicting.

There is tension between the needs of some stakeholders who want to prioritise harmonised question wording for time-series analysis (and for alignment with Equality Act 2010 definitions) with those who want to prioritise non-harmonised questions that use more social model orientated language, or more inclusive language related to specific impairment types.

A summary of the advantages and disadvantages are outlined for the 3 main approaches identified during the discovery phase:

- the GSS harmonised standard questions on long-lasting health conditions and illness, and activity restriction
- the GSS harmonised standard question on impairment
- potential new questions on societal barriers that people with impairments encounter

Various impairment questions were reviewed in addition to the GSS harmonised impairment standard, for example, the Washington Group Short Set and the WHO Model Disability Survey. These alternative impairment questions had both advantages and disadvantages when compared to the GSS harmonised impairment standard. However, given the alternatives also had similar issues, for the sake of simplicity the GSS harmonised question is used as the main basis for comparison.

GSS harmonised ‘core’ questions: long-lasting health conditions or illnesses and activity restriction

Advantages

- **Comparability:** the ‘core’ standards are used in multiple long-running government surveys, in Wales and in the UK more broadly. By using standardised questions, it is possible to measure trends over time (for example, whether outcomes for disabled people in Wales are improving or not) and to compare data between different countries (such as, Wales versus England).
- **Alignment to legislation:** language used within the ‘core’ standards align with the wording of the Equality Act (2010), including its definition of ‘disability’.

- **Practicality:** the ‘core’ standards are quick to administer, eliciting benefits to both survey respondents and data users. Both question guidance and validated Welsh Language translations are also available.
- **Respondent identity:** questions do not refer to ‘disability’ directly - people do not need to self-identify as disabled.

Disadvantages

- **Exclusionary language:** questions use medical model language, which may exclude people who have an impairment that they would not classify as an illness or health condition. For example, neurodivergent people or deaf people will often not describe themselves as ‘having an illness or health condition’.
- **Conflict with social model principles:** the activity restriction question asks whether ‘a health condition or illness reduces your ability to carry out activities.’ This goes against social model principles (that disabled people are limited by societal barriers, not by their health conditions).
- **Restrictive definitions:** the questions ask about illness or health conditions that last, or are expected to last, 12 months or more. It is potentially unclear how these questions should be answered by people with fluctuating impairments or those who are unsure how long their impairment may last.
- **Respondent preference:** the ‘core’ standards were the least preferred option by participants in the deliberative workshops.

GSS harmonised question on impairments

Advantages

- **Comparability:** while less commonly used than the ‘core’ standards, harmonisation means data can be compared across certain UK surveys and countries (for example, Wales versus England).
- **Closer alignment to social model principles:** concepts measured are more aligned with the social model than the GSS harmonised ‘core’ questions, as it attempts to measure impairments rather than health conditions or illnesses.
- **Practicality:** there are more examples of what to include and exclude compared to the GSS harmonised ‘core’ questions. The questions are quick to administer and could be used alongside multiple other socio-demographic questions. Welsh translations are also available.
- **More inclusive language:** although this question is about impairments, it does not mention the word impairment directly; this term was seen as too negative by some participants.

Disadvantages

- **Exclusive language:** the language used is not completely aligned to the social model as the question stem wording still refers to ‘health conditions or illnesses’ as an alternative to mentioning impairments.
- **Outdated or offensive terminology:** the language used around some impairments was considered to be outdated and potentially offensive by some individuals, for example, using ‘autism spectrum disorder which includes Asperger’s’ instead of ‘autism’.
- **Restrictive response options:** the list of impairments was considered by some as incomplete and potentially ambiguous, for example, being affected ‘Socially or behaviourally’. Specific issues were also raised 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 regarding disabled children, and children with Additional Learning Needs.

Existing and example questions on societal barriers that disabled people encounter

Advantages

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

Disadvantages

- **Lack of an existing standard:** existing examples of questions about barriers were designed to supplement questions on health conditions and/or impairments, rather than being a standalone alternative.
- **Respondent burden:** existing examples of questions around barriers were from longer question sets, asked in the context of longer surveys, to disabled people about their lives. The examples were not single questions that could be added to a multiple topic survey without impacting length. Having a higher number of questions is negative from a respondent perspective and could also impact adoption of the questions by data users.

- **Need for further refinement:** reactions to the sample question were mixed, with some participants suggesting that the question was too long-winded and others stating it did not include enough options for barriers encountered.
- **Practical limitations:** any single question could not collect information on all types of potential barriers encountered. There will be a tension between including as many of the potential barriers as possible for different groups of disabled people, while keeping the question sufficiently brief and user-friendly.

5.2. Recommendations for questionnaire development

Based on the findings from the discovery phase we recommend the following options for questionnaire development are prioritised during the next project phase. These options are:

1. an updated impairment question, based on the GSS harmonised impairment standard; and
2. a new question on societal barriers that people with impairments encounter.

These options will not be mutually exclusive. The impairment question should be considered a necessary precursor question to the societal barriers question as it will be required to set the context (for example, to avoid the inclusion of barriers unrelated to impairments). A social model focused impairment question could also be used as a standalone question. An impairment question would meet the needs of data users who described needing questions to monitor uptake of service use amongst disabled people, but also amongst other socio-demographic groups.

The societal barriers question should be considered a highly beneficial supplement for collecting information about disabled people, as it more closely aligns to social model concepts than an impairment question used on its own. However, it should also be noted that a societal barriers question may not be appropriate in all contexts and that its intention would be to supplement, rather than replace, impairment data.

For option 1 (the updated impairment question), we recommend that the design work should focus on fine-tuning the existing harmonised impairment question to address some of the disadvantages raised. The new question should attempt to address the following issues:

- potentially outdated terminology related to ‘disorders’ and ‘illnesses’
- phrasing of conditions that affect people ‘socially’ or ‘behaviourally’
- clarity over fluctuating conditions
- how well the impairment question works for parents who answer about their children

The new question should consider the wording from the various impairment questions identified in the desk-review, with the idea to ‘cherry-pick’ the best features of the different questions. It should be noted that the GSS harmonised impairment standard has been designed for interviewer administered surveys, where interviewers are provided with additional guidance on how to classify ambiguous cases. However, the new question should be tested to establish whether it is suitable for self-completion surveys. Many government surveys are transitioning to web-first designs and likewise many other institutional surveys rely on self-completion formats rather than interviewer administration.

For option 2 (a new question on societal barriers), we recommend producing a single question where participants who state they have impairments are asked to describe whether they have experienced any barriers because of these, from a ‘check-all that apply’ list of possible options. Question development work should focus on developing a high-level list of barriers that will be relevant to both policymakers and to a broad range of disabled people. It is noted that a single question will not collect very granular information on all types of barriers encountered. The priority of the question development would be to work with disabled people to develop a clear list of the barriers they feel are most pressing, and that are most relevant to different types of impairment.

5.3. Retention of existing ‘disability’ questions

It should be noted that, as a result of the discovery phase, it is not recommended for the new questions to replace the GSS harmonised ‘core’ questions (on long-lasting health conditions and illness, and activity restriction) for all Welsh government surveys in the short to medium term. This is because some of the needs raised by data users (for example, maintaining time-series data) would be best addressed by allowing existing measures to run alongside new measures for a period of time, until sufficient data points are available for a new time-series of data to be established.

Combining the existing ‘core’ standard and any new measures would not fully align to the principles of the social model but would still represent a step towards a social model approach. Combining existing and new questions is the optimum way of meeting the conflicting priorities raised by different groups and is likely to help facilitate the adoption of new measures by a wider variety of data users.

5.4. Next steps

The research now moves into the alpha phase. Priorities for this next phase have been reviewed and approved by the project steering group, and the research design will undergo ethical scrutiny before commencement.

Planned strands of the alpha phase work are as follows:

- work package 4 (WP4): develop new measures
- work package 5 (WP5): cognitive testing of new measures
- work package 6 (WP6): field test of new question(s) alongside GSS harmonised 'core' questions

At the end of the alpha phase of the research, a final synthesis report will be produced for Welsh Government. Further information on each of the individual strands of work is covered below.

5.4.1. Work package 4

This strand of work involves the development of new questions that measure impairment and disabled people in a way that is more aligned to the principles of the social model. Multiple options to trial will be produced, including separate versions for adults and for collecting, by proxy, information about disabled children. New measures will be written in plain English and mirror the terminology used by disabled people in work package 3.

All new questions will be designed to be unimodal; they will function equally well in computer assisted personal interviewing (CAPI), computer assisted telephone interviewing (CATI), and web or paper-based administration. Once finalised by Welsh Government, draft questions in Welsh language and BSL will also be produced to take forward to the next strand of work.

5.4.2. Work package 5

Cognitive interviews will be carried out with a diverse range of participants to allow researchers to examine the thought processes that participants go through when completing the new questions. Welsh, English, and BSL versions of the questions will be tested. Participants will be asked the new social model questions; additional feedback about what they were thinking when answering the questions will also be collected.

Multiple versions of the social model questions will, if necessary, be tested within a single interview to get feedback on different options and how they compare. Findings will be used to refine question wording in advance of the next strand of work commencing.

5.4.3. Work package 6

The most up to date versions of the questions will then be piloted on NatCen's random probability panel. Field testing the questions in this way will allow for the collection of quantitative data on how well new question(s) perform in a general population Web-CATI survey. It will enable collection of prevalence estimates of disabled people using the newly developed social model questions and compare the responses collected to current GSS ‘core’ harmonised questions. Questions will be asked to a representative sample of British adults aged 18 and over, with a Welsh respondents’ boost. An analysis plan will be agreed in advance with Welsh Government, but it is anticipated that analysis will provide insights into the existence and size of differences in estimates produced by the new measures compared to the existing harmonised standards.

After work package 6 is complete, a synthesis report will be produced, documenting findings from all the work packages conducted in the alpha phase. This report will detail how well the new questions performed in the cognitive and field tests. Respondent and interviewer feedback on the new items will also be presented, including any sensitivities involved in administration. Accessible executive summaries of this report will be produced, and the research will be published in an accessible PDF format, in both English and Welsh.

Annex A: GSS harmonised standards

Government Statistical Service (GSS) harmonised standards are updated periodically. The versions listed below, and used in the discovery phase, were the most up to date available when the discovery phase was carried out.

- Long lasting health conditions and illness

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

Yes

No

Spontaneous only: Don’t know / Refusal

- Activity restriction

Does your condition or illness / do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?

Yes, a lot

Yes, a little

Not at all

- Duration of restriction

(If participants answer option 1 or 2 at the previous question, an additional question on duration can be asked)

For how long has your ability to carry out day-to-day activities been reduced?

1 Less than six months

2 Between six months and twelve months

3 Twelve months or more

- Impairment

Do any of these conditions or illnesses affect you in any of the following areas?

Showcard of possible responses and code all the answers that apply:

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 1 – Data user workshop: topic guides

1. Welcome and introduction

Welcome to the data user event.

Everybody introduces themselves and their interest in the project.

Reminder of accessibility and adjustments:

- captions
- contributions welcome in the chat and verbally
- ask if any extra time is needed to consider questions
- let us know if you need anything and we will do our best to help

Reminder of anonymity and confidentiality.

Permission to record and transcribe.

2. Background and purpose of this research

The Welsh Government adopted the social model of disability in 2002. The social model of disability recognises that people with impairments are disabled because of barriers to participation that commonly exist in society. Unlike the medical model of disability, in which a person's impairment is viewed as the thing that disables them, the social model defines disability as arising via societal, attitudinal, and environmental barriers.

The Equality, Race and Disability Evidence Units in Welsh Government have commissioned a research project to develop and test a set of survey questions that measure disability, in line with the social model of disability. Their aim is to use these questions, where relevant, across Welsh Government and other government data collections. They will share the questions with various public bodies to ensure they can be used more widely. The research will also be shared with the harmonisation team and other UK nations so the newly developed questions can be adopted across government.

NatCen researcher explains an overview of the project including the different work packages and how these fit together – emphasis that this is not the only occasion to comment, and today's discussion will feed into a broader program of work.

The project delivery program consists of a discovery phase and an alpha phase, with a synthesis report at the end of each phase.

The discovery phase is split into 3 parts:

- work package 1: establish data user needs
- work package 2: review existing measures
- work package 3: deliberative research with disabled people

The alpha phase is also split into 3 parts:

- work package 4: develop measures
- work package 5: cognitive interviews
- work package 6: field test

3. The social model of disability

How familiar are you with the social model of disability?

Participants (2 or 3) asked to share their definitions and understanding of the social model.

NatCen researcher shares 2 or 3 slides recapping the main ideas underpinning the social model.

4. Existing measures

We will now turn our focus to existing survey questions you use to generate statistics identifying people with impairments and/or people disabled by barriers. We want to understand what measures or questions you use or are aware of already, what insights they generate, and their strengths and drawbacks. We are also open to hearing general reflections on measures or questions around impairments and/or barriers.

Online whiteboard activity (participants reminded that they can also comment in the chat or verbally)

On the whiteboard: what measures or questions do you currently use to identify people with impairments in Wales and/or the barriers people experience, and what do you use them for?

> (these could be those used in repeated national surveys (like the Census, Labour Force Survey, etc.) or those used in more ‘ad hoc’ surveys)

- What surveys do you use to collect information on disabled people in Wales or elsewhere?
- What sorts of questions do these ask?

- Are there any questions you find particularly unhelpful? Why? (please share any examples)
- Who or what do you use them for?
- Which policy areas do they, or should we, feed into?

NatCen researchers and the whiteboard instructions encourage participants to write out the specific questions they use, but if they cannot remember it is okay to simply say the survey name.

Please take a few minutes to contribute on the whiteboard. Using a different sticky note for each idea, take some time to list out the current measures you use.

NatCen researchers ask the group to share their contributions, explaining in their own words what is on the board.

Thinking about the existing measures or questions you have just shared, how would you assess these?

Prompts

- What works, what are their strengths? Why?
- What doesn't work? Why?
- What's missing? Conceptually and in terms of the data collected.

10-minute coffee break

Participants return

5. Reflecting on the harmonised questions

To what extent are you aware of different harmonised questions used in national surveys?

NatCen researchers show slide with examples of harmonised questions from the GSS on impairment, activity restriction, and long-lasting illness. Some may have been mentioned on the online whiteboard already.

- To what extent are these harmonised questions useful in your role?
    - What do you use them for?
- What are the issues you are aware of with these questions?
    - Do they leave anything out?
    - How well do they work for different groups?

        - People with different types of impairment, health conditions, or who are neurodivergent.
        - People with multiple or fluctuating conditions.
        - Children and young people.
        - Welsh speakers.
    - Are there other protected characteristics for which these questions may not work?

- To what extent are these different from other existing measures you noted before?

- Views on whether harmonised questions could be amended, versus views on whether they should be retained in their current format but supplemented with new measures that align with the social model (no expectation of consensus here, the aim is to document all views)?
    - Why (possible prompts - time series and comparability; other consequences of changing; importance of aligning language to Welsh Government core values)?
    - What reassurances on quality would you need prior to agreeing any changes?

6. Social model informed measures – thinking about the future

Online whiteboard activities

How would measures or questions framed by the social model (as discussed at the start of the session) avoid the pitfalls identified previously, if at all?

To what extent would these:

- fill gaps left by current models – data or conceptual gaps?
- cohere with policy language or objectives?

How do you intend, or would like to, use an updated set of measures and questions, or the data that are collected using these new questions?

- How will you use these?
- Would these be added to a general population survey?
- Practical constraints we should consider:
    - length or max number of questions

    - response options (tick box, write-in)
    - ability to give multiple responses
    - topics (for example, questions on both impairment and barriers?)
    - different formats of data collection (for example, online, interviewer lead, self-report, proxy responses)
    - other

7. Final summary and prioritisation

Online whiteboard activity

What areas would you most like us to focus on for this project, and what outputs would you find most helpful? What format would these outputs take?

Moderator to give a brief overview of what has been discussed and any conclusions that have been reached.

8. Close and thanks

Thank you very much for taking part today. Is there anything else that we did not cover that you would like to add?

Annex C: Work package 2 – Questionnaire review: list of surveys reviewed

Government Statistical Service (GSS) harmonised standards

Long lasting health conditions and illness harmonised standard

Activity restriction harmonised standard

Impairment harmonised standard

Other UK surveys

National Survey for Wales

Life Opportunities Survey

UK Disability Survey

Annual Disability and Activity Survey

The English Longitudinal Survey of Ageing (ELSA)

The Scottish Health Survey (SHeS)

SEND Futures

The Washington Group on Disability Statistics

The Washington Group Short Set on Functioning (WG-SS)

The Washington Group Enhanced Short Set on Functioning (WG-SS Enhanced)

The Washington Group Extended Set on Functioning (WG-ES)

WG/UNICEF Child Functioning Module (CFM) ages 2 to 4 years, and 5 to 17 years

WG ILO Labor Force Survey Disability Module (LFS-DM)

Other international surveys

The Global Activity Limitation Indicator (GALI)

World Health Organization WHO Model Disability Survey and Functioning Disability Tool (FDD11)

New Zealand Disability Survey (Household Disability Survey)

Canadian Survey on Disability (A New Survey Measure of Disability: The Disability Screening Questions (DSQ))

Survey of Disability, Ageing and Carers (SDAC) by Australian Bureau of Statistics

EQ-5D-5L (EuroQol)

European Health Interview Survey (EHIS)

Annex D: Work package 2 – Questionnaire review: survey review criteria

Evaluation criteria

Descriptive and contextual information:

- who was it developed for or by?
- which country was it developed for?
- survey topic

Concepts measured:

- model of disability aligned to
- other related concepts measured
- impairment types directly measured
- impairment types not measured
- types of barriers experienced measured, if applicable

Meeting data user need:

- any issues raised in the literature review or by data users, if applicable
- any benefits raised in the literature review or by data users, if applicable
- consistent use of social model language
- data user needs met
- comparable with other sources
- alignment with Equality Act, 2010

Administration features:

- type of data collection vehicle
- target population
- mode of administration
- availability of guidance for interviewer or participant
- availability of accessible versions
- availability in languages other than English
- evidence of pre-testing
- proxy data collection status
- guidance on analysing and using data available

Annex E: Work package 3 – Deliberation: recruitment process and quotas

Recruitment, representation, and accessibility

NatCen's recruitment partners recruited disabled adults in Wales across 12 different impairment categories identified by the Welsh Government. The 12 categories included auditory, visual, physical, and mental health impairments, as well as neurodivergence, and others. Quotas were set for each impairment type, and the aim was to recruit 2 groups of 25 participants in each workshop, for a total of 50 people completing the process. Ultimately, 2 groups of 20 (with 40 people in total) participated in the workshops.

Recruitment across all 12 impairment categories was successful. Some groups, such as the auditory impairment group, had fewer people than the target quota; others, such as memory were slightly overrepresented. No British Sign Language (BSL) users were recruited; this group is not reflected in the deliberations. When asked, no participant expressed a need or preference for Welsh language. Though the pre-workshop briefing materials were distributed in English and Welsh, the workshop itself was conducted exclusively in English.

A range of impairment types were accommodated for by providing briefing materials in easy read, BSL video, and audio formats. Slides used in the workshops were drafted using easy read text. Facilitators gave directions verbally and using the chat function on the online meeting platform. Some participants were accompanied by an additional person to support them join and participate in the session. The workshops had longer scheduled breaks and a lower total engagement time (5 hours) than is typical for deliberations.

How impairment types were split across sessions and days

Group 1

Session times: Saturday, 10am to 12pm and Sunday, 10am to 1pm

Impairment types: auditory; learning disability; neurodivergent; energy; memory; speech

Group 2

Session times: Saturday, 1pm to 3pm and Sunday, 2pm to 5pm

Impairment types: visual; long term physical impairment; mobility; emotional; mental health; dexterity

Table 1: Quotas for impairment types in group 1

Impairment type	**Recruitment target**	**Recruited participants**
Auditory	4	2
Learning disability	4	4
Neurodivergence	5	2
Energy	4	4
Memory	4	5
Speech	4	3
Total	**25**	**20**

This table for group 1 shows that recruitment targets were met for most impairment types. Neurodivergent participants and participants with an auditory impairment were the most under-recruited groups. Participants with a memory impairment were marginally over-recruited.

Table 2: Quotas for impairment types in group 2

Impairment type	**Recruitment target**	**Recruited participants**
Visual	4	3
Long term physical impairment	4	4 [Note 1]
Mobility	5	2
Emotional	4	4
Mental health	4	3
Dexterity	4	4
Total	**25**	**20** [Note 1]

This table for group 2 shows that recruitment targets were met for most impairment types. Participants with a mobility impairment were the most under-recruited group.

[Note 1]: one person attended the first group 2 session but not the second, reducing the number of attendees with a ‘long term physical impairment’ from 4 in the first session to 3 in the second session. This also reduced the total number of participants from 20 in the first session to 19 in the second session.

Annex F: Work package 3 – Deliberation: topic guides

Activities

Each of the 4 breakout room activities were followed by facilitators sharing themes from group discussions in the plenary. On the first day, in plenary, participants heard 2 presentations from the Welsh Government, one on the meaning and implications of the social and medical models, and the other describing how the Welsh Government uses surveys. Participants had the opportunity to ask speakers questions.

Day 1 – Information and existing survey questions

Deliberative research on the social model of disability: discussion guide

Summary: the first day of the deliberative workshops will introduce participants to the dialogue by gauging their initial views on ‘disability’ and ‘impairment’. We will present them with information about the social model of disability and existing survey questions relating to impairments and disabled people. Participants will have the chance to hear from guest speakers and ask them questions. Participants will reflect on the main trade-offs underpinning the harmonised ‘core’ questions.

By the end of the session, people will have:

- shared their views on the concepts of disability and impairment, and to what extent these mean different things to them
- gained understanding of how survey questions are currently used to collect information related to disabled people
- gained understanding about the social model of disability and how it differs from the medical model
- shared their views on the GSS harmonised ‘core’ questions
- considered the main trade-offs when designing and wording survey questions on impairments and disabled people

Running order overview – day 1

1. Facilitators and tech support join the call

NatCen lead facilitator

Morning session: 9.30am to 9.50am (20 minutes)

Afternoon session: 12.30pm to 12.50pm (20 minutes)

Sound, cameras, hosting, connections tested, and any tech issues resolved. Communication between facilitators set up and tested (using a messaging platform).

2. Participants welcomed and let into the room

NatCen lead facilitator

Morning session: 9.50am to 10am (10 minutes)

Afternoon session: 12.50pm to 1pm (10 minutes)

Participants are welcomed and asked to rename themselves with their first name, the first letter of their surname, and their location. Any tech, camera, assistive technology, or sound issues resolved. Participants reminded that tech support (NatCen RA) is available.

3. NatCen introduction to the dialogue process, admin and 'housekeeping'

NatCen lead facilitator

Morning session: 10am to 10.10am (10 minutes)

Afternoon session: 1pm to 1.10pm (10 minutes)

Live presentation from NatCen:

- outline of this session and the research as a whole
- roles of Welsh Government, NatCen, and participants
- how we use evidence (reminder of privacy notice)
- housekeeping: recording, ground rules, use of online meeting platform, and accessibility considerations
- introduce first breakout

4. Breakout 1: impairment versus disability

Group facilitators

Morning session: 10.10am to 10.25am (15 minutes)

Afternoon session: 1.10pm to 1.25pm (15 minutes)

An opportunity to gather participants’ views on what the concepts of disability and impairment mean to them, and if they see them as distinct.

5. Speaker 1: the 2 models of disability

Welsh Government speaker

Morning session: 10.25am to 10.35am (10 minutes)

Afternoon session: 1.25pm to 1.35pm (10 minutes)

Live presentation on the social model of disability.

6. Speaker 2: introduction to surveys

Welsh Government speaker

Morning session: 10.35am to 10.45am (10 minutes)

Afternoon session: 1.35pm to 1.45pm (10 minutes)

Live presentation on surveys and data collection.

7. Question and answer

NatCen lead facilitator and Welsh Government speakers

Morning session: 10.45am to 10.55am (10 minutes)

Afternoon session: 1.45pm to 1.55pm (10 minutes)

Participants given the chance to ask questions of the speakers, chaired by NatCen lead.

8. Break

NatCen lead facilitator

Morning session: 10.55am to 11.10am (15 minutes)

Afternoon session: 1.55pm to 2.10 pm (15 minutes)

Participants remain on the call but take a break.

9. Welcome back and introduction to the next breakout

NatCen lead facilitator

Morning session: 11.10am to 11.15am (5 minutes)

Afternoon session: 2.10pm to 2.15 pm (5 minutes)

Everyone comes back to the call and participants are introduced to the next breakout.

10. Breakout 2: harmonised ‘core’ questions

Group facilitators

Morning session: 11.15am to 11.55am (40 minutes)

Afternoon session: 2.15pm to 2.55 pm (40 minutes)

This breakout will gather participants’ views on the questions currently used in surveys to collect information related to disabled people. It will ask participants to reflect on the trade-offs associated with these questions (comparability versus exclusionary language).

11. Closing session in plenary

NatCen lead facilitator

Morning session: 11.55am to 12.00pm (5 minutes)

Afternoon session: 2.55pm to 3.00 pm (5 minutes)

Live 10-minute presentation by NatCen:

- housekeeping
- what the next session will cover

Workshop schedule

1. Introduction (10 minutes)

Objective: to understand the scope, purpose, and structure of the workshops, including the roles of Welsh Government, NatCen, and participants.

- NatCen lead facilitator introduces themselves and welcomes all participants in plenary.
- Live 5-minute presentation from NatCen lead facilitator introducing the research process and any housekeeping.
    - Outline of the process and sessions.
    - Roles of Welsh Government, NatCen, and participants.
    - How we use evidence and data (reminder that all information is in the privacy notice).
    - Housekeeping: recording, ground rules, use of online meeting platform, accessibility information (including tech support and messaging (NatCen researcher) for help troubleshooting).
- NatCen lead facilitator introduces first breakout room discussion and NatCen tech support moves participants into breakout rooms.

2. Breakout 1: impairment versus disability (15 minutes)

Objectives

- To introduce participants to each other and what to expect from breakout rooms.
- To understand what the terms ‘disabled’ and ‘impairment’ mean to participants.
- To gauge whether they see these terms as different.

Facilitator notes: please note that for everything you say, there is a corresponding part to share in the chat.

Text to post in chat is in blue.

Facilitator to introduce themselves and their role and post the basic ground rules for discussion (already outlined by the lead facilitator) in the chat.

Quickly say the ‘rules’ below out loud in addition to posting in the chat.

Breakout room rules and format

- No one is expected to be an expert.
- Communicate with each other rather than directly to the facilitator.
- Everyone’s thoughts and ideas are important.

- You can contribute by speaking, or by typing in the chat.
- It is ok if people do not agree.
- Listen and support each other to share.
- I will verbally explain activities and put them in the chat.

Quickly say the note below out loud in addition to posting in the chat.

If you find the discussions difficult for any reason:

Please let me (the facilitator) know via private chat, or by speaking. If you decide you no longer want to participate, you can leave the breakout room and let the lead facilitator know in the main room.

Activity 1: introduction (3 minutes)

Ask participants to introduce themselves with their first name and share one word or phrase that comes to mind when you hear the word ‘disabled’. Reassure them it is ok if they do not know or if it is a negative view. They can just give their impression or personal view.

Copy and post in chat:

Activity 1: introduction

1) Tell us your first name

2) What is one word or phrase that you think about when you hear the word ‘disabled’?

Facilitator to let participants know you will start the audio recording and to see if there is any objection to recording (objection can be said verbally or sent in chat).

Facilitator to let participants know that they will also be taking notes as they speak and that they are still listening when they look down or elsewhere.

Start recording.

Activity 2: disability versus impairment (12 minutes)

Facilitator to take notes as discussion happens.

Facilitator to ask participants in turn to take a minute to think about the questions and then ask them to share their responses for each question respectively (copy and paste in the relevant question before you ask it).

1. What does disability mean to you? Why?
2. What does impairment mean to you? Why?

3. Do you see the terms ‘being disabled’ and ‘having an impairment’ as having different meanings?

Stop recording.

Facilitator thanks participants and lets them know we will now move back into the main room where they will hear from speakers.

3. Speaker: the 2 models of disability (10 minutes)

Objective: to introduce participants to the main ideas around the social model of disability, and how it differs from the medical model.

- Welsh Government presents on the social model of disability for 10 minutes.
- NatCen lead facilitator introduces the next speaker.

4. Speaker: introduction to surveys (10 minutes)

Objective: to provide context about the surveys currently used by the Welsh Government, and questions they use to gather data on disabled people or impairments.

- Welsh Government presents on surveys for 10 minutes.
- NatCen lead facilitator introduces the question-and-answer session.

5. Question and answer (9 minutes)

Objective: to provide the chance for participants to ask questions of the speakers.

NatCen lead facilitator opens the plenary up to participants to ask any clarification questions they have.

If participants provide comments rather than questions:

- NatCen lead facilitator to acknowledge participants thoughts and views and inform them that there will be an opportunity to discuss in the breakout rooms

If participants have too many questions for time allocated:

- NatCen lead facilitator to acknowledge participants and inform them that if they post their questions in the chat or tell their facilitator in their breakouts, these can be taken away by NatCen researchers and answered at the start of day 2

If participants do not ask any questions, present the 1 or 2 questions pre-prepared with speakers from beforehand.

- The social model says people are disabled by the barriers they face in the world rather than because of their health conditions or impairments. However, people's experiences of the world are hugely variable. How will surveys which are based on the social model capture the variety of experiences people have when they interact with other people, environments, and organisations?
- How much detail would the social model-informed questions require, and how long would social model surveys be?

Plenary before break (roughly 1 minute)

- NatCen lead facilitator to announce that there is a 15-minute break.
- Everyone to stay on the call but just mute and turn off mics and cameras.
- Upon returning turn cameras back on (or post in the chat) so we know you are there.

6. Break (15 minutes)

7. Plenary before breakout room (roughly 1 minute)

NatCen lead facilitator introduces the next breakout room discussion and NatCen tech support moves participants into breakout rooms.

8. Breakout 2: reflections on the harmonised questions (40 minutes)

Start recording.

Objectives

- To introduce participants to the harmonised questions.
- To introduce and understand their views on the harmonised questions trade-offs.
- To get an understanding of how important comparability and inclusive language is to participants when considering the use and design of survey questions.

Facilitator to take notes as discussion happens.

Facilitator welcomes everyone back and explains that they will show them the 2 harmonised standards that are used together to collect information on disabled people. (Context, which facilitators don't need to mention: the harmonised standards are based on the legal definition of disabled in the Equality Act, 2010.) These 2 questions are currently used in the National Survey for Wales and other surveys across the UK:

(Share screen to show slide from facilitators' pack.)

1. long-lasting illness question
2. day-to-day activities question

Facilitator shares screen and shows each question in turn. For each question, facilitators read the question aloud and give participants 2 minutes to read it themselves.

Facilitators then ask participants the following questions (copy and paste the question before asking them):

Activity 1: what do you think of these harmonised questions? (5 minutes)

What are your initial reflections on these questions?

How easy or difficult would it be for you to answer these questions? Why?

Activity 2: considering the trade-offs in the context of harmonised questions (25 minutes)

Facilitators say: using these harmonised questions in surveys (like the National Survey for Wales) means that the information they collect about disabled people can be compared with information from other surveys in the UK and older Welsh data, which also use the harmonised standards.

Using the harmonised standards makes it easier to analyse data wherever it is collected. It means that data collected from different surveys can be assessed together, providing more detailed information about, and a better understanding of, disabled people. Using information from lots of different surveys about disabled people means that better decisions and policies can be made. These policies affecting disabled people can be compared in different places and over long periods of time, making it easier to assess their effectiveness.

(Reference and show slide for detail of benefits.)

However, as you may have noticed, the questions are exclusionary. By asking people if their health condition affects their normal day-to-day activities, they assume that impairments or health conditions are what disable people. They therefore reflect the medical model of disability, which says that people are disabled by their impairments or health conditions. Also, these questions are difficult to answer for certain groups. For example, neurodivergent people may not refer to their neurodivergence as an ‘illness’ or ‘condition.’ People taking medication for an illness or condition may not currently have their activities restricted and can find these questions confusing to answer as a result. The questions are also difficult to answer for those with progressive conditions and fluctuating impairments.

(Show slide with details of how these populations are excluded.)

Considering this…

1. (Priority) What do you think of these questions now? Have your views changed in any way?

    (Prompt) Does the fact these questions generate comparable data outweigh the fact that the questions assume people are disabled by their impairment? Why?

2. Do you think all disabled people would agree with you? Or do you think different people – with different health conditions or impairments – will have different perspectives? Why?

If there’s time, you could ask:

3. If you worked for the Welsh Government or as a policymaker, would you continue using these questions? Why?

Activity 3: importance of comparability and inclusive language (10 minutes)

Facilitator to ask participants: after considering the trade-off in the harmonised questions between comparability and exclusionary language…

(Priority): When it comes to surveys about impairments and disabled people, what matters more to you – comparability (over time and with other surveys) or inclusivity of language?

- For those who prioritise comparability:
    - what is the most important advantage of data comparability (richer data, improved policy, comparisons over time or place)?
- For those who prioritise inclusive language:
    - why is it so important?
    - is there anything that might outweigh the drawbacks of exclusionary language?
        - for example, if a survey was able to reveal a particular insight? or was being used for a particular purpose?

Stop recording.

- Facilitator thanks participants for their contribution today and their time.
- Facilitator to let them know we will now move back into plenary where the lead facilitator will finish up.

9. Closing Plenary (5 minutes)

Objective: to provide participants with information about the next stages of the process.

Lead facilitator to:

- thank participants and emphasise the importance of their contribution
- remind participants to get in touch via email or the number provided if they have any issues, questions, comments, or feedback
- provide a brief overview of what will be covered in the session tomorrow
- thank participants and close

10. Post-workshop

Facilitators to upload notes taken and recording from day 1 session.

Day 2 – The harmonised impairment question and social model-informed measures

Deliberative research on the social model of disability: discussion guide

Summary: the second day of the deliberative workshops will allow participants to review other possibilities for survey questions, including the harmonised impairment question and social model of disability informed survey questions.

By the end of the session, people will have:

- shared their views on what they think about the harmonised impairment question
- shared their views on what they think about social model-informed questions
- considered a series of trade-offs associated with each option

Running order overview – day 2

1. Facilitators and tech support join the call

NatCen lead facilitator

Morning session: 9.30am to 9.50am (20 minutes)

Afternoon session: 1.30pm to 1.50pm (20 minutes)

Sound, cameras, hosting, connections tested, and any tech issues resolved. Communication between facilitators set up and tested (messaging platform).

2. Participants welcomed and let into the room

NatCen lead facilitator

Morning session: 9.50am to 10am (10 minutes)

Afternoon session: 1.50pm to 2pm (10 minutes)

Participants are welcomed and asked to rename themselves with their first name, the first letter of their surname, and their location. Any tech, camera, sound issues can be resolved through contacting tech support to help on the call.

3. NatCen recap of day 1 and any ‘housekeeping’

NatCen lead facilitator

Morning session: 10am to 10.10am (10 minutes)

Afternoon session: 2pm to 2.10pm (10 minutes)

Live presentation from NatCen:

- recap outline of this session and the research as a whole
- recap roles of Welsh Government, NatCen, and participants
- recap use of evidence (reminder of privacy notice)
- recap housekeeping: recording, ground rules, use of online meeting platform, and accessibility rules
- recap of day 1 findings

- introduce first breakout

4. Breakout 1: harmonised impairment question

Group facilitators

Morning session: 10.10am to 10.55am (45 minutes)

Afternoon session: 2.10pm to 2.55pm (45 minutes)

Participants share views on the harmonised impairment question.

5. Plenary feedback of breakout 1

Group facilitator

Morning session: 10.55am to 11.05am (10 minutes)

Afternoon session: 2.55pm to 3.05pm (10 minutes)

Facilitators feedback themes from their respective groups.

6. Break

NatCen lead facilitator

Morning session: 11.55am to 11.25am (20 minutes)

Afternoon session: 3.05pm to 3.25pm (20 minutes)

Participants remain on the call but take a break.

7. Plenary: welcome back and introduction to next breakout

NatCen lead facilitator

Morning session: 11.25am to 11.30am (5 minutes)

Afternoon session: 3.25pm to 3.30pm (5 minutes)

Everyone comes back to the call and are introduced to the next breakout.

8. Breakout 2A: social model of disability questions

Group facilitators

Morning session: 11.30am to 12pm (30 minutes)

Afternoon session: 3.30pm to 4pm (30 minutes)

Participants share views on social model questions and to begin considering the trade-offs.

9. Break in the breakout session

NatCen lead facilitator

Morning session: 12pm to 12.15pm (15 minutes)

Afternoon session: 4pm to 4.15pm (15 minutes)

Participants remain on the call but take a break.

10. Breakout 2B: social model of disability questions in scenarios

Group facilitators

Morning session: 12.15pm to 12.40pm (25 minutes)

Afternoon session: 4.15pm to 4.40pm (25 minutes)

Participants share views on social model questions when considering them within different contexts.

11. Plenary feedback of breakout 2

Group facilitator

Morning session: 12.40pm to 12.50pm (10 minutes)

Afternoon session: 4.40pm to 4.50pm (10 minutes)

Facilitators feedback themes from their respective groups.

12. Closing session in plenary

NatCen lead facilitator

Morning session: 12.50pm to 1pm (10 minutes)

Afternoon session: 4.50pm to 5pm (10 minutes)

Live 10-minute presentation by NatCen:

- housekeeping
- what happens next

Workshop schedule

1. Introduction (10 minutes)

Objective: to recap important items from Day 1 and launch Day 2.

- All participants welcomed by NatCen lead facilitator in plenary. Facilitator to introduce themselves.
- Extremely quick live 5-minute presentation from NatCen lead facilitator to recap the research process and any housekeeping.
    - Outline of the process and sessions.
    - Roles of Welsh Government, NatCen, and participants.
    - How we use evidence and data (reminder that all information is in the privacy notice).
    - Housekeeping: recording, ground rules, use of online meeting platform, accessibility information (including going to the tech support for any troubleshooting queries).
    - Recap of what was done in ‘Day 1’.
- NatCen lead facilitator introduces first breakout room discussion and NatCen tech support moves participants into breakout rooms.

2. Breakout 1: harmonised impairment question (45 minutes)

Objectives

- To understand participants’ thoughts on the harmonised impairment question.
- To get participants to consider trade-offs associated with this question.

Facilitator notes: please note that for everything you say, there is a corresponding part to share in the chat.

Text to post in the chat is in blue.

Facilitator to introduce themselves and their role and post the basic ground rules for discussion (already outlined by the lead facilitator) in the chat.

Quickly say the ‘rules’ below out loud, in addition to posting in the chat.

Breakout room rules and format

- No one is expected to be an expert.
- Communicate with each other rather than directly to the facilitator.
- Everyone’s thoughts and ideas are important.
- You can contribute by speaking, or by typing in the chat.
- It is ok if people do not agree.
- Listen and support each other to share.
- I will verbally explain activities and put them in the chat.

Quickly say the note below out loud, in addition to posting in the chat.

If you find the discussions difficult for any reason:

Please let me (the facilitator) know via private chat, or by speaking. If you decide you no longer want to participate, you can leave the breakout room and let the lead facilitator know in the main room.

Facilitator to let participants know you will start the audio recording and to see if there is any objection to recording (objection can be said verbally or sent in chat).

Facilitator to let participants know that they will also be taking notes as they speak and that they are still listening when they look down or elsewhere.

Start recording.

Facilitator to take notes as discussion happens.

- Facilitator will show participants one question, known as the harmonised impairment question, which is not currently used in the National Survey for Wales, but is used in the Crime Survey for England and Wales, English Housing Survey, Health Survey for England, and Family Resources Survey. This question is part of the UK harmonised ‘core’ questions. The question looks at the functions that a person either cannot perform or has difficulty performing because of their health condition.

(Share screen to the slide with the questions.)

- Facilitator shares screen and shows the question. Facilitators read the question aloud and then give participants 2 minutes to read it themselves.
- Facilitators then ask participants the following questions (copy and paste the question before asking it).

Activity 1: what do you think of the harmonised impairment question? (5 minutes)

What are your initial reflections about this question?

How easy or difficult would it be for you to answer this question? Why?

Activity 2: pros and cons of the harmonised impairment question, and how it compares to the other harmonised standards (30 minutes)

Facilitators say: this question is not like the 2 harmonised questions we looked at yesterday about long-lasting illness and day-to-day activities. This question does not simply ask people whether they have a health condition. Instead, it asks what type of impairment someone has, for example, a visual impairment or a mobility impairment. This means it collects more detailed information about people’s impairments. Also, this question does not ask people if they are disabled but asks if they are ‘affected’ by their condition or illness.

(Reference and show slide for benefits.)

However, the question also has some drawbacks. For instance, it does not account for all impairments, and it uses some insensitive and outdated language, for example referring to autism as a ‘disorder’.

(Reference and show slide for cons.)

Considering this…

(Copy and paste questions and prompts in the chat as you ask them.)

1. (Priority) What do you think about this question now?

Prompts

- How would you feel about being asked about your specific impairment types?
- Is the list of impairments comprehensive and correctly worded? What do you think about the length of the question?

- Is it preferable to be asked about your impairments and if or how they affect you, rather than being asked about the ways you might be disabled?

If a reminder is needed

An impairment is an injury, illness, health condition, or neurodivergence.

Disability is where people with impairments are not able to take part in society on an equal level because barriers stop them.

2. Imagine a neurodivergent person – say, an autistic person – is asked this question. How do you think they would feel about this question?
    a. Or imagine you're a BSL user who identifies as a different language user, not someone with an impairment. How do you think they would feel about this question?

Activity 3: considering the trade-offs in the context of the harmonised impairment question (10 minutes)

Copy and paste questions and prompts below, into the chat as you ask them.

Facilitator to ask participants: after considering the pros and cons of the harmonised impairment question…

- (Priority) Do you think the benefits of this question outweigh the costs? Why or why not?
- If you worked for the Welsh Government or as a policymaker, would you continue using these questions? Why?

Stop recording.

Facilitator thanks participants and lets them know we will now move back into plenary where discussions from groups will be fed back.

3. Feedback from breakout 1 (10 minutes)

Objective: to allow participants to hear the thoughts of all groups on the option of using the harmonised impairment question.

- NatCen lead facilitator welcomes everyone back and explains that we will now hear from facilitators from every group, who will feedback thoughts that have emerged from their groups on the harmonised impairment question.
- Facilitators to feedback the 2 or 3 themes that emerged from their group on their thoughts on the trade-off (activity 3).

- NatCen lead facilitator announces that:
    - there is a 20-minute break
    - everyone to stay on the call, on mute and turn off mics and cameras
    - upon returning, turn cameras back on (or post in the chat) so we know you are there

4. Break (20 minutes)

5. Plenary before breakout (5 min)

NatCen Lead facilitator welcomes everyone back and introduces next breakout.

NatCen tech support moves participants into breakout rooms.

6. Breakout 2A: social model of disability question (30 minutes)

Objectives

- To understand participants' views on the social model question.
- To get participants to consider the trade-offs of using the social model question as opposed to the current harmonised questions.

Start recording.

Facilitator to take notes during discussion.

Facilitator to explain that they will show them a question which is not currently used in surveys (share slide with social model question).

- Facilitator shares screen and shows the question. Facilitators read the question aloud and then give participants 2 minutes to read it themselves.
- Facilitators then ask participants the following questions (copy and paste the question into the chat before asking).

Activity 1: what do you think of the social model of disability question? (5 minutes)

1. What are your initial reflections on this question?
2. How easy or difficult would it be for you to answer this question? Why?

Activity 2: considering the trade-offs in the context of social model questions (25 minutes)

Facilitators say: this question is more aligned with the principles of the social model of disability. The question asks people about the barriers in the world that might prevent them from doing the things they want, and how these interact with health conditions. It asks about different types of barriers: attitudinal, institutional, communication, and environmental, and recognises that some people will experience multiple barriers. The question also uses appropriate and sensitive language (reference and show slide of benefits).

However, as you may have noticed, the question does not capture all possible barriers. Also, because the question does not ask about impairment categories, by itself, it will not tell us which barriers affect which impairment types. This means that even if the barriers identified through this question were addressed, we would not know which people were impacted by the changes (reference and show slide of cons).

Considering this…

1. What do you now think of this question?

Prompts

- How would you feel about being asked about the barriers you encounter in the world?
- Compared to the other questions we have looked at, do you think this question is missing anything? What, if anything, would it fail to capture?
    - (The thing that is missing is: insights into which impairments people have.)
- How would you feel about being asked this question, together with the harmonised impairment question?
    - (This would allow Welsh Government to link data on barriers with data on impairments, and understand which people were impacted by which barriers.)

Break in the breakout (15 minutes)

- Facilitator to announce that there is a 15-minute break.
- Everyone to stay on the call but please mute and turn off mics and cameras.
- Upon returning, turn cameras back on (or post in the chat) so we know you are there.

7. Breakout 2B: social model question in scenarios (25 minutes)

Objective

- To consider the trade-offs for the social model questions.
- To understand participants’ views on the social model questions under different scenarios.

Activity 3: social model survey scenario

Facilitators say: if the Welsh Government adopted entirely new social model-informed survey questions, there would be advantages including more inclusive and accurate wording when describing different impairments, and a greater focus on the barriers people encounter. However, data from these surveys would be less comparable with other surveys about disabled people - in the UK, or older Welsh data.

Facilitators show participants a slide outlining a scenario.

Scenario: currently, the UK government run a number of surveys to see how well different groups of people, including disabled people, are faring in society. For example, they collect information on how many disabled people are out of work, disabled people’s levels of wellbeing, and disabled people’s views about public services in their area. The UK surveys use the harmonised standards to define and measure ‘disability’. If Wales measures ‘disability’ in a different way to other countries, it becomes hard to tell if disabled people are better off in Wales compared to England, Scotland, or Northern Ireland. It becomes more difficult to judge if Welsh policies that aim to improve the lives of disabled people are effective, or not, compared to policies used in other countries.

Facilitators ask participants the following questions:

1. would the benefit of social model-informed questions (for example, a focus on barriers not impairments, more sensitive language) outweigh the potential drawbacks of not being able to compare Welsh data with wider UK data?
    a. how concerned are you about the possibility of Welsh data on disability not being comparable to UK data? Why?

Stop recording.

8. Feedback from breakout 2A and 2B (10 minutes)

Objective: to allow participants to hear the thoughts of all groups on the option of using the social model question(s).

- NatCen lead facilitator welcomes everyone back and explains that we will now hear from facilitators from every group, who will feedback thoughts that have emerged from their groups on the social model question.
- Facilitators to feedback the 2 or 3 themes that emerged from their group.

9. Closing Plenary (10 minutes)

Objective: provide participants with information about the next stages of the process.

Lead facilitator to:

- thank participants and emphasise the importance of their contribution
- remind participants to get in touch via email or the number provided if they have any issues, questions, comments, or feedback
- brief overview of next steps, including when to expect incentive
- thank participants and close

10. Post-workshop

Facilitators to upload notes taken and recording from day 2 session.

Annex G: Work package 3 – Deliberation: example social model survey question

Below is the example of what a social model aligned question might look like, that was used at the deliberation workshops. Attendees were informed that this is just an example and was not the final version.

We now want you to think about the barriers or lack of adjustments that limit or stop you from doing things in your day-to-day life. In the past 12 months, have you experienced any of the following:

- barriers to accessing and using public buildings, for example, schools, libraries, hospitals
- barriers to accessing and using public transport
- lack of accessible information
- lack of suitable technologies or equipment that would help me in my day-to-day life
- discriminatory behaviour towards you because of your physical or mental health condition(s), neurodivergence, or use of BSL
- other barriers to taking part in society – such as, societal attitudes (such as, not expecting disabled people to be able to do something), or barriers in the home (like not having low kitchen surfaces or wide enough doorways)
- none of these