

# **Data collection and publication guidance**

## **Disability**

**March 2022**

# Data collection and publication guidance - Disability

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## Introduction

The Equality Act 2010 (the 2010 Act)<sup>1</sup> protects people from discrimination because of disability. The legislation covers areas including education, employment, the provision of goods and services to the public and the exercise of public functions.

The 2010 Act also introduced a public sector equality duty<sup>2</sup>, which came into force on 5 April 2011. The duty requires public authorities, including the Scottish Ministers, to give due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. The duty covers nine protected characteristics,<sup>3</sup> including disability.

In addition to the public sector equality duty, Scottish Ministers have the power to supplement the public sector equality duty by placing specific duties on certain Scottish public authorities, and have done so by means of the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012<sup>4</sup>.

It is recommended that all public authorities follow good practice in gathering and using relevant evidence and information. Disability statistics are important for monitoring discrimination and inequality. Good quality disability data will help with understanding the issues faced by disabled people, allowing for

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<sup>1</sup> [Equality Act 2010 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

<sup>2</sup> [Equality Act 2010 – Section 149 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

<sup>3</sup> The duty only applies to the protected characteristic of marriage and civil partnership in relation to eliminating unlawful discrimination etc. relating to work under Part 5 of the 2010 Act.

<sup>4</sup> [The Equality Act 2010 \(Specific Duties\) \(Scotland\) Regulations 2012 \(legislation.gov.uk\)](https://www.legislation.gov.uk), as amended ([link to original version, with subsequent amendments not yet incorporated](#)).

intersectional analysis with other socio-demographic characteristics, including those protected by the 2010 Act. The information may also be used to inform policy formulation and service delivery.

## Background

The 2010 Act provides that a person has a disability if they have a physical or mental impairment and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

To promote consistency, the Scottish Government, the Office for National Statistics (ONS) and the Office for Disability Issues (ODI) worked on a harmonised suite of questions on disability for use in surveys in Scotland. The guidance, published in 2012, was reviewed in 2021 and this document sets out the revised guidance. Testing found a similar prevalence of disability for the recommended questions and Scotland's Census 2011, on which Scotland's Census 2022 questions are based, suggesting that these questions allow for reliable estimates between censuses.

The approach taken to develop the recommended questions followed the guidelines set out in the International Classification of Functioning, Disability and Health (2001)<sup>5</sup>, where disability is presented as a process bringing together medical, individual and societal factors in its definition. It recommends that the concepts of **illness/condition** (an attribute of the individual e.g. glaucoma), **impairment** (a reduction in physical or mental functioning e.g. sight loss) and **disability** (a restriction in activities and participation related to the interaction

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<sup>5</sup> [International Classification of Functioning, Disability and Health \(ICF\) \(who.int\)](https://www.who.int/classifications/icf)

between functional impairment and the provision of supports whether personal, mechanical or environmental/societal) should not be confused.

Definitions of disability are largely centred around two conceptual models; a medical model and a social model. The medical model of disability situates the problem of disability on an individual's impairment, rather than on society's inability to provide for their needs, rights, and aspirations. The social model of disability scrutinises the environment and attitudes that disables the individual with an impairment.

This guidance note reflects the current development of a harmonised set of questions to produce measures of disability, and presents questions similar to those used in Scotland's Census and many UK Government statistics, such as the Annual Population Survey (APS), Labour Force Survey (LFS), and Family Resources Survey (FRS), all of which fall under the medical model.

The Inclusive Data Taskforce (IDTF) Recommendations Report (2020)<sup>6</sup> however, notes that survey questions are often considered outdated, including questions for collecting disability data, with those consulted calling for a shift from focus on the medical model towards the social model of disability.

The Scottish Government is committed to the social model of disability, and the collection of data based in that model is strongly advocated by stakeholders in Scotland. While there are currently no tried and tested questions in use in official surveys, work to provide a harmonised set of questions in line with the social model of disability is ongoing.

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<sup>6</sup> [Inclusive Data Taskforce recommendations report: Leaving no one behind – How can we be more inclusive in our data? – UK Statistics Authority](#)

More information on the social model and the Inclusive Data Taskforce is provided at the end of this guidance.

## Recommended questions

The recommended questions set out in this guidance note are designed to identify respondents who may have rights relating to disability under the 2010 Act.<sup>7</sup>

### Presentation of the questions and terminology

The words used in the *disability* questions have been carefully selected and tested to be as acceptable as possible to respondents, to aid understanding of what is being asked and to provide the most reliable data for users. If the wording is changed then people may not answer or may answer in a different way and comparisons will not be possible. Like the wording of the question, the categories have been carefully selected and tested.<sup>8 9</sup>

### Question 1a

Question 1a is used to collect data solely on long lasting health and illnesses. Further guidance on what is included is provided in the Additional Guidance for Interviewers section. This question does not capture temporary conditions,

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<sup>7</sup> It should be noted that the total figure received when answering this question may not include everyone with rights relating to disability under the 2010 Act, which extends rights to other groups, including people with progressive conditions which may be non-symptomatic or in remission, since the effects may not meet the definition set out here.

<sup>8</sup> [Long lasting health conditions and illness harmonised standard – GSS \(civilservice.gov.uk\)](https://www.civilservice.gov.uk/long-lasting-health-conditions-and-illness-harmonised-standard-gss)

<sup>9</sup> [Activity restriction harmonised standard – GSS \(civilservice.gov.uk\)](https://www.civilservice.gov.uk/activity-restriction-harmonised-standard-gss)

however serious they might be. It is not designed to measure impact on an individual's daily activities, which is measured by question 2.

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

- Answer:
1. Yes
  2. No
  3. Don't know (Spontaneous only)
  4. Refusal (Spontaneous only)
  5. Prefer not to say (non-interviewer led questionnaires only)

## Question 1b (optional)

For surveys seeking to add detail about the **impairment** associated with the health condition or illness identified in question 1a, we recommend asking the following question after question 1a and **before** question 2<sup>10</sup>:

If answer 'Yes' to 1a (do you have a physical or mental health condition or illness lasting or expected to last 12 months or more):

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

- Answer:
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 or 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)
  13. Prefer not to say (non-interviewer led questionnaires only)

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<sup>10</sup> [Impairment harmonised standard – GSS \(civilservice.gov.uk\)](https://civilservice.gov.uk/gss/impairment-harmonised-standard)



## Question 2

Question 2 measures the extent of restrictions in carrying out day-to-day activities if a person has any long lasting health conditions or illness. To determine whether someone is disabled under the 2010 Act both questions 1a and 2 must be asked.

If answer **'Yes'** follow up with the second part of the question:

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

Answer:

1. Yes, a lot
2. Yes, a little
3. Not at all
4. Refusal (spontaneous only)
5. Prefer not to say (non-interviewer led questionnaires only)

## Additional guidance for interviewers

### Instructions and 'prefer not to say'

Instructions should be given at the beginning of the interview/survey saying why all of the questions are being asked, that they are all voluntary and, if a respondent does not wish to answer any of the questions, they do not have to. This ensures all questions are treated the same.

Testing by the ONS has shown that provision of a 'prefer not to say' option results in an increase in non-responses in telephone/face-to-face interviews. As such the recommendation is that this should only be included in online and paper surveys where refusal is not otherwise possible with the caveat that this may increase the rate of non-response to this question.

If a 'prefer not to say' option is added to this question then it should be added to all questions. In interviewer-led surveys clear instruction at the beginning

should advise people that they do not have to answer any question that they do not wish to.

#### Question 1a

Interviewers should provide guidance about the coverage of conditions and illnesses if asked for clarification. For example, a respondent may state their mobility is impaired but is unsure whether this classifies as a long lasting condition or illness.

As a guide, this question includes physical or mental health conditions:

- lasting or expected to last for 12 months or more
- that a person is likely to have for the rest of their life
- that are likely to need some level of supervision and treatment over a long period of time
- that are not curable, even if medication or treatment can control symptoms
- which flare up intermittently, but the exacerbation has a shorter duration than 12 months (e.g. hay fever)
- which may not be perceived as serious and do not affect day-to-day activities but are nevertheless long lasting
- which are managed by treatment and lifestyle adjustments and do not affect day-to-day activities, but are nevertheless long lasting

The question is designed to include:

- sensory deficits
- non-temporary mobility problems including dyspraxia and cerebral palsy
- developmental conditions such as Autism Spectrum Disorder (ASD), which includes Asperger's syndrome, and Attention Deficit Hyperactivity Disorder (ADHD)
- conditions associated with learning impairments such as Down's syndrome or dyslexia
- common conditions and illnesses such as: asthma, diabetes, heart and other circulatory conditions, respiratory conditions, digestive conditions,

anxiety and depression – if they have lasted or are expected to last 12 months or more

- seasonal conditions such as hay fever which recur and have lasted or are expected to recur in the future

This question is not designed to measure impact on an individual's daily activities. Nor is a person considered disabled under the 2010 Act solely by answering 'Yes' to this question as additional information about substantial impact will be required.

Question 1b (optional)

This question was developed to gather information about how the health condition or illness affects functioning. It will provide an estimate of the prevalence of category specific impairments in adults with a long lasting physical or mental health condition.

Historically, surveys have asked for information on the actual condition. However, extensive research and consultation by the ONS has shown that classification of functional impairment is both more straightforward and also more appropriate.

As an introduction to this question, interviewers should state:

“The purpose of this question is to establish the type of impairment(s) you experience currently as a result of your health condition or illness. In answering this question, you should consider whether you are affected in any way by your health condition or illness in any of these areas whilst receiving any treatment or

medication or using devices to help you such as a hearing aid, for example”.<sup>11</sup>

Respondents may select as many responses as apply to them. Interviewers should steer respondents to using the pre-defined categories wherever possible, and avoid collecting precise conditions such as obstructive pulmonary disease, which would code to the category stamina or breathing or fatigue.

The interviewer should hand the show card to the respondent and ask them to state the categories that apply, coding up to ten.

## Question 2

As an introduction to this question, interviewers may state:

“This question asks about whether your health condition or illness currently affects your ability to carry out normal day-to-day activities, either a lot or a little or not at all. In answering this question, you should consider whether you are affected in any way by your health condition or illness while receiving any treatment or medication for your condition or illness and/or using any devices such as a hearing aid, for example.”

The respondent should answer based on their current activity restriction.<sup>12</sup>

If asked to clarify whether the second question refers to the ability to carry out day-to-day activities with or without medication, the respondent should be

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<sup>11</sup> Where treatment, medication or devices do not entirely negate the impairment relating to a condition or illness then the respondent should answer yes to questions 1b and 2.

<sup>12</sup> This question is currently intended to capture the impact on the day of questioning. Work is ongoing to address the validity of this question for collecting data on fluctuating conditions. Where survey creators prefer, a clarification indicating that what is “usual” for the respondent can be given as response.

prompted to think about what is most usual for them; if they usually take medication then they should think about whether their ability to carry out day-to-day activities is reduced in any way, when they are on medication.

If interviewers are asked for clarification on the meaning of day-to-day activities the following may provide a guide.

Normal day to day activities can include:

- washing and dressing
- household cleaning
- cooking
- shopping for essentials
- using public or private transport
- walking a defined distance
- climbing stairs
- remembering to pay bills
- lifting objects from the ground or a work surface in the kitchen
- moderate manual tasks such as gardening
- gripping objects such as cutlery
- hearing and speaking in a noisy room

Interpretation of limiting 'a little' or 'a lot' is in the context of how much assistance a person needs to carry-out daily activities, and whether they are house bound. 'A lot', for example, means usually needing the assistance of family, friends or personal social services for a number of or all normal daily activities. The respondents should answer based on their current extent of activity restriction after any treatment, medication or other devices (such as a hearing aid) they may receive or use has been taken into account.

An additional optional question regarding the length of time activity restriction is expected to occur, or has already occurred for, is provided by ONS, though this question is less widely used than those already detailed. This question can

be asked to all respondents aged 16 and over who responded “yes” to question 1a **and** responded “yes, a lot” or “yes, a little” to question 2.

Question: For how long has your ability to carry out day-to-day activities been reduced?<sup>13</sup>

Answer: 1. Less than six months  
2. Between six and twelve months  
3. Twelve months or more

Further information regarding this question can be found on the ONS’ activity restriction harmonisation standard webpage.<sup>14</sup>

### Proxy responses

If the respondent is under 16 years of age the questions must only be asked by proxy. The questions can also be asked by proxy if the respondent is aged 16 or over and unable to respond in person. If responding in a language other than English is preferred, professional interpreters, including BSL interpreters, should be used to assist with data collection.

### Online surveys

There has been no specific testing for displaying the questions online, either aesthetically (formatting of tick boxes and page design) or in terms of the content (question wording, spontaneous response options etc.). The ONS questions recommended here adopted the online Census 2021 question

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<sup>13</sup> This question is currently intended to capture the impact on day-to-day activity up to the day of questioning. Work is ongoing to address the validity of this question for collecting data on newly diagnosed conditions. Where survey creators prefer, a clarification indicating that expected length of impact can be given as response.

<sup>14</sup> [Activity restriction harmonised standard – GSS \(civilservice.gov.uk\)](https://www.civilservice.gov.uk/activity-restriction-harmonised-standard-gss)

wording for England and Wales, so the questions have been tested and used in an online format, which can be seen in section 6 of the question development page.<sup>15</sup>

No specific testing has been done for an online ‘prefer not to say’ (PNTS) option, however ONS have tested and implemented a ‘show on skip’ version of the PNTS option for the online Labour Market Survey. Where a respondent skips the question, they will see the full list of response options repeated on the subsequent screen, with the inclusion of a PNTS option *as well as* a statement above the question emphasising the importance of providing a response for data collection purposes.

## Analysis and presentation of results

When producing disability breakdowns it is recommended to include the following categories, as these are designed to closely match the 2010 Act disability definition:

Disabled:	Q1a = ‘Yes’; AND Q2 = ‘Yes, a lot or ‘Yes, a little’
<b>Non-disabled:</b>	Q1a = ‘No’; OR Q2 = ‘Not at all’

It may be useful to include a clarification of what is meant by disability, i.e. a “long-term limiting physical or mental health condition” in a table footnote or in the publication/chapter introduction. Footnotes should be printed in the same font size as the main text for accessibility purposes.

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<sup>15</sup> [Health and unpaid care question development for Census 2021 - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/health-and-unpaid-care/question-development-for-census-2021)

It is the data collector's decision whether to include the optional question 1b and the additional question regarding duration of activity restriction, depending on the needs of your users.

## Intersectionality

An intersectional analysis gives an insight into how a combination of socio-demographic characteristics might relate to specific forms of disadvantage. For example disadvantage for a young, minority ethnic, disabled woman may be different to an older, white, disabled man.

There is an increasing awareness that taking an intersectional approach to research, policy making and operational decisions is important. This is because intersectionality can give insight into the experiences of different groups in society, and how particular characteristics can combine to impact on an individual's experiences. However, there is not always disaggregated data available to support such an approach. This is likely to mean that the information on which important decisions are made is not fully representative of the population it is intending to measure.

For example, data on demographic characteristics may be collected by a public body, but not disaggregated in an intersectional way due to issues around sample size and risk of disclosing an individual's identity. In these cases, organisations should not risk disclosing information about an individual's disability status or their disabilities.

Where sample size and data quality allows, data should be disaggregated, including by sex, gender reassignment, race, religion or belief, age, disability, and sexual orientation, where combinations of these factors can result in discrimination, disadvantage and inequality. Being able to identify cases where



combinations of factors are resulting in disadvantage enables policies to be developed and action taken to address these issues.

## Contact us

This document has been provided to help people collect information on disability in Scotland. We welcome any comments you have on this guidance note. It will be revised and updated periodically.

[social-justice-analysis@gov.scot](mailto:social-justice-analysis@gov.scot)

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## Annex 1: towards a social model of disability

The section below sets out a range of ongoing work to identify a set of questions to measure the social model of disability and participation restriction. As these questions are still under development this is included for interest, information and consideration only, not as guidance. The guidance will be revised in due course to reflect the development of these questions.

### Health condition, impairment, and disability

The Health, Disability and Carers Harmonisation Sub-group (HDCHS) initiated a project in 2008 to establish a framework for disability definition and develop questions to measure the definition for use in social surveys. One of the outputs of this work was the initial set of harmonised questions for capturing data on disability, on which the current recommended questions are based.

Consultation workshops showed overwhelming support for separating out concepts of health condition, impairment and disability.<sup>16</sup> The importance of developing a second set of questions to produce measures of disability based on participation restriction caused by physical and social barriers was also demonstrated, as they have a disproportionately adverse effect on people with impairments.

### The Life Opportunities Survey

The Life Opportunities Survey (LOS) is the first major survey to explore disability in terms of the barriers to participation that people experience.<sup>17</sup> It was conducted by the ONS on behalf of the Department for Work and Pensions

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<sup>16</sup> [\[Archived Content\] UK Government Web Archive - The National Archives](#)

<sup>17</sup> [\[Archived Content\] Health Statistics Quarterly, No. 51, Autumn 2011 - ONS \(nationalarchives.gov.uk\)](#)

(DWP) between 2009 and 2014, and assessed the level of participation of people with impairments, and the barriers they face in participating in key areas including work, education, social activities, and transport and public services.

The HDCHS consultations included the LOS in their comparisons of surveys that collect disability data, which found that the rate of disability reported by the LOS was higher than that reported by medical model based surveys. As such, there may be implications for population estimates of disability used to inform service need and policy development, and conduct international comparisons.

An example question from the LOS, extracted from a series of questions on participating in work, can be found in Annex 2. Most of the questions from the LOS follow this structure. Further examples and exact presentation of the questions can be found in the LOS questionnaire documents<sup>18</sup>.

#### Inclusive Data Taskforce

The Inclusive Data Taskforce (IDTF) was established in 2020 to improve the UK's inclusive data holdings in a broad range of areas, including the nine protected characteristics of the Equality Act 2010.

The IDTF Recommendations Report<sup>19</sup> notes that survey questions are often considered outdated by relevant groups and individuals. This specifically includes disability data, with those taking part in the consultations calling for a

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<sup>18</sup> Life Opportunities Survey, June 2010: [Waves 1-2 Questionnaire 2009-2012 \(ukdataservice.ac.uk\)](https://ukdataservice.ac.uk)

<sup>19</sup> [Inclusive Data Taskforce recommendations report: Leaving no one behind – How can we be more inclusive in our data? – UK Statistics Authority](https://www.statistics.gov.uk/keystory/2021/01/20/inclusive-data-taskforce-recommendations-report-leaving-no-one-behind-how-can-we-be-more-inclusive-in-our-data)

shift from a focus on the medical model towards the social model of disability. As part of its recommendations the IDTF states that as a priority,

“ONS should transition its measures of disability to approaches more firmly based upon the WHO ICF and ICF-CY biopsychosocial model conceptual frameworks.”

### Moving forwards

The body of work being undertaken following the release of the IDTF Recommendations Report is substantial, and the work to provide a harmonised set of questions in line with the social model of disability is ongoing. Furthermore the National Disability Strategy (NDS)<sup>20</sup>, published in 2021, will have implications for public bodies in Scotland, however the exact impact and requirements are as yet unknown.

For the time being, the existing harmonised disability measure guidance recommended in the main body of this guidance is in use. However, the IDTF recommendations and the NDS have drawn attention to the need to regularly revisit harmonised standards, and this guidance will continue to be revisited and updated as new recommendations are made. The harmonised standards homepage<sup>21</sup> contains further information on the ONS harmonised question series and the National Statistician’s response to the IDTF recommendations.

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<sup>20</sup> [National Disability Strategy - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/national-disability-strategy)

<sup>21</sup> [Harmonised standards and guidance by topic – GSS \(civilservice.gov.uk\)](https://civilservice.gov.uk/gss/standards)

## Annex 2: Life Opportunities Survey - example question

### Question 1

APPLIES IF: In employment (from core) & Wave 1

Are you limited in the type or amount of paid work that you do, for example, what you can do, how long you can work for, when you can work or where you can work?

(1) Yes

(2) No

### Question 2

APPLIES IF: Work = Yes

SHOWCARD

Why are you limited in the type or amount of paid work that you do? Code all that apply

- (1) Lack of job opportunities
- (2) Family responsibilities
- (3) Lack of qualifications/experience/skills
- (4) A health condition, illness or impairment
- (5) A disability
- (6) Difficulty with transport
- (7) Difficulty getting into buildings
- (8) Difficulty using facilities
- (9) Caring responsibilities
- (10) Lack of special aids or equipment
- (11) Lack of help or assistance
- (12) Anxiety/lack of confidence
- (13) Attitudes of colleagues
- (14) Attitudes of employers
- (15) Affects receipt of benefits
- (16) Other reasons (please specify)

### Question 3

APPLIES IF: In employment (from core) & Wave 1

#### SHOWCARD C4

Has anything on this card helped you at work? Code all that apply

- (1) Modified hours or days or reduced work hours
- (2) Modified duties
- (3) A job coach or personal assistant or mentor
- (4) Changes to your work area or work equipment
- (5) Building modifications, such as handrails or ramps, easy-to-access work area, toilets or lifts
- (6) Tax credits (you may qualify for a tax credit if you work but earn low wages)
- (7) Employer/staff attended disability awareness training
- (8) Other equipment or services (please specify)
- (9) None of these



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