

Scottish Government: Collecting Equality Information Series

Guidance note on asking questions on: disability

Introduction: why is it necessary to collect information about disability?

The Equality Act 2010 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 Act also introduces a public sector equality duty which came into force on 5 April 2011. The duty requires Government and public authorities to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. The duty covers nine protected characteristics, including disability. It is recommended that Government and public authorities follow good practice in gathering and using relevant evidence and information. Disability statistics are important for monitoring discrimination and inequality. The information may also be used to inform policy formulation and service delivery.

“Poor measurement and a lack of transparency have contributed to society and governments being unable to tackle persistent inequalities and their causes. The data available on inequality are utterly inadequate in many ways, limiting people’s ability to understand problems and their causes, set priorities and track progress. And even where data do exist, they are not consistently used well or published in a way that makes sense”.

This was one of the conclusions of ['Fairness and Freedom, The Final Report of the Equalities Review'](#) in 2007. This was followed by a [report from the Office for National Statistics](#) which identified 8 principles for collection and dissemination of equality data. Principle 4 states that:

“Consistency of methods, concepts and classifications is fundamental in the collection, analysis and presentation of equality statistics”.

In order to promote more consistency the Scottish Government has been working with the Office for National Statistics and the Office for Disability Issues on providing a harmonised suite of questions on disability for use in surveys in Scotland. The concept of disability is multi-faceted and previous definitions have so far largely centred around two conceptual models; the social model and the medical model. The programme of work with the Office for National Statistics and the Office for Disability Issues has encompassed the development of questions on disability based on the social model definition, and this work is ongoing. More information on the social model questions is provided at the end of this guidance note.

Section 1(2) of the Disability Discrimination Act (1995) broadly defined someone as disabled if ‘he or she has a physical or mental impairment which has a substantial and long-term adverse effect on her or his ability to carry out normal day-to-day activities’. This legislation has been super-ceded from 1 October 2010 by provisions

contained within the Equality Act. While the definition of disability in the Equality Act is similar to that which preceded it, the legislation now no longer requires a disabled person to demonstrate their impairment adversely affects their ability to carry out a normal day-to-day activity in at least one of a specified list of capacities such as moving, speech, continence.

The approach taken to develop the recommended questions followed the guidelines set out in the International Classification of Functioning, Disability and Health (2001) which presents disability as a process that brings together medical, individual and societal factors in its definition. This framework recommends the concepts of illness, impairment and disability are not confused, and defines disability as restriction in activities and participation related to the interaction between functional impairment and the provision of supports (personal, mechanical and environmental\societal).

Recommended questions

The recommended questions set out in this guidance note are designed to identify respondents who may have rights under the Equality Act 2010¹.

Presentation of the question and terminology

The words used in the question stem 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.

1a. Question: Do you have a physical or mental health condition or illness lasting or expected to last 12 months or more?

Answer: 1. Yes
 2. No

¹ It should be noted that the estimate will not reflect the total number of people who may have rights under the Equality 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.

- 3. Don't know (Spontaneous only)
- 4. Refusal (Spontaneous only)

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

2. Question: Does your condition or illness reduce your ability to carry-out day-to-day activities?

- Answer:
- 1. Yes, a lot
 - 2. Yes, a little
 - 3. Not at all

Additional Instructions

Question 1

If interviewers are asked for clarification on the first of these questions the following may provide a guide:

Any impairments such as sensory deficits, non temporary mobility problems, depression, developmental disorders such as autism and Asperger's syndrome, learning disabilities such as Down's syndrome or cerebral palsy as well as common illnesses such as asthma, diabetes, heart and other circulatory conditions, respiratory conditions, digestive conditions etc. are covered 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 should be included. The progressive conditions HIV, cancer and Multiple Sclerosis should also be included even if non-symptomatic or in remission.

Question 2

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 prompted to think about what is most usual for them; if they usually take medication then they should think about whether their day-to-day activities are reduced when they are on medication and otherwise not.

If interviewers are asked for clarification on the meaning of day to day activities the following may provide a guide: *day to day activities are washing and dressing,*

household cleaning, cooking, shopping for essentials, using public or private transport, walking a defined distance, climbing stairs, remembering to pay bills, and lifting objects from the ground or a work surface in the kitchen.

Guidance on interpreting extent categories are 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 on the basis of their current extent of activity restriction taking account of any treatment, medication or other devices such as a hearing aid they may receive or use.

For surveys wanting to add detail about the impairment associated with the health condition or illness identified in question 1a, we would recommend asking the following question after question 1a and before question 2:

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):

1b. Question: Does this condition or illness 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, attention deficit disorder or Aspergers' syndrome)
 10. Other (please specify)
 11. None of the above (spontaneous only)

Additional Instructions

Question 1b

This question was developed to gather information about how the health condition or illness affects functioning. Historically, surveys have asked for information on the actual condition however extensive research and consultation by the Office of National Statistics has shown that classification of functional impairment is both more straightforward and also more appropriate.

Respondents can select as many responses that 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 him/her to state the categories that apply, coding up to ten.

As an introduction to the third 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 of these areas whilst receiving any treatment or medication or using devices to help you such as a hearing aid for example”.

This question will provide an estimate of the population prevalence of category specific impairments in adults with a physical or mental health condition that is long lasting in nature.

Proxy Responses

If respondents are unable or are too ill to respond on their own behalf, and if present, proxy responses from a family member or friend can be recorded. For those not able to speak English, professional interpreters should be used to assist with data collection.

Development of the questions

The Health, Disability and Carers Harmonisation Sub-group, containing representation across government, arms length bodies and academia, initiated a

project in 2008 to establish a conceptual framework for disability definition and develop questions to measure the definition for use in social surveys.

The outcome of a series of consultation workshops showed an overwhelming support for separating out concepts of health condition, impairment and disability. A **condition** is an attribute of the individual (e.g. glaucoma) an **impairment** is a reduction in physical or mental functioning (e.g. sight loss) and **disability** relates to activity and/or participation restriction resulting from a range of social and environmental factors that do not take account of the needs of people with people impairments.

A draft of questions was developed to reflect the findings of the consultation process. The questions underwent a series of testing, including cognitive testing and two rounds of quantitative testing. The questions were tested to compare estimates with existing measures of disability from the Family Resources Survey, the General Lifestyle Survey, the Life Opportunities Survey and the Scottish Census 2011 questions.

Comparing the 2011 Scottish Census questions with the recommended harmonised questions

Testing showed similar prevalence of disability for the recommended questions and the 2011 Scottish Census suggesting that the recommended questions will allow for reliable inter-censal estimates. It is recommended that these questions are used in a high level household survey context. Estimates of the population with a particular condition are collected by other sources, including the Scottish Health Survey and by the Scottish Consortium for Learning Disabilities.

Measuring social model disability and participation restriction

A further finding from the consultation demonstrated the importance of developing a second standard set of questions to produce measures of disability based on participation restriction caused by physical and social barriers which have a disproportionate adverse effect on people with impairments.

The Scottish Government is committed to the social model of disability which distinguishes impairment from disability; measuring disability as the additional disadvantage participating in key areas of life, such as education and employment, experienced by people with impairment. The Life Opportunities Survey is the first major survey to explore disability in terms of the barriers to participation that people experience by assessing the level of participation of people with impairment and the

barriers to participation they face. More information about the Life Opportunities Survey can be found by accessing the link below.

The programme of work with the Office for National Statistics and the Office for Disability Issues has also carried out work to develop a suite of questions to measure social model disability and participation restriction. Initial findings have demonstrated the difficulty of estimating a social model disabled population. In addition, imposing an exclusively social model definition on traditional survey sources could radically alter the estimates of disability used by public authorities to inform service need, policy development and conduct international comparisons. Therefore, we propose that the social model definition is a complementary measure of disability which has utility in informing policy solutions to improve the life chances of disabled people and identify and mitigate the physical and social barriers which differentially disadvantage people with impairments relative to people without impairments.

It should be noted that this guidance note reflects the current state of play in the development of a harmonised set of questions to produce measures of disability. At the time of publication, the set of questions to measure social model disability and participation restriction are still undergoing analysis and development. It is for this reason that these questions are not included in this guidance note. However, this guidance note will be revised in due course to reflect the findings of the development of these questions.

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 when necessary.

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Useful Links

Equalities Review:

<http://webarchive.nationalarchives.gov.uk/20100807034701/http://archive.cabinetoffice.gov.uk/equalitiesreview/>

UK Statistics Authority - Code of Practice:

<http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html>

ONS Report from the review of equality data:

<http://www.ons.gov.uk/ons/guide-method/measuring-equality/equality/equality-data-review/review-of-equality-data--final-report.pdf>

Life Opportunities Survey

<http://www.ons.gov.uk/ons/about-ons/surveys/a-z-of-surveys/life-opportunities-survey/index.html>