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Chris White Office for National Statistics
In brief

What can the ONS Longitudinal Study tell us about the mortality of the 'golden cohort'?

It is well documented that the generations born around 1930 (between 1925 and 1934) are consistently showing higher rates of mortality improvement than the generations either side of them. There is currently no evidence that these differentials are declining. In current Office for National Statistics (ONS) National Population Projections, it is assumed that these birth cohorts will continue to experience higher rates of improvement. However, it is not yet precisely clear why this is so. Understanding what is causing the significant decrease in mortality for this generation is particularly important for forecasting the population at older ages.

The forthcoming paper 'What can the ONS Longitudinal Study tell us about the mortality of the "golden cohort"?', due to be released in the September issue of Population Trends, details research carried out using the ONS Longitudinal Study to try to better understand why the members of the generation born around the early 1930s in England and Wales have been enjoying higher rates of mortality improvement throughout their adult life.

Health and Life Events Division user engagement strategy

The ONS Health and Life Events Division (HLED) has now published a user engagement strategy:


This is a living document and further information, such as dates of specific consultations, will be added over time.

As part of the strategy, user feedback surveys are currently being trialled on a number of HLED outputs. These will help ONS determine user requirements and improve our outputs.

Comments on the user engagement strategy and plan are welcomed by emailing the divisional business manager steve.brown@ons.gov.uk

ONS review of conception statistics

ONS consulted users of conception statistics between 22 February and 19 April 2011. The outcome of the review has now been published:


The main change is that annual conception statistics will be published once a year (around February) rather than twice a year. For further information email vsob@ons.gov.uk.
Planned changes to the Vital Statistics: Population and Health Reference Tables

The Vital Statistics: Population and Health Reference tables are published alongside Health Statistics Quarterly and Population Trends. They provide summary figures for a range of topics which include population; conceptions; live births; mortality; marriages; divorces; civil partnerships and internal and international migration. Some tables provide data for the UK and its constituent countries while others provide data for England and Wales. Tables currently provide annual figures while some also include quarterly data providing users with a timely indication of current trends.

ONS is planning to make changes to the reference tables from Autumn 2011. The planned changes will reduce the cost of producing quarterly statistics making our business processes more efficient. The quarterly and annual tables will facilitate comparisons over time and between UK countries. For more information see the 'Information Note' published alongside the latest release of the reference tables on the ONS website or email vsob@ons.gsi.gov.uk.

New and improved ONS website to launch 28 August 2011

The Office for National Statistics (ONS) has been developing a new website, which will deliver the following improvements:

- quicker and easier to find information, including better search and navigation
- easier to use the information, by downloading data, charts and graphs
- improved accessibility to ONS content for users with sight or other impairments
- prompt release of outputs at 9.30am sharp

The new website will be launched on 28 August.

Content will be transferred from the current website to the new one, but some existing bookmarks and links will no longer work. Bookmarks can be recreated once the new website has gone live.

After the initial launch, there will be further developments to the new website. These include:

- an online data explorer tool, allowing users to customise, interact with and download datasets
- an Application Programming Interface, enabling re-use of ONS data by others

Find out more at: www.ons.gov.uk

ERRATUM

In the article entitled ‘Social inequalities in alcohol-related adult mortality by National Statistics Socio-economic Classification, England and Wales, 2001-03’ (HSQ volume 50), the sentence 'Within England, the North West showed the largest inequalities' on pp: 4 should have read 'The North West of England had the highest overall rate of alcohol-related mortality'. The greatest inequalities in alcohol-related mortality for men were observed in Wales and for women were in London.
Update on the harmonisation of disability data collection in UK surveys (Part 1)

Chris White Office for National Statistics

Abstract

Background

This article reports progress to date in the development of new National Statistics harmonised questions: measuring disability in established national social survey sources using a face-to-face interviewing mode of data capture. The harmonisation of these questions across these survey sources will enhance the availability of consistent disability statistics to government and the wider user community.

This work began in response to the recommendation of the Review of Equality Data published in 2007: to develop and apply a principled approach to data collection to meet future data needs, following the introduction of equality legislation in 2010. It also contributes to improving international comparability, by better meeting the definitions for measures of long-standing illness and disability derived from the European Union’s Statistics on Income and Living Conditions (EU-SILC).

Further work is currently being undertaken to adapt questions for use in surveys applying different methods of data capture, such as paper-based and on-line surveys.

The project also developed questions which measure disability as a restriction in participation in key areas of life such as employment, and the self-perceived social barriers affecting participation (that is aspects of society and the physical environment, which do not take adequate account of the needs of people with impairments). However, at the time of writing, a finalised standard had not been agreed: these data inputs will be reported on in a future Health Statistics Quarterly article.

Methods

The National Statistics Harmonisation Group (NSHG) and its Health, Disability and Carers Sub-Group contain representation across government, related public sector bodies and academia. These groups agreed the following project objectives for disability data harmonisation:
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a) Establish a conceptual framework for disability definition

b) Develop question inputs to measure the definition for use in social surveys using a face-to-face interviewing method of data capture

c) Test the performance of these questions for interpretability and consistency with established sources, and refine questions, where indicated, through the findings of testing and consultation

d) Recommend harmonised standards for implementation across sources

A process of question suite development included: user consultation, which gathered cross-sector views to clarify and prioritise data needs; cognitive testing, which guided question formats, content and terminology, and interviewer probes and instructions. The findings of these exercises were used in the construction of questions which were subsequently field tested for coherence with other data sources and described in an accompanying article in this issue of Health Statistics Quarterly.

Results

The definition of disability developed to harmonise standard data inputs and outputs is founded on the Disablement Process (Verbrugge and Jette 1994), and the bio-psycho-social model of disability used in the International Classification of Functioning, Disability and Health (ICFDH) (WHO, 2001). This model presents disability as a process bringing together medical, societal and individual factors which affect daily activities and participation and disentangles concepts of illness, impairment and disability. Disability is defined as restriction in activities and participation related to the interaction between functional impairment and the provision of supports (personal, mechanical and environmental/societal).

The results of cognitive testing found issues with the proposed question formats, interpretation of key terms such as ‘disability’ and sensitivities to the negative focus of questions; the researchers made a number of recommendations to improve the flow of questions and improve interpretation, including better signposting and use of interviewer probes and instructions, and changes to the terminology used in the body of questions and their response categories.

Conclusions

The extensive consultations undertaken, including government departments, other public sector bodies, academia and third sector organisations, demonstrates a clear commitment on the part of the Health, Disability and Carers Harmonisation Sub-Group to gather a wide range of views to identify the deficiencies in existing data inputs to social survey data sources; guide priorities as equitably as possible to meet the variety of needs expressed; and to lessen the sensitivities associated with existing question terminology when drafting question inputs.
The application of respected conceptual frameworks and internationally recognised definitions and classifications to the data needs identified, and the modifications suggested following cognitive testing has given the draft questions for field testing a stronger relevance to the concept of disability advocated in the Prime Minister's Strategy Unit Report 'Improving the Life Chances of Disabled People' and championed in the Office for Disability Issues Equality 2025 agenda.
Introduction

This article reports progress made in revising questions on persistent illness, impairment and activity restriction for collection in national social survey data sources using a face-to-face interviewing method of capture. It updates the material presented in an earlier article by (White, 2009). The findings of cognitive question testing and the extensive consultation across government, academia and the third sector during 2008–09 were used to develop draft questions for field testing during 2009 and 2010, the results of which are reported in an accompanying article in this issue of Health Statistics Quarterly.

Further work is currently being undertaken to adapt these questions for use in surveys, applying different methods of data capture such as paper-based and on-line surveys.
The project also invested considerable effort developing questions measuring disability as restriction in participation in key areas of life, such as employment and leisure, because of aspects of society which do not take adequate account of the needs of people with impairments. However, at the time of writing, a finalised standard had not been agreed: these data inputs will be reported on in a future Health Statistics Quarterly article.

## Background

The Review of Equality Data (ONS, 2007) identified a need to improve the co-ordination, comparability, quality, accessibility and presentation of disability statistics through developing and applying a principled approach to data collection and its propagation. It made a specific recommendation that the Office for Disability Issues (ODI) and the Government Equalities Office (GEO) should work with the Office for National Statistics (ONS) to develop harmonised standards for disability measurement across data sources to meet this need.

A project was initiated in early 2008 with the following objectives:

a) conduct a cross-sector consultation on data needs and priorities and replicate consultations at key stages

b) develop a conceptual framework for disability definition taking account of consultation responses, national legislation and European regulations

c) frame a short suite of questions to measure disability in accordance with the definition, and sensitive to the issue of data continuity with existing survey estimates

d) test the performance of these questions in terms of interpretability and coherence with established sources collecting similar information

e) recommend to the NSHG and the Government Statistical Service Statistical Policies and Standards Committee (GSS SPSC) an implementation of harmonised data inputs across social survey data sources using a face-to-face method of data capture to harmonise the presentation of statistical measures of disability.

This article contains the following sections:

- Overview of initial consultations
- Development of conceptual framework for the disability definition
- Cognitive testing stage

## Overview of initial consultations

Two preliminary consultation workshops were held, the first hosted by ODI in February 2008 and the second by ONS in June 2008. The first workshop brought together statutory organisations with a remit for policy development in the area of disability, and therefore with a requirement for disability data to determine needs for services and to monitor indicators. The organisations represented at the workshop are shown in Annex A.

The first workshop found the following:
a) there was widespread support for recommendation 4.3 of the Review of Equality Data to develop harmonised standards for disability data collections and outputs

b) standards should take account of any changes in disability definition and data requirements arising following the introduction of the Single Equality Act, planned for 2010

c) there was a need to strike a balance between differential national and European data requirements; ideally each should be met from the same set of harmonised standards

d) definitions of disability and data inputs in social survey sources used by statutory bodies were varied; specifically, there were differences in question terminology, time frames, output categories and coverage of target populations

e) the review of survey sources found that most government departments used two core questions to classify disability, some of them adding detail by capturing type of condition, impairment or capacity to perform daily activities

f) a distinction was often present in sources; some capturing the type of condition or impairment, while others captured a person’s capacity in an area of functioning. For example, the former would capture ‘learning disability’, and the latter would ask whether a person had difficulty with learning and understanding

g) the need for the harmonised standards to encompass a social model approach to disability measurement was acknowledged as relevant in light of the forthcoming equality legislation and the Prime Minister’s Strategy Unit report ‘Improving the Life Chances of Disabled People’ (PMSU, 2005)

The aim of the second workshop was to build on the findings of the initial workshop and develop a first draft of questions for consultation. The organisations attending are again shown in Annex A.

There was agreement that the harmonised standard definitions and questions should meet the following priorities:

a) monitor the core population with potential rights under the Disability Discrimination Act (DDA) 1995 (National Archive, 1995) and Amendment Act 2005 (National Archive, 2005): namely those who have a health condition, illness or impairment which has a substantial adverse effect on their ability to carry out normal day-to-day activities in one or more capacity domains such as mobility; however there was an understanding that the future equality legislation may modify this case definition

b) have additional functionality to supply EU-SILC data required by the European Commission on persistent health problems or illnesses and limitation in the daily activities people usually perform

c) an adequate level of continuity with estimates currently derived from national household surveys and a known relationship with the proposed 2011 Census question on disability

d) measure the social barriers affecting the participation in key areas of life of people with impairments

The preferences for question suite content were also discussed with the following consensus:

a) two core questions should be used to enumerate people with potential rights under the core DDA definition
b) a 12-month time frame should be standard, while the differences in prevalence that arise with a 6-month time frame specified in the European Union’s-Statistics on Income and Living Conditions (EU-SILC) regulation should be evaluated using existing data where possible, or tested in the field

c) the ‘non-core’ disabled population, such as those with past disability or one of the three progressive conditions identified in the DDA Amendment Act 2005 (HIV/AIDS, cancer and multiple sclerosis) should continue to be collected in the FRS using existing questions

d) the merits of capturing those who would be disabled without medication with revised harmonised questions were uncertain and should be subject to cognitive testing

e) impairment types or capacities should be collected in addition to the core questions, to allow prevalence of specific functional impairments to be collected

f) participation restriction and their causes should have a basis in the International Classification of Functioning, Disability and Health

These preferences guided the development of questions for wider consultation across government and non-government sectors, which fed into the testing conducted in 2009.

Using the workshop findings to frame further development, ONS and ODI then developed a first-draft suite of questions (Annex B: excludes those questions developed to measure participation restriction and their causes) in autumn 2008. Consultation was extended to a wider range of organisations including academia and the third sector, as further shown in Annex A.

The majority of third sector organisations representing disabled people expressed concerns about the terms ‘impairment’ and ‘disability’ featuring in the first question, which went against the grain of the Prime Minister’s Strategy Unit report (PMSU 2005) which had emphasised the need to separate out concepts of health conditions and illnesses, functional impairments and disability. These organisations suggested the interpretation of the term ‘impairment’ should be a priority for cognitive testing, but advocated excluding the term ‘disability’. The academic community predominantly concurred with this viewpoint.

The use of Plain English response categories in question 2b (see Annex B) received support from the academic and third sectors; while the term ‘limited’ was perceived to have negative connotations. The impairment list examples were also criticised as too focussed on health conditions rather than functional impairments.

The question capturing activity restriction in the absence of medication was criticised as cumbersome and unlikely to deliver useful information. Views largely centred around the need to identify activity restriction currently and for how long, not to ask respondents to hypothesise or speculate about their likely restriction if medication was withdrawn. It was thought that the latter issue added unnecessary complexity and would introduce a high level of subjectivity between respondent perceptions, potentially leading to spurious results.

All the views received were synthesised by ONS and ODI during February 2009 and recommendations for cognitive testing priorities followed.
Development of conceptual framework for the disability definition

The concept of disability is multi-faceted and definitions vary (Bajekal et al, 2004). The approach to definition taken by the harmonisation sub-group was to follow the guidelines set out in the ICFDH (WHO, 2001) as the starting point: these depict disability as a process that brings together medical, individual and societal factors in its definition, emphasizing a person’s functional status, as opposed to medical diagnosis, and the relationship between a person’s capabilities and performance. This approach is consistent with the collection of traditional data on long-standing illness, impairment and activity restriction, but also extends the relevant data to aspects of society which restrict the participation of people with impairment relative to those without impairment (the work pertinent to this latter aspect of the conceptual framework will be reported on in a future article).

There was strong support among sub-group members and the stakeholders consulted to develop harmonised standards which are consistent with a conceptual framework of disability that encompasses biological, psychological and social aspects of functioning, as documented in the ICFDH and the World Health Organisation’s definition of disability; while having the functionality to meet the needs of national and European administrations for data continuity and the definitions and guidelines contained in UK and EU legislation, including the Equality Act 2010 and the European Commission’s EU-SILC regulation (European Commission, 2004).

The primary harmonised standard applies to the collection of data on health conditions or illnesses of a long-lasting nature, the type of impairment associated with the condition(s), and the impact on day-to-day activities. A secondary standard, collecting data on participation in key areas of life, such as employment, and the perceived social barriers to participation, will be reported on at a future date.

The components relevant to these standards were adapted from the Disablement Process (Verbrugge and Jette, 1994); a representation of this process is presented in Figure 1. This process describes how disease and illness affects functioning in body systems and takes account of personal and environmental factors contributing to or mitigating activity and participation restriction.

A useful attribute of the process is the succession of elements leading to a classification of disability, which the process defines as restriction in activities and participation:

a) long-standing health condition or illness
b) impairment of function
c) restriction carrying out day-to-day activities
d) duration of restriction of activity
e) restriction participating in key areas of life and the personal, mechanical and social/environmental factors involved
Figure 1  The disablement process

![Diagram of the disablement process]

Adapted from Verbrugge and Jette, 1994

The following primary harmonised definition of disability was agreed by the National Statistics Health, Disability and Carers sub-group to guide the further development of harmonised data inputs and statistical measures of disability (see Box 1).

**Box 1  Primary harmonised definition of disability for statistical purposes**

A disabled person is someone with a (physical or mental) health condition or illness, lasting or expected to last for 12 months or more, which impairs their functioning and reduces their ability to carry out day-to-day activities

**Long-standing health condition or illness**

The current questions asked on the General Lifestyle Survey (GLF), Continuous Household Survey of Northern Ireland (CHS), Family Resources Survey (FRS), Life Opportunities Survey (LOS), English Housing Survey (EHS), Health Survey for England (HSE), Welsh Health Survey (WHS), Scottish Health Survey (SHS) and the Annual Population Survey (APS) mix the concepts of illness, disability, infirmity and impairment, suggesting these terms are interchangeable. The importance of the social model approach to classifying disability outlined in the Prime Minister’s Strategy Unit
The document (PMSU, 2005), the Equality Act legislation and the clear distinction drawn in EU-SILC guidelines (Eurostat, 2010) for collecting information on persistent illness distinct from disability strongly opposes the mixing of concepts in this question. At the same time, however, group members were concerned about the effect of excluding the terms disability or impairment on data continuity. These issues were prioritised for cognitive and field testing.

A second factor discussed was the time frame relevant to the definition and the need to exclude temporary illnesses and conditions such as infection, where full recovery was likely. As the purpose of the existing questions is to capture persistent conditions and illnesses leading to impairment, and the time frames are predominantly non-specific or lasting 12 months or more, there was a need to standardise the time frame.

The EU-SILC guideline advises a time frame of six months or more spanning the past and future. As the nature of chronic diseases are long-lasting in nature and likely to last for the remainder of the person’s life, the shorter EU-SILC time frame was thought to be unnecessary to consider. The Equality Act 2010 guidance does not explicitly refer to a 12-month time frame for the duration of the impairment, but does state a 12-month or longer time frame for activity restriction linked to an impairment, implying the condition or impairment has an equivalent or longer time frame than 12 months; therefore the sub-group adopted the use of a 12-month time frame as the standard, with the assumption that this would also adequately represent the EU-SILC concept.

**Type of impairment**

The next component considered was how to capture impairment, and what should be the scope. Preference for the format and content of a question for this purpose was discussed in detail at the workshop in June 2008. The advantage of open responses, recording up to six impairments or conditions, as opposed to a predefined list of common categories was unknown and needed cognitive testing. The risks of underestimating impairment prevalence by routeing from the long-lasting health condition or illness question was uncertain and required field testing.

A number of sources were referred to in deciding on the content and scope of the impairment list. These included the DDA list of capacities (National Archive, 1995) used to estimate the population prevalence of disability for FRS publications, the Scottish Health Conditions Census 2011 proposed question and the impairment categories captured on the LOS (ONS 2010).

**Restriction carrying out day-to-day activities**

The capture of information on restriction carrying out day-to-day activities enables the operationalisation of a definition of disability made statute in the Equality Act; but also have functionality to capture persistent illness and disability data required in the EU SILC data set.

There were four principal aspects of data inputs to resolve in this component. First, to assess the most appropriate responses categories based on historical data collections, national legislation, EU-SILC regulation and the question on disability planned for the decennial 2011 Census of population. Second, whether the data should be collected only from those reporting a health condition or illness or across the whole sample. Third, what time frame should be applied to measure duration. Fourth, whether frequency of restriction should be captured in addition to extent, to take adequate account of those with intermittent activity restriction effects.
The Equality Act (National Archive, 2010) generally defines a disabled person as someone with a physical or mental health condition or impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. This differs from the definition in the DDA 1995 and 2005, which also required the disabled person to show that their normal day-to-day activities were adversely affected in one or more specific capacities (see Box 2) such as mobility, speech, or memory.

**Box 2 Disability Discrimination Act 1995 list of capacities**

1. Mobility (moving about)
2. Lifting, carrying and moving objects
3. Manual dexterity (using your hands to carry out everyday tasks)
4. Continence (bladder and bowel control)
5. Communication (speech, hearing or eyesight)
6. Memory or ability to concentrate, learn or understand
7. Recognising when you are in physical danger
8. Your physical co-ordination (e.g.: balance)
9. Other health condition or disability

The DDA defined a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities:

*substantial means neither minor nor trivial*

*a normal day-to-day activity must affect one of the 'capacities' listed in the Act which include mobility, manual dexterity, speech, hearing, seeing and memory*

The EU-SILC guideline requires capturing data on limitation carrying out daily activities that people usually do, for the past six months and by the extent of limitation.

The capture of the extent to which health conditions and impairments affect daily activities was also deemed beneficial; but required testing to examine any interpretation issues using the term ‘substantial’ in the Equality Act and the term ‘severely limited’ in the EU-SILC guideline to harmonise with the European Health Interview Survey (EHIS). The use of the plain English response categories ‘limited a lot’ and ‘limited a little’, as proposed in the 2011 Census question on disability, was also prioritised for testing possible differences in interpretation and recognition with regard to the terms ‘substantially limited’, ‘severely limited’ and ‘limited, but not severely’.

The classification of core DDA disability used in FRS publications applies routeing, isolating the capture of substantial difficulty in one or more capacities to only those reporting a health condition
or ‘disability’ in a previous question. The guidelines contained in the Equality Act (Office for Disability Issues, 2010) also suggest routeing is appropriate to measure the core group. However, the guidelines for EU-SILC advise that activity restriction should be administered to all those sampled. The possibility of false negatives arising by routeing was prioritised as a hypothesis to test in the field.

The time frame for ascertaining duration also differed between the guidance in the Equality Act and the EU-SILC regulation: the former applies a 12-month or longer time frame for previous or expected future duration; the latter stipulates a past 6-month or longer time frame. The variation in disability prevalence arising by applying these criteria was prioritised for testing.

The risk of people with intermittent activity restriction being misclassified as not disabled and thereby affecting population prevalence was also deemed necessary to investigate in testing, by incorporating a question capturing frequency with ordinal response categories (i.e. a ranking of categories increasing in intensity, such as Sometimes, Often, Always).

Cognitive testing stage

Background and Methods

Independent Social Research (ISR) were commissioned to conduct the cognitive testing after a competitive tendering exercise carried out in February 2009; their report is available for download from the ODI website at [www.odi.dwp.gov.uk/docs/res/dd/disability-survey-questions.pdf](http://www.odi.dwp.gov.uk/docs/res/dd/disability-survey-questions.pdf).

The testing of the draft questions (see Annex C) involved 31 individual in-depth interviews with respondents, which formed the basis for a detailed examination of their reactions to the separate items and to the question suite as a whole. A detailed description of the recruitment process, the socio-demographic characteristics of those recruited and their health condition and impairment status is available in the research report (Sykes and Groom, 2009).

The main objectives of this stage were to test:

a) the accuracy of the intended meaning and consistency of respondent understanding, and interpretation of the questions and the terminology used

b) the respondents' thought processes when formulating their answers

c) the appropriateness of the answer categories in terms of how well they correspond to the way in which respondents think about the issues concerning them and their completeness

d) the effect of question order on the answers given

e) the extent to which respondents feel able and willing to provide answers to the survey questions

The questions cognitively tested covered the key components discussed above:

- physical or mental health condition
- type of condition or impairment
- restriction in daily activities and its extent
- medication or treatment effects in mitigating restriction
• the progressive conditions specified in the Disability Discrimination Amendment Act 2005
• participation restriction in key areas of life
• the causes of participation restrictions including social barriers

The latter two components, although not described here, are available in the cognitive testing report referenced above.

Two versions of the test questionnaire were developed to trial alternative question wordings or formats. ODI and ONS prioritised the following in the project brief:
• how do respondents interpret the terms illness, condition, mental, impairment and disability, and how do they distinguish between the terms with regard to their effect and relative severity?
• what conditions do they include and exclude when considering a long-standing illness?
• are they comfortable with revealing that they experience a sensitive and possibly stigmatising condition such as AIDS, cancer or schizophrenia?
• their preference to select a condition or impairment from a pre-defined restricted list, or recall conditions and impairments in an open response format?
• what they consider are normal day-to-day activities?
• how they decide what is substantial or severe limitation and what constitutes a lower order of extent, and do they include activities affected by mental conditions?
• can they hypothesise about the extent of activity limitation they would experience without medication or treatment?

Results and recommendations

The term ‘disability’ used in some questions raised issues: it was often interpreted as a technical or official label linked to benefits such as Disability Living Allowance and the ‘Blue Badge’, with some respondents uncertain about applying it to themselves in the absence of benefits of some kind.

The researchers recommended the question suite would benefit from an introductory script for interviewers to read out, to provide a broad overview of the questions and why they are being asked. In addition, scripted verbal ‘signposting’ in specific question introductions was recommended to provide cues about the kind of information that is relevant and give more time and opportunity for cognitive processing to improve accuracy and consistency in reporting.

The researchers also recommended an exploration of how minor re-wording of the questions may improve the general flow of the question suite and of the individual question items.

Long-standing health condition or illness and type of condition or impairment

The first question tested captures data on persistent health conditions, illnesses, impairments or disabilities with two formats for adding detail about the type of condition or impairment; an open ended approach and a show card containing a pre-defined list from which a respondent could select a relevant category. Cognitive testing showed both versions communicated the question’s purpose to respondents; that is, to capture a diverse range of non-trivial, long-standing conditions or impairments. However, some variation in interpretation of the key terms, specifically the term
disability, caused confusion as to whether it related to receipt of benefits or not. Respondents expressed difficulty distinguishing between the terms ‘impairment’ and ‘disability’: most considered disability more serious, but some believed the terms were synonymous, and impairment represented a more acceptable term, with fewer negative connotations.

The mixing of concepts of illnesses, impairment and disability in the same question also confused respondents as they were unsure whether a yes response required all to apply and the thread of the question was confusing because of the number of sub-clauses and its general length. The question also risked underreporting of episodic conditions not currently active; conditions in remission such as cancer; and conditions not always viewed as a health condition, impairment or disability, such as dyslexia or Asperger’s syndrome.

Respondents preferred the closed version of the health conditions and impairments list with a show card, because it provided a clearer frame of reference, and acted as an aide memoir. However, a weakness identified was its limited nature; two respondents with impaired vision were not sure whether the category blindness applied to them.

The specific examples used in the long-term illness category (that is ‘multiple sclerosis or cancer’) were thought by some respondents to be odd, causing reluctance to select the category and choosing the less specific category ‘Other long-standing health condition or disability’.

The researchers recommended the following to improve the terminology and interpretability of this question:

- exclude the term ‘disability’ on the grounds that it has specific and varying meanings and connotations;
- develop scripted interviewer probes to encourage reporting of health conditions or impairments that meet the criteria specified, before moving on to the next question;
- give preference to using a show card listing the alternative conditions and impairments categories to provide respondents with a clear frame of reference for answering and an aide memoir for relevant conditions or impairments that they may overlook in an open format;
- interviewers should read out the list item by item, to give respondents sufficient time to digest and think about each category.
- revise the response categories to better represent service needs and policy requirements, that is:
  a) split blindness, deafness and communication into separate categories, using the terms vision, speech and communication impairment, with illustrative categories such as blind or partial sight, deaf or partial hearing
  b) use examples which are more generic to the underlying category
  c) replace the term disability with impairment in the category Other Long-standing health condition or disability
  d) add the categories mobility, dexterity and memory to the list as they have greater policy relevance
- consider splitting the question to establish whether the person has a health condition and then ask about the type of condition or impairment in a separate routed question.
Activity restriction by extent

The second question cognitively tested was to establish whether normal day-to-day activities were limited for reasons linked to having a persistent health condition or impairment. The question also captures the extent to which daily activities were limited using the categories ‘severely limited’ and ‘limited, but not severely’. The understanding of the question’s purpose differed on whether the answer to the first question was in the affirmative or the negative. For those with a condition or impairment, there was general understanding that the question aimed to establish whether activities were limited; however, for those without a condition or impairment, the interpretation was perceived as another attempt to elicit health conditions or impairments. This difference in understanding suggests the merit of asking the whole sample this question is doubtful.

The cognitive testing of question variants demonstrated the term ‘difficulty’ was more easily understood than ‘limited’. The term ‘day-to-day activities’ was generally taken by respondents to refer to routine activities and some found the term helpful in providing a frame of reference to ‘visualise normal things’. The following day-to-day activities were among those most commonly mentioned by respondents in response to follow-up probes:

- dressing
- shopping
- cooking and cleaning
- DIY
- driving a car
- visiting a library
- looking after children or other family members
- gardening and other moderate manual tasks
- crossing a busy road
- walking a defined distance or climbing stairs
- lifting items from a shelf at head height
- talking in a noisy room
- sitting in a confined space on a journey by car or train
- gripping objects such as a pen or cutlery

Respondents did not interpret a difference in the depth of connection between a health condition or impairment and restriction in daily activities using either the term ‘because’ or ‘mean that’ in the body of the question.
The response categories presented a number of issues for respondents:

a) difficulty applying the categories for those with intermittent limitations

b) respondents generally applied a personal benchmark to distinguish between the extent categories; most believed the benchmark should be determined by the level of independence and control the individual had

c) some reluctance to use the higher category

d) no difference in interpretation of the terms ‘substantial’ and ‘severely’; each were perceived as representing serious restrictions

e) an adjustment in activities made in the past affected responses, particularly with regard to the ‘severely limited’ category

The in-depth interviews sought respondents’ views on using alternative response categories to this question; specifically ‘limited a lot’, ‘somewhat limited’, ‘limited a little’, and ‘not limited at all’. These categories were viewed as burdensome and confusing because of over use of the term ‘limited’.

The researchers recommended the following to develop the question further:

a) restriction in daily activities should be asked only of those respondents who report a condition or impairment

b) simple list of day-to-day activities should be constructed for interviewers in the field to provide respondents with examples to standardise their frames of reference before answering

c) the linkage between question 1 and 2 should be strengthened through the wording used in each

d) establish whether activities are limited before the extent is captured

e) the terms ‘substantial’ and ‘severely’ risks underreporting because of the connotations implied and the differential benchmarking applied

Duration or expected duration of restricted activities

The third question cognitively tested aimed at capturing the duration of the activity restriction, not the health condition or impairment. This distinction was problematic for some respondents; in some cases the time between onset of the condition and onset of the effect on daily activities was marginal and therefore of negligible relevance, but for others direct misinterpretation occurred. Further probing mitigated misinterpretation.

The response categories (see Annex C) were straightforward to apply, partly because most respondents with activity restriction had experienced it for a longer duration than 12 months. Answering questions about their expectations of future activity restrictions was not a problem for those respondents to whom the questions applied.

There were no substantive issues arising from cognitive testing for this question.

The effect of taking medication and treatment on daily activities
The fourth question tested examined the effect of medication or treatment withdrawal on activity restriction. The DDA confers rights under the act for those whose activities would be restricted without taking medication or receiving other treatment. For this reason, it was necessary to test the difficulties that might arise when capturing this information.

The question has two parts, asked only of those answering yes to question 1 and not responding ‘severely limited’ to question 2. Firstly, respondents’ medication and/or treatment status was established, and secondly whether their daily activities would be limited or more limited without medication and/or treatment, using the same extent categories as in question 2.

A key problem with this question for some was the limiting effect of the side effects of medication and other treatment; while for others the life threatening impact that would arise without their medication or other treatment made the question response options defective. However, most respondents were able to interpret the speculative nature of the question and formulated their answers on the basis of medical advice previously received. Another issue was the requirement to hypothetically determine the appropriate extent category.

The respondents generally included regular prescribed medicines, although some included over the counter medicines; however, none mentioned alternative therapies such as herbal remedies or alternative treatments such as massage.

The findings suggest this question should be asked only of those reporting they have a health condition and answering their daily activities were ‘not limited at all’; a compilation of relevant medications and treatments should be available to interviewers to refer to if asked for clarification by respondents.

Consultation following cognitive testing findings – June–August 2009

The findings of the cognitive testing were used to make interim amendments to the questions before discussion at an ODI hosted cross-department workshop at the end of June 2009. The changes prioritised for consultation before finalising draft questions for field testing included:

a) whether to harmonise the health conditions and impairments categories with the Scottish Census health conditions question planned for 2011
b) whether to focus on broad categories of impairments rather than specific health conditions – to improve the scope to measure outcomes disaggregated by impairment type
c) to drop the term ‘limited’ in relation to daily activities and replace with the phrase ‘have difficulty with’
d) the inclusion of a question capturing frequency of activity restriction to mitigate possible problems faced by those with intermittent effects answering the question
e) avoid the medical model emphasis of activity restriction in the suite by replacing the word ‘because’ with ‘in relation to’ health conditions, illnesses or impairments.

These suggestions were consulted on throughout the summer of 2009 involving the government sector and Equality 2025; third sector disabled people’s organisations; and leading disability studies academics in the field. ODI and ONS reviewed feedback from these consultations and made further revisions to the suite (see accompanying article in this issue of Health Statistics Office for National Statistics 19).
Quarterly). A brief overview of the consultation responses and reasons for question changes are documented below.

The list of capacities identified in the DDA (see Box 2) was criticised for impeding analyses of the outcomes for disabled people disaggregated by separate impairment categories. For example, people with visual, hearing and speech impairments are included in the same category. The list also lacked a separate category for people with conditions that affect mental health – something raised in a previous Government green paper (Department for Communities and Local Government, 2007). A reference to the exclusion of DDA capacities under the Equality Bill White Paper (‘A framework for a fairer future’, 2008) was raised, which provided an opportunity to develop an alternative list. The revised impairment categories for field testing reflect those impairments deemed most useful and relevant for categorisation to aid policy development, policy monitoring and service needs assessment.

Another improvement raised by disability studies academics was to make a clear distinction between conditions and impairments; the disease, physical or mental characteristic or illness which the individual has (for example glaucoma) and the impaired function (for example, partial sight or blindness) The consultation responses emphasised the importance for analysts to be able to make these distinctions, with impairments more relevant for social care, housing and independent living, and conditions and illnesses more relevant for medical care.

The ambition to cover both conditions and impairments in one category list was challenged in consultation; the level of detail required was unrealistic for a succinct suite aiming to capture functional impairment and activity restriction to classify disability in general household social surveys. Harmonisation sub-group members concluded the most useful data to capture was areas of difficulty or impairment that people have, regardless of their different conditions; the capture of specific health conditions and diseases was deemed unnecessary for disability measurement.

The idea to avoid using the term ‘impairment’ because of interpretation issues in the question capturing persistent health conditions and illnesses was backed by academics and third sector organisations. However, government stakeholders were uncertain about the implications of removing it and insisted field-tested estimates should be benchmarked against established sources such as the FRS, GLF and LOS.

The use of plain English response categories of ‘a little’ and ‘a lot’ in the question capturing activity restriction found general support among those consulted.

A further concern raised in consultation was the exclusion of the non-core disabled population covered in both the DDA and Equality Bill White Paper, which identified three progressive conditions (that is HIV/AIDS, cancer or multiple sclerosis) where people have legal coverage regardless of whether they currently have an impairment or experience difficulty with day-to-day activities. ODI and ONS responded by drawing stakeholders attention to the inclusion of a question on progressive conditions asked on LOS and FRS sources, and that this component is not currently included in the core measure of DDA disability used in FRS publications, and therefore falls outside the scope of the harmonisation project.
The issue of developing harmonised standard questions, which encompass the other non-core elements of the DDA (such as likelihood of activity restriction without medication and past disability) conferring rights was raised by government stakeholders. The sub-group members argued the non-core elements should be excluded from the suite for the following reasons:

a) the problems associated with capturing valid data on the three specified progressive conditions found in cognitive testing and in the LOS field testing

b) the prohibitively high additional costs and added interview burden associated with implementing an additional three elements across general social survey sources

c) the questions capturing these non-core elements of the DDA and future Equality Act will be maintained in the FRS and the LOS allowing continuity in population prevalence estimates

The body of evidence gathered from the workshops, consultations and cognitive testing guided the specification of two question suite variants for field testing. These question suites and the results of field testing are available in an accompanying article in this issue of Health Statistics Quarterly.

**Conclusion**

This article has described the work undertaken by the Health, Disability and Carers Harmonisation Sub-Group: to improve and harmonise the collection of disability data in response to changing demands for such data brought about by the national equality legislation, the European Union SILC regulation and the data deficiencies raised in the Review of Equality Data.

The application of respected conceptual frameworks (a set of structured values and definitions, which communicate and operationalise the concepts of the subject in question) and internationally recognised definitions and classifications to the data needs identified has given the draft questions for field testing a stronger relevance to the concept of disability advocated in the Prime Minister’s Strategy Unit Report ‘Improving the Life Chances of Disabled People’ and championed in the Office for Disability Issues Equality 2025 agenda.

The extensive consultations undertaken, including arm’s length bodies, academia and third sector organisations demonstrates a clear commitment on the part of the Health, Disability and Carers Harmonisation Sub-Group to gather a wide range of views to identify the deficiencies in existing data inputs to social survey data sources, guide priorities as equitably as possible to meet the variety of needs expressed and mitigate the sensitivities associated with existing question terminology when drafting question inputs.

Both the findings of the consultation activities and the recommendations following the cognitive testing of the proposed questions fed into the field testing projects which are described in an accompanying article in this issue of Health Statistics Quarterly.
References


### Annex A

**Table A1**  
Organisations participating in the consultation

<table>
<thead>
<tr>
<th>Government body</th>
<th>Represented at February 2008 workshop</th>
<th>Represented at June 2008 workshop</th>
<th>Not able to send a representative</th>
<th>Stakeholders consulted by correspondence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office for Disability Issues</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government Equalities Office</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Office for National Statistics</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scottish Government</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Welsh Assembly Government</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Department of Finance and Personnel Northern Ireland</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Department for Work and Pensions</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Department of Health</td>
<td>✓</td>
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<tr>
<td>Department for Communities and Local Government</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Department for Children Schools and Families (now DfE)</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Department for Transport</td>
<td>✓</td>
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<tr>
<td>Department for Business, Enterprise and Regulatory Reform (now BIS)</td>
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<tr>
<td>Equalities and Human Rights Commission</td>
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<td>✓</td>
<td></td>
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<tr>
<td>Ministry of Justice/Home Office</td>
<td>✓</td>
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<tr>
<td>Local Government Association</td>
<td>✓</td>
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</tr>
<tr>
<td><strong>Statutory Sector:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equality Measurement Group and National Statistics</td>
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<td></td>
<td></td>
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<tr>
<td>Harmonyisation Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Centre for Health and Social Care (DH)</td>
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<td></td>
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<td></td>
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<tr>
<td>Eurostat</td>
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<tr>
<td><strong>Third Sector:</strong></td>
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<tr>
<td>United Kingdom Advisory Network for Disabled People</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Royal Association for Disability and Rehabilitation</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Universities:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leicester, Manchester, Lancaster, Durham, De Montfort, Leeds, Loughborough, Essex</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Annex B

Draft primary harmonised standard questions submitted for initial consultation

<table>
<thead>
<tr>
<th>Q1a. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please include those that are due to old age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
<tr>
<td>Q1b. Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please include those that are due to old age</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
<tr>
<td>IF 1:</td>
</tr>
<tr>
<td>What is the nature of your physical or mental health condition, impairment or disability?</td>
</tr>
<tr>
<td>0. Open text – code up to 6 replies</td>
</tr>
<tr>
<td>Q1c. Do you have any of the following long-standing physical or mental health conditions or impairments that have lasted or are expected to last 12 months or more? Select all that apply. Please include those that are due to old age</td>
</tr>
<tr>
<td>1. Blindness, deafness or other communication impairment</td>
</tr>
<tr>
<td>2. Mobility impairment, such as difficulty walking</td>
</tr>
<tr>
<td>3. Learning difficulty or disability, such as Down’s syndrome</td>
</tr>
<tr>
<td>4. Mental health condition, such as depression</td>
</tr>
<tr>
<td>5. HIV, Multiple Sclerosis or cancer</td>
</tr>
<tr>
<td>6. Other long-standing health condition or disability</td>
</tr>
<tr>
<td>7. None</td>
</tr>
<tr>
<td>Q2a. Are your day-to-day activities limited because of any physical or mental health condition, impairment or disability? Please include those that are due to old age.</td>
</tr>
<tr>
<td>Would you say you are:</td>
</tr>
<tr>
<td>1. Severely limited</td>
</tr>
<tr>
<td>2. Limited but not severely</td>
</tr>
<tr>
<td>3. Not limited at all</td>
</tr>
<tr>
<td>Q2b. Do your physical or mental health condition(s), impairment(s) or disability(ies) mean that your day-to-day activities are limited? Please include those that are due to old age.</td>
</tr>
<tr>
<td>Would you say you are:</td>
</tr>
<tr>
<td>1. Limited a lot</td>
</tr>
<tr>
<td>2. Limited a little</td>
</tr>
<tr>
<td>3. Not limited at all</td>
</tr>
<tr>
<td>IF Q2 = 1 or 2</td>
</tr>
<tr>
<td>Q3. How long have your day-to-day activities been limited?</td>
</tr>
<tr>
<td>1. Less than 6 months</td>
</tr>
<tr>
<td>2. At least 6 months but less than 12 months</td>
</tr>
<tr>
<td>3. At least 12 months</td>
</tr>
<tr>
<td>IF 1 or 2:</td>
</tr>
<tr>
<td>Do you expect your day-to-day activities to be limited for 12 months or more altogether?</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
<tr>
<td>IF 1 to Q1b or 1 thru 6 to Q1c AND 2 or 3 to Q2:</td>
</tr>
<tr>
<td>Q4. Do you take any medication for your long-standing health condition(s) or disability(ies)?</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
<tr>
<td>IF 1:</td>
</tr>
<tr>
<td>If you did not have this medication, do you think your activities would be limited by your long-standing health condition(s) or disability(ies)?</td>
</tr>
<tr>
<td>1. Severely limited</td>
</tr>
<tr>
<td>2. Limited but not severely</td>
</tr>
<tr>
<td>3. Not limited at all</td>
</tr>
</tbody>
</table>
Notes

- **question 1** versions establish the presence of conditions, impairments and disabilities, with open and prescribed breakdowns elicited in version b and c respectively.

- **question 2** aims to establish the presence of limitations in day-to-day activities the respondent experiences: the questions differ in the strength of linkage of the condition or impairment with the limitation and in routeing; version (b) is routed from q1 and version (a) is not.

- **question 3** aims to place the limitations in daily activities into a time frame consistent with DDA and European data needs, 12 months or more in case of the DDA and for at least 6 months in the case of EU-SILC.

- **question 4** asks the respondent whether he is taking medication for his condition or impairment and if s/he answered no to question 2 whether her/his daily activities would be limited without it.
Annex C

Questions used in the cognitive testing stage

Question 1

Purpose: To establish the presence of self-reported physical or mental health condition or impairment (or disability – version A only).

<table>
<thead>
<tr>
<th>Asked first in Version A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1a) Do you have any long-standing physical or mental health condition, impairment or disability that has lasted or is expected to last 12 months or more? Please include those that are due to old age.</td>
</tr>
<tr>
<td>Yes 1, GO TO Q1b)</td>
</tr>
<tr>
<td>No 2, GO TO Q2a)</td>
</tr>
</tbody>
</table>

IF YES AT Q1a) ASK:

Q1b) What is the nature of your physical or mental health condition, impairment or disability? PROBE FULLY AND RECORD RESPONSES VERBATIM (UP TO SIX).

<table>
<thead>
<tr>
<th>Asked first in Version B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1c) SHOW CARD</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mobility impairment, such as difficulty walking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning difficulty or disability, such as Down’s syndrome</td>
</tr>
<tr>
<td>Mental health condition, such as depression</td>
</tr>
<tr>
<td>Long-term illness, such as Multiple Sclerosis or cancer</td>
</tr>
<tr>
<td>Other long-standing health condition or disability</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Blindness, deafness or other communication impairment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility impairment, such as difficulty walking</td>
</tr>
<tr>
<td>Learning difficulty or disability, such as Down’s syndrome</td>
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<td>Mental health condition, such as depression</td>
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<tr>
<td>Long-term illness, such as Multiple Sclerosis or cancer</td>
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<td>Other long-standing health condition or disability</td>
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</table>

<table>
<thead>
<tr>
<th>Blindness, deafness or other communication impairment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility impairment, such as difficulty walking</td>
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<td>Mental health condition, such as depression</td>
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<tr>
<td>Long-term illness, such as Multiple Sclerosis or cancer</td>
</tr>
<tr>
<td>Other long-standing health condition or disability</td>
</tr>
</tbody>
</table>

None 7, GO TO Q2b) | NONE 7, GO TO Q2a)
**Question 2**

**Purpose:** To establish if day-to-day activities are felt to be limited for reasons linked with physical or mental health condition, impairment or disability.

**Asked first in Version A**

**ASK ALL**

Q2a Are your day-to-day activities limited because of any physical or mental health condition, impairment or disability? Please include those that are due to old age.

Would you say you are... READ OUT

- Severely limited \( \rightarrow \) GO TO Q3
- Limited but not severely
- Not limited at all \( \rightarrow \) GO TO Q4

**Asked first in Version B**

IF CODE 7 AT Q1c), ASK Q2a):

Q2a Are your day-to-day activities limited because of any physical or mental health condition, impairment or disability? Please include those that are due to old age.

Would you say you are... READ OUT

- Severely limited \( \rightarrow \) GO TO Q3
- Limited but not severely
- Not limited at all \( \rightarrow \) GO TO Q4

IF CODES 1 TO 6 AT Q1c), ASK Q2b)

Q2b) Do your physical or mental health condition (s), impairment(s) or disability(ies) mean that your day-to-day activities are limited? Please include those that are due to old age.

Would you say you are... READ OUT

- Severely limited \( \rightarrow \) GO TO Q3
- Limited but not severely
- Not limited at all \( \rightarrow \) GO TO Q4
### Question 3

**Purpose:** To measure duration/expected duration of any perceived day-to-day activity limitation linked with physical or mental health condition, impairment or disability. The time frame is consistent with DDA (12 months) and European (at least 6 months) data needs.

** Asked in both Version A and Version B **

If CODES 1 OR 2 at Q2a), ASK Q3:

**Q3a)** How long have your day-to-day activities been limited? SHOW CARD AND READ OUT

<table>
<thead>
<tr>
<th>Duration</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>1</td>
</tr>
<tr>
<td>6 months but less than 12 months</td>
<td>2</td>
</tr>
<tr>
<td>At least 12 months</td>
<td>3</td>
</tr>
</tbody>
</table>

Go to Q3b if either CODE 1 OR CODE 2 at Q3a), ASK:

**Q3b)** Do you expect your day-to-day activities to be limited for 12 months or more altogether?

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>
Question 4

**Purpose:** To establish if medication is taken for reported long-standing health condition(s) or disability(ies) and to measure perceived impact of medication on limitation of day-to-day activities.

**Asked in both Version A and Version B**

IF CODES 2 OR 3 AT Q2a), ASK (Version A filter):

IF CODES 1 TO 6 AT Q1c) AND CODES 2 OR 3 AT Q2b)

OR CODE 7 AT Q1c) AND CODES 2 OR 3 AT Q2a), ASK (Version B filter):

**Q4a)** Do you take any medication for your long-standing health condition(s) or disability(ies)?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

IF YES AT Q4a), ASK:

**Q4b)** If you did not have this medication, do you think your activities would be limited by your long-standing health condition(s) or disability(ies)?

Do you think you would be... READ OUT

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Severely limited</td>
<td>1</td>
</tr>
<tr>
<td>Limited but not severely</td>
<td>2</td>
</tr>
<tr>
<td>Not limited at all</td>
<td>3</td>
</tr>
</tbody>
</table>
Update on the harmonisation of disability data collection in UK surveys (Part 2)

Chris White Office for National Statistics

Abstract

Background

This article reports on the field testing work undertaken, leading to the proposals for a primary harmonised standard for disability data inputs: designed to derive statistical measures of disability from social surveys using a face-to-face mode of data capture. These proposals were submitted to the National Statistics Harmonisation Group (NSHG) for approval in December 2010. The proposed primary harmonised standard data inputs are designed to meet the data needs arising from the equality legislation introduced in 2010 and improve international comparability: by better meeting the definitions for measures of long-standing illness and disability derived from the European Union’s Statistics on Income and Living Conditions (EU-SILC).

Methods

Field testing was conducted during two discrete periods: between October 2009 and February 2010 for stage 1 testing, and between May and July 2010 for stage 2 testing. The Office for National Statistics (ONS) Opinions Survey acted as the data collection vehicle and the design was a split sample in each case. In stage 1, question suite variants were compared, together with the Family Resources Survey (FRS) Disability Discrimination Act module running on the Opinions Survey in equivalent months. The second stage also applied a split sample to compare the revised proposed harmonised questions with the question on disability planned for the 2011 Census.

Derivations of disability to meet measures required under the national Equality Act legislation and the European Union-Statistics on Income and Living Conditions were applied to field-test estimates to assess coherence with contemporaneous external sources.

Results

The field test results found good comparability with estimates of disability used in the FRS publications and with the field tested 2011 Census disability question.
In stage 1 testing, the measure of disability derived from the version 1 suite was closer to the FRS measure of disability used in FRS publications than that derived from version 2’s questions. In stage 2, the proximity of the measure derived from the proposed harmonised questions to the FRS measure of disability improved, with a 0.5 percentage point difference.

The stage 2 measure of disability was found to be consistent with the EU-SILC measure of disability in 2009 for the UK published on the Eurostat website. Furthermore, the harmonised questions produced a similar estimate of disability to the 2011 Census question, also field tested concurrently with the proposed harmonised questions.

Conclusions

The harmonised questions tested provide appropriate data inputs to measure persistent illness, impairment and disability, consistent with the components of disability used in the disablement process and the International Classification of Functioning Disability and Health. Their implementation across social survey data sources using a face-to-face mode of data capture will enhance the consistency of statistical measurement and their relevance to the data requirements embodied in national Equality legislation and the EU-SILC European regulation.
Introduction

This article reports progress made in revising standard UK social survey questions on persistent illness, impairment and activity restriction for collection in social survey data sources using a face-to-face mode of data collection. It updates the material presented in an accompanying article in this issue of HSQ detailing the consultations and cognitive testing components of the project (White 2011). The findings of consultation and cognitive question testing were used to amend the draft questions for field testing, and the evidence gained from field testing enabled the refinement of data inputs to derive statistical measures of disability, which are described below.

Background

The Review of Equality Data (ONS, 2007) identified a need to improve the co-ordination, comparability, quality, accessibility and presentation of disability statistics through developing and applying a principled approach to data collection and its circulation. It made a specific recommendation that the Office for Disability Issues (ODI) and the Government Equalities Office (GEO) should work with the Office for National Statistics (ONS) to develop harmonised standards for disability measurement across data sources to meet this need.

A project was initiated in early 2008 with the following objectives:

- conduct a cross-sector consultation on data needs and priorities and replicate consultations at key stages
- develop a conceptual framework for disability definition taking account of consultation responses, national legislation and European regulations
- frame a short suite of questions to measure disability in accordance with the definition and sensitive to the issue of data continuity
- test the performance of these questions in terms of interpretability and comparability with established sources collecting similar information
- recommend to the National Statistics Harmonisation Group (NSHG) and the Government Statistical Service Statistical Policy and Standards Committee (GSS SPSC) an implementation of harmonised data inputs across social survey sources to harmonise the presentation of statistical measures of disability

This article contains the following sections:

- The results from two stages of field testing
- Final consultation on the implications of these results
- Recommendation of a primary harmonised standard to key fora, including the NSHG and the GSS SPSC.

The article provides a condensed overview of field test results; the finalised field testing reports will be published on the ONS website during the autumn and will be available for downloading.
Field Testing Stage 1

Methods

Data Source and Study population

ODI commissioned the first field testing project, and used the ONS Opinions Survey (OS) as the data collection vehicle (ONS Opinions Survey, 2011). The OS is multi-purpose, designed to test questions in the field before embedding them into other established data sources; the sampling approach ensures delivery of a representative sample of Great Britain aged 16 years and over, with one household member selected for interview. The data was collected over a five-month period from October 2009 to February 2010.

Question suite versions and design

Two question suite versions (see Annex A) were tested. The first version asked Disability Discrimination Act (DDA) (National Archive, 1995) related questions, including a question on frequency of activity restriction; but excluded a question on duration. It routed respondents to the impairment list question only if they reported having a persistent health condition or illness in the previous question. The question capturing persistent health conditions and illnesses excluded the terms disability, infirmity and impairment and asked respondents to consider whether they had any physical or mental health conditions or illnesses that have lasted 12 months or more.

The second version asked questions about participation restriction and the perceived causes of restriction first (not reported on here) before asking DDA related questions. Version 2 excluded the capture of frequency of activity restriction but included a question on duration, and the type of impairment question was asked across the whole sample, not routed as in version 1. The question capturing persistent health conditions and illnesses also excluded the terms disability, infirmity and impairment and asked respondents whether they had any physical or mental health conditions expected to last 12 months or more.

The sample was split in half, with one half administered the version 1 questions and the other half the version 2 questions. The sample size for version 1 was 2,403 and for version 2, was 2,384.

Elements of testing

The primary purpose of this stage of testing was to judge comparability of estimates of disability derived using each field-tested version with those derived from the FRS’s disability module (See Annex B) and estimates of long-standing illness and disability provided by the General Lifestyle Survey’s (GLF) questions (See Annex C) designed to capture two variables included in the European Union’s Statistics on Income and Living Conditions’ (EU-SILC) Minimum European Health Module (MEHM).
The broad testing elements included:

a) the extent of comparability in component-specific prevalence estimates of illness, impairment and disability between suite versions and external sources, and capability to estimate core current DDA disability and disability derived from the EU-SILC MEHM

b) the performance and adequacy of the impairment list in capturing respondents’ impairment

c) the extent of agreement between the proposed harmonised impairment list and the FRS list of capacities

Results and recommendations

Comparability in component specific prevalence

The prevalence of persistent illness varied between field test versions, with version 1 producing a 4.2 percentage point higher prevalence than version 2 (Table 1). Table 1 documents the question wording used in each source and tested version, together with the percentage prevalence detected in those aged 16 years and over.

<table>
<thead>
<tr>
<th>Source and Question</th>
<th>Per cent Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Resources Survey 2008–09</strong>&lt;br&gt;Do you have any long-standing illness, disability or infirmity lasting or expected to last 12 months or more?</td>
<td>29.2</td>
</tr>
<tr>
<td><strong>Life Opportunities Survey 2009–10</strong>&lt;br&gt;Do you have any long-standing physical or mental impairment, illness or disability lasting or expected to last for a period of 12 months or more? By long-standing I mean anything that has affected you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months.</td>
<td>35.1</td>
</tr>
<tr>
<td><strong>General Lifestyle Survey 2008</strong>&lt;br&gt;Do you have any long-standing illness, disability or infirmity – by long-standing I mean anything that has troubled you over a period of time or is likely to affect you over a period of time?</td>
<td>34.4</td>
</tr>
<tr>
<td><strong>Annual Population Survey 2006–08</strong>&lt;br&gt;Do you have any health problems or disabilities that you expect will last for a year or more?</td>
<td>35.9</td>
</tr>
<tr>
<td><strong>Field Test stage 1 version 1 Opinions 2009–10</strong>&lt;br&gt;Do you have any physical or mental health conditions or illnesses which have lasted for 12 months or more?</td>
<td>32.5</td>
</tr>
<tr>
<td><strong>Field Test stage 1 version 1 Opinions 2009–10</strong>&lt;br&gt;Do you have any physical or mental health condition(s) or illnesses that are expected to last 12 months or more?</td>
<td>28.3</td>
</tr>
</tbody>
</table>

A comparison with external sources showed the field-tested questions produced predominantly lower percentage prevalence, although version 1’s question was found to be more proximal than version 2’s. The possible risk of suppressing prevalence by excluding the terms disability or impairment from the body of the field tested question and leading to a discontinuity is contentious as the FRS question contains the term disability, but this source produced a lower prevalence compared with the version 1 field test question; however, all other sources investigated, which contained one or other of these terms produced a higher prevalence.
The field-test questions are more specific in what they capture (that is physical or mental health conditions or illnesses) and they reference only either the past 12 months (version 1) or the future 12 months (version 2), which may contribute to a lower prevalence found, compared with the GLF, LOS and APS questions.

A second component tested was the possible impact on prevalence of specific impairments by routeing the impairment question to only those reporting a physical or mental health condition in question 1, as applied in version 1, compared with total sample coverage applied in version 2 (Table 2).

Table 2  
Percentage prevalence of impairment by version, persons aged 16 years and over

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Version 1</th>
<th>Version 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeing (due to blindness or partial sight)</td>
<td>3.5</td>
<td>4.2</td>
</tr>
<tr>
<td>Hearing (due to deafness or partial hearing)</td>
<td>4.2</td>
<td>6.6</td>
</tr>
<tr>
<td>Mobility (difficulty walking short distances, climbing stairs, lifting or carrying objects)</td>
<td>14.8</td>
<td>14.7</td>
</tr>
<tr>
<td>Learning or Concentrating or Remembering</td>
<td>4.1</td>
<td>6.0</td>
</tr>
<tr>
<td>Mental Health</td>
<td>3.7</td>
<td>3.9</td>
</tr>
<tr>
<td>Stamina or Breathing</td>
<td>7.4</td>
<td>8.5</td>
</tr>
<tr>
<td>Social learning difficulty (e.g. due to Autistic Spectrum Disorder or Aspergers’)</td>
<td>0.3</td>
<td>0.5</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>4.4</td>
<td>2.7</td>
</tr>
<tr>
<td>Any impairment</td>
<td>25.0</td>
<td>29.7</td>
</tr>
</tbody>
</table>

Source: ONS Opinions Survey 2009–10

Prevalence of impairment overall was 4.7 percentage points higher using version 2’s administration approach, with higher prevalence in the majority of specific categories. The overall version 2 prevalence of 30 per cent concurred well with the overall prevalence found in the Life Opportunities Survey (LOS) interim wave 1 report (ONS, 2010), and suggests a small number of respondents will differentiate between having a health condition and having an impairment.

The prevalence of activity restriction, and thereby the prevalence of disability, using version 1’s questions which capture frequency and extent of restriction, was 19.7 per cent, suggesting approximately a fifth of the population were restricted either ‘a lot’ or ‘a little’ ‘sometimes’ or more frequently. In comparison, version 2’s question suggested a population prevalence of only 18.9 per cent (Table 3.).
Table 3  
**Percentage prevalence of activity restriction by source: Persons aged 16 years and over**

<table>
<thead>
<tr>
<th>Source</th>
<th>Weighted percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field test version 1 suite.– Opinions 2009–10</strong></td>
<td></td>
</tr>
<tr>
<td>To what extent do you have difficulty carrying out day to day activities?</td>
<td>19.7</td>
</tr>
<tr>
<td>Yes a lot of difficulty or yes a little difficulty?</td>
<td></td>
</tr>
<tr>
<td>Yes, a lot of difficulty</td>
<td>7.9</td>
</tr>
<tr>
<td>Yes, a little difficulty</td>
<td>11.8</td>
</tr>
<tr>
<td><strong>Field test version 2 suite.– Opinions 2009–10</strong></td>
<td></td>
</tr>
<tr>
<td>In relation to your condition(s) or illnesses, to what extent do you have difficulty carrying out day to day activities?</td>
<td>18.9</td>
</tr>
<tr>
<td>Yes a lot of difficulty or yes a little difficulty?</td>
<td></td>
</tr>
<tr>
<td>Yes, a lot</td>
<td>7.6</td>
</tr>
<tr>
<td>Yes, a little</td>
<td>11.3</td>
</tr>
<tr>
<td><strong>FRS question – 2008–09</strong></td>
<td></td>
</tr>
<tr>
<td>Does this/do these health problems or disabilities mean that you have substantial difficulties with any of these areas of your life?</td>
<td>21.4</td>
</tr>
<tr>
<td>Mobility; lifting; manual dexterity; continence; communication; memory, concentrate, understand or learn; physical danger; balance; other</td>
<td></td>
</tr>
<tr>
<td><strong>LOS question 2009–10 interim results</strong></td>
<td></td>
</tr>
<tr>
<td>Does this/do these health problems or disabilities mean that you have substantial difficulties with any of these areas of your life?</td>
<td>25.9</td>
</tr>
<tr>
<td>Mobility; lifting; manual dexterity; continence; communication; memory, concentrate, understand or learn; physical danger; balance; other</td>
<td></td>
</tr>
<tr>
<td><strong>GLF question 2008</strong></td>
<td></td>
</tr>
<tr>
<td>Does this illness or disability (Do any of these illnesses or disabilities) limit your activities in any way?</td>
<td>19.5</td>
</tr>
<tr>
<td>Limited or strongly limited</td>
<td></td>
</tr>
<tr>
<td>Strongly limited</td>
<td>8.5</td>
</tr>
</tbody>
</table>

The routeing approach differed in each version; version 1 respondents were routed from the first question only if answering ‘yes’; however, in version 2 respondents were routed if they either reported a health condition or illness in question 2a or an impairment in question 2b (see Annex A).

The lower prevalence detected using version 2’s questions could have arisen by misclassifying those with intermittent restrictions because of the absence of a question capturing frequency; however, the lower prevalence of health conditions or illnesses in version 2 is a plausible alternative explanation.

The frequency category with the highest prevalence in version 1’s frequency question was ‘sometimes’ – exceeding the prevalence of the other two categories combined (that is ‘always’ and ‘most of the time’). The scale of this difference suggests the non-capture of those with intermittent restrictions was an unlikely explanation for the lower prevalence detected in version 2, as it is arguable that the difference in prevalence would have been considerably greater if respondents with intermittent restrictions had been reluctant to affirm activity restriction in version 2’s question for this reason. Consequently, there is an absence of clear evidence supporting the need to collect frequency of restriction to avoid the misclassification of those with intermittent restriction effects.

The field-test results refute the perceived risk of suppressing the prevalence estimates of activity restriction, and thereby disability, by routeing to the impairment question. While the prevalence of
impairment itself is somewhat lower in the routed sample, there is no evidence of a knock-on effect for measures of activity restriction (that is disability), suggesting the non-routed sample is capturing impairments not associated with activity restriction. As it is the impaired population with activity restriction that is the most useful for policy, the additional costs incurred by administering the impairment question across the whole sample seems unnecessary.

The prevalence of activity restriction is notably lower than LOS. However, compared with the FRS and GLF, on which the questions are benchmarked, the field test questions produce similar estimates.

The perceived risk that the capture of extent of restriction using the plain English response categories ‘a lot of difficulty’, or ‘a little difficulty’ would inflate overall prevalence compared with dichotomised response options using ‘Yes’ and ‘No’ response categories is not borne out by these field-test results.

**Performance and adequacy of the impairment list**

The performance and adequacy of the impairment list was judged on the basis of what proportion of the sample used the ‘Other impairment’ category, and whether those with a health condition or illness report one or more of the impairment categories.

The proportion of the sample reporting an impairment using the ‘Other impairment’ category was low (4.4 per cent of the version 1 sample and 2.7 per cent of the version 2 sample). In version 1, of those reporting an impairment using the ‘Other impairment’ category, two-fifths provided answers which were collapsible into an existing category; while in version 2, a quarter could be collapsed (Table 4.).

The most common conditions reported under the ‘other impairment’ category which were not obviously collapsible were circulatory disorders, gastrointestinal disorders and diabetes. With guidance it may be possible for interviewers to probe further; for example for those with diabetes interviewers could ask whether it affects their vision, and for circulatory disease whether it affects their stamina or breathing. Some respondents mentioned frequent tiredness connected with specific conditions such as diabetes. These respondents clearly did not connect their problem with a ‘stamina’ difficulty and the inclusion of the term ‘fatigue’ or ‘tiredness’ within the ‘stamina or breathing’ category may offer an additional opportunity to make the connection with their health condition and avoid using the ‘other impairment’ category for free text transcription.

A possible candidate for inclusion as a separate category was ‘pain’; a number of respondents reported pain associated with their specific condition or conditions. Pain is often a symptom of a number of conditions, as well as connected with medication side effects and the effects of hospital investigations and procedures, and is relevant to activity restriction.
Table 4  Other impairments which collapsed into an existing impairment category

<table>
<thead>
<tr>
<th>Version 1</th>
<th>% collapsible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility/dexterity –</td>
<td>19.1</td>
</tr>
<tr>
<td>back problems; stretching problems; writing difficulty (use of hands); balance; bone problems; osteoporosis; limited joint movements; arthritis; disc lesions; inability to maintain physical positions.</td>
<td></td>
</tr>
<tr>
<td>Stamina/breathing –</td>
<td>8.1</td>
</tr>
<tr>
<td>asthma; breathing problems; bronchitis.</td>
<td></td>
</tr>
<tr>
<td>Seeing –</td>
<td>4.1</td>
</tr>
<tr>
<td>eye condition; colour blindness.</td>
<td></td>
</tr>
<tr>
<td>Mental health –</td>
<td>5.9</td>
</tr>
<tr>
<td>depression; panic; alcoholism; social phobia; nervousness.</td>
<td></td>
</tr>
<tr>
<td>Learning/memory –</td>
<td>2.5</td>
</tr>
<tr>
<td>memory loss; learning difficulties; dyslexia.</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>39.7</td>
</tr>
</tbody>
</table>

| Version 2                                      |               |
| Mental health –                                | 4.9           |
| depression; alcohol abuse; anxiety:            |               |
| Learning/memory –                              | 6.7           |
| short-term memory loss; learning difficulties; dementia, dyslexia; alzheimers: |               |
| Mobility/dexterity –                           | 13.8          |
| back problems; movement restrictions; arthritis; loss of grip; osteoporosis; un-operable hernia: |               |
| Social learning –                              | 1.0           |
| difficulties with social interaction           |               |
| Total                                          | 26.4          |

Source: Opinions 2009–10

Another weakness of the list relates to the combining of ‘learning’ and ‘concentrating’ with ‘remembering’. There was evidence to suggest the ‘learning’ and ‘concentrating’ components dissuaded respondents with conditions affecting ‘memory’ from selecting this category. There was also evidence from consultation that the analysis of disaggregated categories to support policy would benefit from separating out ‘memory’ from ‘learning’ and ‘concentrating’ as the needs of these people are different.

Correspondence between the impairment list and the FRS list of capacities

The FRS disability module asks respondents about whether they have ‘substantial’ difficulty in a number of capacities such as mobility. There was interest among stakeholders in what level of correlation existed between the impairments contained in the field-test question and the FRS capacities, where similarity in categories existed. The OS also collected the FRS capacities for three of the five months of field testing allowing direct measurement at the individual level of the overlap in the reporting of impairments and capacities.

Table 5 shows the matrix of reporting of DDA capacities by the version 1 and version 2 impairment categories.
### Table 5

**Percentage prevalence of impairment in those reporting substantial difficulty in a specific capacity domain**

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Version 1</th>
<th>Version 2 (percentage reporting capacity and impairment)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Seeing</td>
<td>Hearing</td>
</tr>
<tr>
<td>Moving about</td>
<td>13.2</td>
<td>17.5</td>
</tr>
<tr>
<td>Balance/Coordination</td>
<td>16.4</td>
<td>29.3</td>
</tr>
<tr>
<td>Lifting</td>
<td>12.0</td>
<td>18.1</td>
</tr>
<tr>
<td>Manual dexterity</td>
<td>19.0</td>
<td>24.4</td>
</tr>
<tr>
<td>Bladder/Bowel</td>
<td>18.5</td>
<td>16.1</td>
</tr>
<tr>
<td>Communication</td>
<td>33.1</td>
<td>42.3</td>
</tr>
<tr>
<td>Learn/Memory</td>
<td>16.1</td>
<td>19.2</td>
</tr>
<tr>
<td>Danger</td>
<td>38.7</td>
<td>26.6</td>
</tr>
<tr>
<td>Other</td>
<td>12.6</td>
<td>19.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Seeing</th>
<th>Hearing</th>
<th>Mobility</th>
<th>Learning</th>
<th>Mental Health</th>
<th>Stamina</th>
<th>Social Learning</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moving about</td>
<td>12.7</td>
<td>16.9</td>
<td>89.5</td>
<td>18.5</td>
<td>11.4</td>
<td>34.3</td>
<td>1.3</td>
<td>5.2</td>
</tr>
<tr>
<td>Balance/Coordination</td>
<td>16.0</td>
<td>22.8</td>
<td>71.7</td>
<td>35.3</td>
<td>16.7</td>
<td>32.2</td>
<td>6.1</td>
<td>6.8</td>
</tr>
<tr>
<td>Lifting</td>
<td>10.3</td>
<td>19.3</td>
<td>72.0</td>
<td>15.2</td>
<td>7.3</td>
<td>32.2</td>
<td>1.2</td>
<td>4.4</td>
</tr>
<tr>
<td>Manual dexterity</td>
<td>13.7</td>
<td>20.4</td>
<td>76.8</td>
<td>26.9</td>
<td>20.2</td>
<td>36.2</td>
<td>3.3</td>
<td>8.8</td>
</tr>
<tr>
<td>Bladder/Bowel</td>
<td>9.3</td>
<td>17.6</td>
<td>56.4</td>
<td>17.0</td>
<td>10.6</td>
<td>26.1</td>
<td>0.0</td>
<td>7.9</td>
</tr>
<tr>
<td>Communication</td>
<td>34.7</td>
<td>52.1</td>
<td>42.7</td>
<td>34.1</td>
<td>16.2</td>
<td>20.9</td>
<td>6.2</td>
<td>7.3</td>
</tr>
<tr>
<td>Learn/Memory</td>
<td>13.8</td>
<td>16.7</td>
<td>49.4</td>
<td>65.3</td>
<td>30.2</td>
<td>30.2</td>
<td>7.1</td>
<td>9.2</td>
</tr>
<tr>
<td>Danger</td>
<td>20.1</td>
<td>15.3</td>
<td>50.4</td>
<td>55.9</td>
<td>50.3</td>
<td>36.7</td>
<td>13.9</td>
<td>0.0</td>
</tr>
<tr>
<td>Other</td>
<td>19.1</td>
<td>17.4</td>
<td>33.3</td>
<td>19.7</td>
<td>34.5</td>
<td>37.3</td>
<td>5.1</td>
<td>11.8</td>
</tr>
</tbody>
</table>

Source: ONS Opinions Survey 2009–10

A compelling level of correspondence is suggested in this matrix between some capacities and impairments. The reporting of ‘mobility’ impairment has a strong overlap with the capacities ‘moving’, ‘balance’, ‘lifting’ ‘manual dexterity’ and ‘continence’. Another important overlap is present between the capacity ‘learning’ and the impairment ‘learning or concentrating or remembering’.

### Conclusions of stage 1 field test

The question capturing persistent physical or mental health conditions or illnesses should contain a 12-month time reference encompassing the past and future 12 months to improve the time frame comparability with the current FRS and LOS questions. The exclusion of the terms ‘disability’ and ‘impairment’ should continue as the evidence suggests prevalence estimates are insufficiently discrepant with other sources by their exclusion, and the application of the disablement process and the International Classification of Functioning, Disability and Health (WHO, 2001) advocates...
the separation of concepts of illness, functional impairment and disability (that is activity and participation restriction).

The impairment list should route from the question capturing persistent physical or mental health conditions or illnesses; the added benefit of capturing impairment for the whole sample is unsubstantiated and adds to interview length and costs.

Some avoidance of the use of the ‘other impairment’ category is possible through the provision of interviewer instructions and guidance on probing. For example, probing the respondent to consider whether ‘stamina or breathing’ is affected by his or her heart condition.

The merits of including the term ‘fatigue’ in the ‘stamina or breathing’ category and a separate category eliciting ‘pain’ should be judged following any further evidence supporting their inclusion from the stage 2 field test results.

To improve policy relevance, the category ‘learning or concentrating or remembering’ requires amendment; specifically creating new categories of ‘memory impairment’ and ‘learning or concentrating or understanding impairment’.

The measurement of activity restriction can be captured effectively using the terms difficulty and the plain English extent categories of ‘a little’ and ‘a lot’. There was an absence of evidence supporting the capture of frequency of restriction to offset any misclassification of those with intermittent activity restriction. The duration of activity restriction should have categories enabling breakdowns to meet alternative legislation guidelines set nationally and in Europe.

**Field Testing Stage 2**

**Introduction**

The second stage of field testing was conducted to further test the performance of the questions in measuring the population prevalence of Equality Act (National Archive, 2010) disability and the relationship the field-test questions have with the question on disability included in the decennial 2011 Census of population.

Two question suites were tested (see Annex D):

1. the proposed harmonised disability question suite, amended to take account of stage 1 field test findings
2. the Scottish 2011 Census question on health conditions and the 2011 Census question on disability asked across the UK constituent countries

The specific purposes for this stage of field testing are to:

a) compare the prevalence of core disability, as measured by the FRS with the proposed harmonised disability question suite

b) assess the level of agreement in prevalence between the harmonised suite’s derivation of disability by extent and that derived from the 2011 Census question on disability

c) assess the scope to deliver Equality Act and EU-SILC outputs with and without the duration filter
Methods

Data source and study population

The ONS Opinions Survey provided the data collection vehicle to test these questions during the months of May, June and July 2010. The estimates derived were compared with other sources collecting similar data for external validation. These included:

a) Family Resources Survey
b) Life Opportunities Survey
c) General Lifestyle Survey

The Opinions survey sample was split into two equal parts; one half of the sample were given the proposed harmonised questions, while the other half were given the questions planned for the decennial 2011 Census of population. The sample sizes were 1,726 for the proposed harmonised question suite and 1,768 for the census questions.

Question Suite Versions

The proposed harmonised suite included questions determining:

a) the presence of a physical or mental health condition or illness
b) impairment status, by type
c) extent of difficulty carrying out day-to-day activities, by duration

A number of changes to the proposed harmonised questions were introduced in stage 2. First, the time frame in the question eliciting the presence of a persistent health condition or illness is more inclusive, referring to both the past 12 months and also an expectation of duration for a further 12 months. Second, the impairment list has separated out the terms ‘memory’ from ‘learning, understanding or concentrating’ and replaces the term ‘social learning difficulty’ (referring to autistic spectrum conditions) with ‘socially or behaviourally’. Third, the question eliciting activity restriction includes the term ‘reduce your ability to carry out day-to-day activities’ with running prompt plain English response categories ‘yes, a lot’, ‘yes, a little’, or ‘not at all’. Fourth, a question measuring frequency of activity restriction is excluded.
Scope of testing elements

A number of criteria were set to determine the fitness for purpose of these questions:

a) Is the prevalence of a physical or mental health condition lasting or expected to last 12 months or more consistent with estimates derived from the equivalent questions asked on the FRS 2008–09, the LOS 2009–10 and the GLF 2008 and 2009?

b) How does prevalence of impairment compare with LOS published estimates (ONS, 2009)?

c) Is there evidence that estimates of activity restriction fall from the stage 1 level by excluding a question on frequency?

d) Is the estimate of core Equality Act disability prevalence, derived from the proposed harmonised questions, comparable with that derived from the proposed 2011 Census question on disability and with external source estimates derived from the FRS 2008–09 and 2009–10 and LOS 2009–10 questions

e) Is the estimate of persistent illness and disability derived from the proposed harmonised questions plausible for EU-SILC data requirements based on historical estimates published on the Eurostat website? Does the duration filter improve coherence?

f) Is there evidence that the capture of extent of activity restriction inflates prevalence compared with sources using dichotomised ‘Yes’ and ‘No’ response choices?

Results and recommendations

Physical and mental health conditions

Table 6 compares the prevalence of a health condition or illness measured using the field test stage 2 question with estimates derived from the FRS 2008–09 and 2009–10, the LOS 2009–10 and the GLF 2008 and 2009 data.

For persons, the stage 2 field test prevalence was 5.4 percentage points higher than the version 2 stage 1 field test prevalence. The stage 2 prevalence is also somewhat higher than the equivalent question asked on the FRS using both 2008–09 and 2009–10 data; however, it is lower than both the LOS 2009–10 and the GLF 2008 and 2009 estimates. The field test question’s estimate across ages and by sex are more consistent with LOS and the GLF than with the estimates derived from the FRS.
### Table 6  
**Percentage prevalence of a physical or mental health condition: by source**

**Great Britain**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Field test</th>
<th>LOS 09–10</th>
<th>FRS 08–09</th>
<th>FRS 09–10</th>
<th>GLF 2008</th>
<th>GLF 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons</td>
<td>33.7</td>
<td>35.1</td>
<td>29.2</td>
<td>29.6</td>
<td>34.1</td>
<td>35.2</td>
</tr>
<tr>
<td>Men</td>
<td>31.5</td>
<td>34.0</td>
<td>28.2</td>
<td>28.8</td>
<td>33.6</td>
<td>35.0</td>
</tr>
<tr>
<td>Women</td>
<td>35.7</td>
<td>36.1</td>
<td>30.2</td>
<td>30.3</td>
<td>34.6</td>
<td>35.5</td>
</tr>
<tr>
<td>Persons 16–24:</td>
<td>15.9</td>
<td>12.5</td>
<td>10.4</td>
<td>10.7</td>
<td>13.0</td>
<td>12.5</td>
</tr>
<tr>
<td>Persons 25–64:</td>
<td>28.4</td>
<td>30.9</td>
<td>24.2</td>
<td>24.5</td>
<td>28.1</td>
<td>29.4</td>
</tr>
<tr>
<td>Persons 65 and over:</td>
<td>64.6</td>
<td>63.6</td>
<td>61.4</td>
<td>61.1</td>
<td>60.5</td>
<td>61.6</td>
</tr>
</tbody>
</table>

While the exclusion of the terms ‘disability’ and ‘impairment’ from the body of the field tested question may have a marginal effect on suppressing prevalence, the proposed harmonised question has the advantage of disentangling concepts of health conditions or illnesses and disability, and is therefore more specific in what it is measuring; that is the prevalence of any physical or mental health conditions or illnesses. Questions which mix these concepts leave uncertainty about the distribution between these states and they carry the potential inconsistency of classifying disability in the absence of activity restriction, which runs counter to the harmonised definition agreed and presented in the accompanying article in this issue of Health Statistics Quarterly (White, 2011), and the EU-SILC guideline of separating out the measurement of chronic illness from disability.

For these reasons the sub-group agreed the harmonised standard question should:

1. exclude the terms ‘disability’ and ‘impairment’
2. adopt a 12-month or more time frame taking account of the past duration and expected future duration

**Prevalence of impairment**

The question on impairment was given only to those reporting a physical or mental health condition in the previous question in stage 2 testing. The prevalence of impairment is shown in table 7 together with the LOS impairment prevalence (the LOS collected data on a wider range of impairments and therefore for some impairments, no equivalent figure is available from the field tested question).

The most common impairment using the field test question was ‘mobility’ at 16.6 per cent, encompassing difficulty climbing stairs, walking short distances and lifting and carrying objects; ‘stamina and breathing’ impairment affected 9.0 per cent of the population. The prevalence estimates are higher in each case across all impairment categories than that found in stage 1 testing.

The prevalence of impairment overall using the field-test question was 4.1 percentage points lower than that found in LOS, but this does not compare like with like as LOS collects a wider range of impairments across the whole sample which may affect the overall prevalence estimate.
### Table 7

**Percentage prevalence of impairment: by source, persons aged 16 years and over**

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Field Test</th>
<th>LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>4.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Hearing</td>
<td>4.1</td>
<td>3.0</td>
</tr>
<tr>
<td>Speaking</td>
<td>*</td>
<td>1.0</td>
</tr>
<tr>
<td>Mobility (encompasses dexterity in field test question)</td>
<td>16.6</td>
<td>8.0</td>
</tr>
<tr>
<td>Dexterity</td>
<td>*</td>
<td>6.0</td>
</tr>
<tr>
<td>Long-term pain</td>
<td>*</td>
<td>18.0</td>
</tr>
<tr>
<td>Learning</td>
<td>2.7</td>
<td>2.0</td>
</tr>
<tr>
<td>Intellectual</td>
<td>*</td>
<td>0.0</td>
</tr>
<tr>
<td>Memory</td>
<td>2.9</td>
<td>3.0</td>
</tr>
<tr>
<td>Mental Health</td>
<td>3.9</td>
<td>4.0</td>
</tr>
<tr>
<td>Stamina or Breathing (breathing only in LOS)</td>
<td>9.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Behavioural (e.g. autistic spectrum conditions)</td>
<td>0.7</td>
<td>1.0</td>
</tr>
<tr>
<td>Chronic health conditions</td>
<td>*</td>
<td>12.0</td>
</tr>
<tr>
<td>Other</td>
<td>3.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Any Impairment</td>
<td>25.9</td>
<td>29.0</td>
</tr>
</tbody>
</table>

*Source: ONS Opinions Survey 2010 and Life Opportunities Survey 2009–10*

The prevalence of sight and hearing impairment is approximately 1 percentage point lower in LOS, while a good level of equivalence is found for ‘learning’, ‘memory’, ‘mental health’ and ‘behavioural’ impairment. Mobility impairment is not consistent with LOS; however, as LOS separates out ‘dexterity’ from ‘mobility’ and the proposed harmonised question combines them, the aggregated LOS ‘mobility’ and ‘dexterity’ prevalence estimate improves consistency with the field-test question.

The routeing approach of the harmonised question produces a good level of consistency with the non-routed LOS impairment categories, suggesting reliable prevalence estimates are achievable using routeing. Consequently, the sub-group recommended only those with a health condition or illness are asked about type of impairment.

However two changes to the list were recommended following field test findings: These were:

a) adding the term ‘fatigue’ to the ‘stamina and breathing’ category, to take account of responses citing tiredness as a consequence of their health condition or illness

b) a mobility-specific category, encompassing an ability to walk short distances and climb stairs; and a ‘dexterity’ category, with examples of moving and carrying objects and using work related devices such as a keyboard

The latter change improves consistency with the LOS and takes account of the different policy needs presented by mobility and dexterity impairment for care and fitness for work.
Effect of excluding ‘frequency’ on estimates of activity restriction

The proposed questions produce estimates of activity restriction of 21.9 per cent, exceeding those estimates captured at stage 1 where a question on frequency was asked. Consequently, the risk of misclassifying people with intermittent restrictions by excluding a question capturing ‘frequency’ of activity restriction is unlikely, suggesting activity restriction can be captured adequately using a question capturing extent of restriction. Therefore the sub-group recommended the exclusion of a question capturing frequency, thereby saving interview time.

Comparability in estimates of disability

There was a need to test how comparable estimates of disability using the proposed harmonised questions are with those likely from the decennial 2011 Census of population and estimates derived from other social survey data sources. Table 8 compares estimates derived from the proposed harmonised questions, the 2011 Census question, and external social survey sources.

There is a good level of agreement in estimates derived from the proposed harmonised questions and the 2011 Census question both overall and by extent of disability. Both questions measure disability at 21.9 per cent of the population aged 16 years and over; the harmonised question’s higher category of ‘a lot’ is estimated at slightly more than 10 per cent, which exceeds the GLF estimate of 8.7 per cent prevalence of ‘strongly limited’ in 2009; but overall disability coheres well with the GLF 2009 estimates. The prevalence of core disability measured in the FRS 2008–09 data is 21.4 per cent, and in the FRS 2009–10 data is 21.3 per cent, which also compares favourably with the proposed harmonised question; however, the LOS wave 1 interim estimate is 4 percentage points higher.

The comparability in prevalence with the 2011 Census question and with the FRS and GLF estimates, despite wording and routeing differences, suggests the harmonised questions will provide the functionality to measure inter-censal prevalence of disability from a census benchmark in 2011, and not risk a radical discontinuity to FRS or GLF estimates.
Table 8  
Percentage prevalence of activity restriction by extent, persons aged 16 years and over

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Field test question – Opinions 2010</td>
<td></td>
</tr>
<tr>
<td>Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry out day-to-day activities</td>
<td>21.9</td>
</tr>
<tr>
<td>‘Yes a lot’ or ‘Yes a little’?</td>
<td></td>
</tr>
<tr>
<td>‘Yes, a lot’</td>
<td>10.3</td>
</tr>
<tr>
<td>‘Yes, a little’</td>
<td>11.7</td>
</tr>
<tr>
<td>FRS question – 2008–09</td>
<td></td>
</tr>
<tr>
<td>Does this/do these health problems or disabilities mean that you have substantial difficulties with any of these areas of your life? Mobility; lifting; manual dexterity; continence; communication; memory, concentrate, understand or learn; physical danger; balance; other</td>
<td>21.4</td>
</tr>
<tr>
<td>FRS question – 2009–10</td>
<td></td>
</tr>
<tr>
<td>Does this/do these health problems or disabilities mean that you have substantial difficulties with any of these areas of your life? Mobility; lifting; manual dexterity; continence; communication; memory, concentrate, understand or learn; physical danger; balance; other</td>
<td>21.3</td>
</tr>
<tr>
<td>LOS question 2009–10 interim results</td>
<td></td>
</tr>
<tr>
<td>Does this/do these health problems or disabilities mean that you have substantial difficulties with any of these areas of your life? Mobility; lifting; manual dexterity; continence; communication; memory, concentrate, understand or learn; physical danger; balance; other</td>
<td>25.9</td>
</tr>
<tr>
<td>GLF question 2009</td>
<td></td>
</tr>
<tr>
<td>Does this illness(ies) or disability(ies) limit your activities in any way?</td>
<td>21.2</td>
</tr>
<tr>
<td>Limited or strongly limited</td>
<td></td>
</tr>
<tr>
<td>Strongly limited</td>
<td>8.7</td>
</tr>
<tr>
<td>Field Test of 2011 Census question – Opinions 2010</td>
<td></td>
</tr>
<tr>
<td>Are your day-to-day activities limited because of a health problem or disability which has lasted or is expected to last 12 months or more?</td>
<td>21.9</td>
</tr>
<tr>
<td>Yes, limited a lot or yes limited a little</td>
<td></td>
</tr>
<tr>
<td>Yes, limited a lot</td>
<td>10.7</td>
</tr>
<tr>
<td>Yes, limited a little</td>
<td>11.2</td>
</tr>
</tbody>
</table>

The prevalence of disability derived using the field-tested question’s terminology of ‘reduced ability carrying out day-to-day activities’ and the plain English response categories coheres well with estimates from other sources and the 2011 Census question, suggesting the plain English response options are interpreted by respondents in a similar way to terms such as ‘substantial difficulty’ and ‘limited activities’.

**Plausibility for EU-SILC estimates of persistent illness and disability**

The EU-SILC variable guideline requires capturing data on limitation carrying out daily activities people usually do for the past six months or more by extent of limitation. Consequently, the EU-SILC classification for disability requires the application of the duration question filter to ensure the past six months or more criterion is complied with.

Table 9 shows the estimates for EU-SILC disability derived from the proposed harmonised questions with the EU-SILC estimates available from the EU-SILC health variables data cube on the Eurostat website (Eurostat a, 2011).
Table 9  EU-SILC derived disability percentage prevalence, persons aged 16 years and over

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
<th>95% confidence limits</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field test question – Opinions 2010</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For how long has your ability to carry out day-to-day activities been reduced?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than six months or between 6 and 12 months or 12 months or more</td>
<td>21.9</td>
<td>20.0 – 23.9</td>
</tr>
<tr>
<td>Less than six months</td>
<td>1.3</td>
<td>0.7 – 1.8</td>
</tr>
<tr>
<td>Between 6 months and 12 months</td>
<td>1.8</td>
<td>1.2 – 2.5</td>
</tr>
<tr>
<td>12 months or more</td>
<td>18.8</td>
<td>17.0 – 20.7</td>
</tr>
<tr>
<td>Revised EU-SILC estimate taking account of duration</td>
<td>20.7</td>
<td>18.8 – 22.6</td>
</tr>
<tr>
<td>Revised EU-SILC estimate of ‘Severely hampered in daily activities’ using the activity restriction category ‘Yes, a Lot’ and the duration categories ‘between six months and 12 months’ and ‘12 months or more’</td>
<td>9.9</td>
<td>8.5 – 11.3</td>
</tr>
<tr>
<td>Revised EU-SILC estimate of ‘Hampered in daily activities to some extent’ using the activity restriction category ‘Yes, a little’ and the duration categories ‘between six months and 12 months’ and ‘12 months or more’</td>
<td>10.8</td>
<td>9.3 – 12.2</td>
</tr>
<tr>
<td>EU-SILC 2009 estimate on Eurostat website – conflated categories ‘Severely hampered in daily activities’ and ‘Hampered in daily activities to some extent’</td>
<td>20.8</td>
<td></td>
</tr>
<tr>
<td>EU-SILC 2009 estimate on Eurostat website – ‘Severely hampered in daily activities’</td>
<td>9.1</td>
<td></td>
</tr>
<tr>
<td>EU-SILC 2009 estimate on Eurostat website – ‘Hampered in daily activities to some extent’</td>
<td>11.7</td>
<td></td>
</tr>
</tbody>
</table>

Sources: ONS Opinions Survey 2010; Eurostat

The harmonised questions have a satisfactory level of consistency with the EU-SILC estimates recorded on the Eurostat website, both overall and separated out into extent categories. This represents reassuring evidence that the proposed harmonised questions not only provide a closer affinity with the EU-SILC target variable concept and guidelines, but will also deliver an acceptable level of continuity with previous activity limitation estimates.

The prevalence of long-standing illness in 2009 for the UK published on the Eurostat website (Eurostat b, 2011) for persons aged 16 years and over was 33.6 per cent. The prevalence of a physical or mental health condition or illness lasting or expected to last 12 months or more derived from the proposed harmonised question tested at stage 2 delivered a prevalence of 33.7 per cent. The proximity of these estimates suggest the proposed harmonised question wording and time frame used will not risk a serious discontinuity in the EU-SILC time series of long-standing illness, and has the added benefit of greater compliance with the EU-SILC target variable concept and guidelines for the collection of long-standing illness.

The sub-group members agreed the proposed question inputs for EU-SILC data collections would fulfil the requirements under the EU regulation.
Inflation in prevalence by capturing extent of activity restriction

The prevalence of activity restriction estimates reported in table 8 suggest the capture of extent will not lead to an artefactual increase in the prevalence of activity restriction compared with questions using dichotomised response categories of ‘Yes’ or ‘No’, (that is, the possible risk that survey respondents perceive the threshold for reporting restriction to be lower using the category ‘Yes, a little’. The perceived risk of a greater number of people willing to use the ‘Yes a little’ category in the proposed harmonised question and the category ‘Yes, limited a little’ in the 2011 Census, but reluctant to use a ‘Yes’ response when asked whether their activities were ‘limited’ in a ‘Yes’ or ‘No’ response option was not borne out in these results.

Conclusions of stage 2 field test

The results from the second stage of field testing suggests the absence of the term ‘disability’ from the body of the proposed harmonised question will not introduce a serious discontinuity in the prevalence estimates following implementation in social survey sources. The added value of specificity in what is measured and the avoidance of mixed concepts in the same question produces greater alignment with the conceptual frameworks of disability stipulated in national legislation, European regulation and the internationally recognised ICFDH.

The capture of type of impairment requires two amendments to the list; specifically, the addition of the term ‘fatigue’ to the ‘stamina and breathing’ category, and the addition of a ‘dexterity’ category to take account of the different policy needs presented by people with dexterity impairment as opposed to those with mobility impairment.

The routeing of the impairment question from the question eliciting a physical or mental health condition or illness appears justified as prevalence estimates are similar to the estimates achieved in LOS. However, government stakeholders asked for an acknowledgement in the harmonised standard to allow administration of the impairment question to the whole sample for those surveys wanting to capture impairment type among the general population – whether a respondent reported a physical or mental health condition or illness or not. The sub-group agreed to this proviso and an alternative version of the question for general sample administration was developed and is shown under the heading ‘data inputs’ below.

The proximity between the estimate of core DDA disability derived from the criterion (standard on which a judgement is made) ‘a substantial difficulty in one or more capacity domains’ used in FRS publications and the estimates from both the field test question’s combined categories of ‘Yes, a lot’ or ‘Yes, a little’ reduced ability to carry out day-to-day activities and the 2011 Census combined categories ‘Yes, limited a lot’ and ‘Yes, limited a little’ suggests the term ‘substantial difficulty’ in at least one capacity domain agrees with the combined responses of ‘Yes, a lot’ and ‘Yes, a little’.

The field test results show that the effect of using a duration filter (that is, a question determining how long a person has had activity restriction) to classify a case of disability will reduce prevalence estimates marginally; a 12 months or more time filter reduces the prevalence of activity restriction to 18.8 per cent, while a 6 months or more time filter reduces prevalence to 20.7 per cent. Consequently, the application of the duration filter is dubious for both Equality Act estimates of the core currently disabled population or for benchmarking with the 2011 Census disability estimate.
However, the sub-group members agreed the inclusion of the duration filter question as tested should be retained in the primary harmonised standard to provide data users with the agility to either exclude or include depending on the purpose of the analysis.

The application of the duration filter improves comparability with the EU-SILC 2009 estimate; the estimate of ‘Yes, a lot’ of reduced ability carrying out day-to-day activities in question 2a and filtering using the duration categories ‘between 6 months and 12 months’ and ‘12 months or more’ is 9.9 per cent which compares favourably with the EU-SILC 2009 estimate of ‘severely hampered in daily activities’ of 9.1 per cent, while the estimate of ‘Yes, a little’ reduced ability carrying out day-to-day activities and the same duration categories is 11.0 per cent, which also compares favourably with the EU-SILC 2009 estimate of ‘hampered to some extent’ of 11.8 per cent. These estimates have a satisfactory level of coherence with the 2009 UK estimates published on the Eurostat website (Eurostat, 2011).

**Harmonised standard disability data inputs and statistical measures**

The following question inputs were agreed as the primary harmonised standard questions to provide derivations of statistical measures of persistent illness and disability for implementation in household social surveys using an in-person interview mode of data collection (Box 1). They have been scrutinised by the NSHG, the GSS SPSC and the Heads of Profession.

These questions are designed to derive the following classifications of persistent health conditions and illnesses and disability for Equality Act 2010 monitoring and EU-SILC data collections (Box 2).
### Box 1 Primary harmonised questions

**Question 1a:**

**To establish whether a person has a physical or mental health condition or illness**

Ask all if $\geq$16 years of age, ask by proxy if <16 or not fit to respond in person.

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

1. Yes;
2. No

Spontaneous only:
3. Don’t know;
4. Refusal

**Question 1b(i) (standard version):**

**The effect of any physical or mental health conditions or illnesses on functioning**

Ask if 1a = Yes.

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

Show card and code all 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 Asperger’s syndrome and other autistic spectrum conditions)
10. Other (please specify)

Spontaneous only:
11. None of the above
12. Refusal
### Box 1  Primary harmonised questions

Ask if Q1b=10

Please specify how your condition(s) or illness(es) affect you. (STRING 255)

**Question 1b(ii) (optional version):**

Whether any physical or mental health condition or illness affects functioning, irrespective of whether a positive answer was given to Question 1a

Ask All.

Do you have any health conditions or illnesses which affect you in any of the following areas?

Continue as for Question 1b(i)

**Question 2a:**

Whether a person with any physical or mental health conditions or illnesses have activity restriction

Ask if 1a = Yes.

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

Running prompt:

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

**Question 2b:**

For what period of time has the person experienced activity restriction.

Ask if 2a = Yes, a lot or Yes, a little.

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

Running prompt:

1. Less than six months
2. Between six months and 12 months
3. 12 months or more
### Box 2  Key classifications based on the primary harmonised questions

<table>
<thead>
<tr>
<th>Classification of disability for the core population with rights under the Equality Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1a = Yes</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Question 2a = Yes, a little OR Yes, a lot</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EU-SILC long-standing health condition or illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1a = Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EU-SILC classification of disability by extent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Estimate of severely hampered in daily activities</strong></td>
</tr>
<tr>
<td>Question 1a = Yes</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Question 2a = Yes, a lot</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Question 2b = Between six months and 12 months OR 12 months or more</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Estimate of hampered in daily activities to some extent</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1a = Yes</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Question 2a = Yes, a little</td>
</tr>
<tr>
<td>AND</td>
</tr>
<tr>
<td>Question 2b = Between six months and 12 months OR 12 months or more</td>
</tr>
</tbody>
</table>
Further documentation to aid implementation, including those existing questions the primary harmonised standard questions will replace, interviewer instructions, output categories, the timetable for implementation in ONS social survey sources and the future reporting of survey estimates will be made available on the ONS harmonisation website during the course of 2011.

**Next Steps**

The primary harmonised disability questions are planned for implementation on the Integrated Household Survey (IHS) core module in January 2012, replacing the traditional two questions on long-standing illness and activity restrictions. This will facilitate the derivation of measures of disability using the new harmonised question inputs and classification at national and sub-national level, which can be updated annually in IHS statistical bulletins. Annual estimates of disability-free life expectancy at sub-national level will also be feasible using prevalence data from this data source in future years, enabling the years of life expected to be spent free from disability to be regularly and reliably updated for Unitary Authorities and Local Authority Districts.

The capture of chronic illness and activity restriction data for EU-SILC data collection is expected to transfer from the GLF to the FRS in April 2012: this will provide the data inputs for Eurostat to construct measures of disability for the UK, based on the harmonised standard questions, and UK official measures of the core currently disabled population with rights under the Equality Act used in FRS publications.

More literature pertaining to the revised harmonised questions, including the cognitive testing and field testing reports and a guide for implementation on surveys using alternative data collection modes, such as postal surveys, will be uploaded onto the National Statistics Harmonisation Group website during 2012.

Further work on harmonisation planned for 2011–12 are to:

a) assess the need to adapt the questions using alternative modes of data capture such as postal and online surveys

b) conduct further consultation on the development of a secondary harmonised standard to capture the social barriers to participation in key areas of life and the functionality of data inputs to derive measures of participation restriction and the disproportionate impacts of social barriers on people with impairments relative to people without impairment

c) carry out a fact finding exercise on disability data collections in administrative sources with a view to improving the harmonization of this data and its fitness for use to derive statistical measures of disability to support planning

**Conclusion**

This article has updated developments in the harmonisation of disability data collection to provide greater consistency in the statistical measures of disability from national household social surveys using a face-to-face mode of data collection. The primary harmonized standards have a stronger foundation in an internationally recognized framework of disability and in the World Health Organisation’s International Classification of Functioning, Disability and Health.
The field testing of these harmonised standard questions has provided evidence of their fitness for use in social surveys to deliver the outputs necessary to meet the legislative criteria specifying the core currently disabled population with rights under the Equality Act 2010, the data required by Eurostat to compare disability and derive the Healthy Life Years Structural Indicator across member states of the European Union, and have affinity with the estimates of disability expected from the 2011 Census.

The improvement in consistency expected through harmonisation and the stronger anchoring of these questions to an internationally recognised conceptual framework of disability will improve the relevance of the statistical measures of disability derived for monitoring the inequality experienced by people with impairment, setting outcome measures to mitigate these inequalities and support wider service needs assessment.
References


Annex A

Field Test Stage 1 Question Suites: following cognitive testing and consultation findings

Version 1 questions used in half the ONS Opinions Survey sample (October 2009 – February 2010)

Introductory statement

The following questions are asked on behalf of the Office for National Statistics. They ask you about any health conditions you have which are long-lasting in nature and any problems you have with normal daily activities.

ASK ALL

Q1a. Do you have any physical or mental health conditions or illnesses which have lasted for 12 months or more?

1. Yes
2. No

Spontaneous only

3. Don’t Know
4. Refuse

ASK IF Q1a=1 and code all that apply

Q1b. Do you have difficulty in any of the following areas because of your health condition(s) or illnesses?

Show card and code all that apply

1. Seeing (due to blindness or partial sight).
2. Hearing (due to deafness of partial hearing).
3. Mobility, such as difficulty walking short distances, climbing stairs, or lifting and carrying objects.
4. Learning or concentrating or remembering.
5. Mental Health
6. Stamina or breathing difficulty
7. Social Learning difficulty (for example, due to Autistic Spectrum Disorder or Asperger's)
8. Other (please state)…………………………………………………………
9. None of the above

ASK IF Q1b = 8

Please specify the other area(s) in which you have difficulty?
ASK IF Q1a=1

Q2a. For at least the past 12 months, have you had difficulty in carrying out day-to-day activities (in the home, at work or during leisure time)?

Running prompt

1. Always
2. Most of the time
3. Sometimes
4. Not at all

ASK IF Q2a IS LESS THAN 4

Q2b. To what extent do you have difficulty carrying out day-to-day activities?

Running prompt

1. A little difficulty OR
2. A lot of difficulty
Version 2 questions used in half the Opinions Survey sample (October 2009 – February 2010)

Introductory statement

The following questions are asked on behalf of the Office for National Statistics. They ask you about any problems you have with normal daily activities and any health conditions you have which are long-lasting in nature.

ASK ALL

Q2a. Do you have any physical or mental health condition(s) or illnesses that are expected to last 12 months or more?

Running prompt

1. Yes
2. No

Spontaneous only

3. Don’t Know
4. Refuse

ASK ALL

Q2b. Do you have difficulty in any of the following areas because of a health condition(s) or illnesses?

Show card

1. Seeing (due to blindness or partial sight)
2. Hearing (due to deafness of partial hearing)
3. Mobility, such as difficulty walking short distances, climbing stairs, lifting & carrying objects.
4. Learning or concentrating or remembering.
5. Mental Health
6. Stamina or breathing difficulty
7. Social Learning difficulty (for example, due to Autistic Spectrum Disorder or Asperger’s’)
8. Other (please state).................................................................
9. None of the above.

ASK IF Q2b = 8

Please specify the other area(s) in which you have difficulty?
ASK IF Q2a=1 or Q2b LESS THAN 9

Q3a In relation to your condition(s) or illnesses, to what extent do you have difficulty carrying out day to day activities?

Running prompt
1. A lot of difficulty
2. A little difficulty
3. No difficulty

ASK IF Q3a=1 or 2

Q3b. For how long have you had difficulty with day-to-day activities?

Running prompt
1. Less than 6 months
2. Between 6 & 12 months
3. 12 months or more
Annex B

Family Resources Survey Disability Module (2008–09)

FRS0805B.BU.QHealth1.Adult.Health

Do you have any long-standing illness, disability or infirmity? By 'long-standing' I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months.

(1) Yes
(2) No

ASK IF Health = YES:

FRS0805B.BU.QHealth1.Adult.HProb

Does this physical or mental illness or disability (Do any of these physical or mental illnesses or disabilities) limit your activities in any way?

(1) Yes
(2) No

ASK IF Health = YES:

FRS0805B.BU.QHealth1.Adult.DisDif

Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?

(1) Moving: Mobility (moving about)
(2) Lifting: Lifting, carrying or moving objects
(3) Hands: Manual dexterity (using your hands to carry out everyday tasks)
(4) Bladder: Continence (bladder and bowel control)
(5) Speech: Communication (speech, hearing or eyesight)
(6) Learn: Memory or ability to concentrate, learn or understand
(7) Danger: Recognising when you are in physical danger
(8) Balance: Your physical co-ordination (eg: balance)
(9) Other: health problem or disability
(10) None: None of these
Annex C

General Lifestyle Survey questions on long-standing illness and activity limitation

Ask all

LSIll

Do you/does (..) have any long-standing illness, disability or infirmity – by long-standing I mean anything that has troubled you over a period of time or that is likely to affect you/him/her over a period of time?

Yes ................................................................................................1

No ..................................................................................................2

Ask if LSIII=1

IllLim

Does this illness or disability (Do any of these illnesses or disabilities) limit your/his/her activities in any way?

Yes .................................................................................................1

No ...................................................................................................2
Annex D

Proposed harmonised question suite following stage 1 field test and further consultation

Sample 1 ONS Opinions Survey (May 2010 – July 2010)

Introduction

These questions are asked on behalf of the Office for National Statistics. They ask you about any health conditions you have which are long-lasting in nature, the effect of any health conditions in your functioning and any problems you have with normal day-to-day activities.

ASK ALL

Q1a. Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

1. Yes
2. No

Spontaneous only

3. Don’t Know
4. Refuse

ASK IF Q1a = 1

Q1b. Does this condition or illness/do these conditions or illnesses affect you in any of the following areas?

Show Card code all 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 or lifting/carrying objects)
4. Learning or understanding or concentrating
5. Memory
6. Mental Health
7. Stamina or Breathing
8. Socially or Behaviourally (for example, Autism or Asperger’s Syndrome)
9. Other, please specify
10. None of the above (Spontaneous only)
11. Don’t Know (Spontaneous only)
12. Refusal (Spontaneous only)

ASK IF Q1b = 9
Please specify how your condition(s) affect you. (String 255)

ASK IF Q1a = 1

Q2a. Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?

Running prompt

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

ASK IF Q2a = 1 or 2

Q2b. For how long has your ability to carry out day-to-day activities been reduced?

Running prompt

1. Less than six months
2. Between six months and 12 months
3. 12 months or more
Scottish Census 2011 Health Conditions and UK Census 2011 Disability Questions

Sample 2 ONS Opinions Survey (May 2010 – July 2010)

Introduction

These questions ask you about any long-standing health conditions you may have and any problems you have with day-to-day activities.

ASK ALL

Q1. Do you have any of the following conditions which have lasted or are expected to last at least 12 months?
   1. Deafness or partial hearing loss
   2. Blindness or partial sight loss
   3. A learning disability (for example, Down’s syndrome)
   4. A learning difficulty (for example, dyslexia)
   5. A developmental disorder (for example, autistic spectrum disorder or Asperger’s syndrome)
   6. A physical disability
   7. A mental health condition
   8. A long-term illness, disease or condition
   9. Any other condition (please specify)
   10. None of these (Spontaneous only)
   11. Don’t know (Spontaneous only)
   12. Refusal (Spontaneous only)

ASK IF Q1 = 9

Please specify your condition (STRING 255)

ASK ALL

Q2. Are your day-to-day activities limited because of a health problem or disability which has lasted or is expected to last at least 12 months?
   1. Yes, limited a lot
   2. Yes, limited a little
   3. No