Update on the harmonisation of disability data collection in UK surveys (Part 1)

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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:

- 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.

Contents

Abstract.....	3
Introduction	6
Background.....	7
Results and recommendations	15
Conclusion	21
References.....	22
Annex A	24
Annex B	25
Annex C	27

List of Figures

Figure 1 The disablement process.....	11
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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**

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

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 routing 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 (eg: 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.

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

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.

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Annex A

Table A1 Organisations participating in the consultation

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

Annex B

Draft primary harmonised standard questions submitted for initial consultation

<p>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</p> <p>1. Yes 2. No</p>	<p>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</p> <p>1. Yes 2. No</p> <p>IF 1:</p> <p>What is the nature of your physical or mental health condition, impairment or disability?</p> <p>0. Open text – code up to 6 replies</p>	<p>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</p> <p>1. Blindness, deafness or other communication impairment 2. Mobility impairment, such as difficulty walking 3. Learning difficulty or disability, such as Down's syndrome 4. Mental health condition, such as depression 5. HIV, Multiple Sclerosis or cancer 6. Other long-standing health condition or disability 7. None</p>
<p>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.</p> <p>Would you say you are:</p> <p>1. Severely limited 2. Limited but not severely 3. Not limited at all</p>	<p>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.</p> <p>Would you say you are:</p> <p>1. Limited a lot 2. Limited a little 3. Not limited at all</p>	
<p>IF Q2 = 1 or 2</p> <p>Q3. How long have your day-to-day activities been limited?</p> <p>1. Less than 6 months 2. At least 6 months but less than 12 months 3. At least 12 months</p> <p>IF 1 or 2:</p> <p>Do you expect your day-to-day activities to be limited for 12 months or more altogether?</p> <p>1. Yes 2. No</p>		
<p>IF 1 to Q1b or 1 thru 6 to Q1c AND 2 or 3 to Q2:</p> <p>Q4. Do you take any medication for your long-standing health condition(s) or disability(ies)?</p> <p>1. Yes 2. No</p> <p>IF 1:</p> <p>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)?</p> <p>1. Severely limited 2. Limited but not severely 3. Not limited at all</p>		

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 routing; 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).

Asked first in Version A

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.

Yes	☐	1.	GO TO Q1b)
No	☐	2.	GO TO Q2a)

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).

Asked first in Version B

Q1c) SHO W CARD

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. READ OUT

Blindness, deafness or other communication impairment.	☐	1.	}GO TO Q2b)
Mobility impairment, such as difficulty walking	☐	2.	
Learning difficulty or disability, such as Down's syndrome	☐	3.	
Mental health condition, such as depression	☐	4.	
Long-term illness, such as Multiple Sclerosis or cancer	☐	5.	
Other long-standing health condition or disability	☐	6.	
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 AASK 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	☐	}GO TO Q3
Limited but not severely	☐	
Not limited at all	☐	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	☐	}GO TO Q3
Limited but not severely	☐	
Not limited at all	☐	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	☐	}GO TO Q3
Limited but not severely	☐	
Not limited at all	☐	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

Less than 6 months	<input type="text"/>	1	}GO TO Q3b
6 months but less than 12 months	<input type="text"/>	2	
At least 12 months	<input type="text"/>	3	GO TO Q4

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?

Yes	<input type="text"/>	1
No	<input type="text"/>	2

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)?

Yes	<input type="text"/>	1
No	<input type="text"/>	2

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

Severely limited	<input type="text"/>	1
Limited but not severely	<input type="text"/>	2
Not limited at all	<input type="text"/>	3