



Final recommended questions for the 2011 Census in England and Wales

Health

April 2010

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1. Summary

Question development for the 2011 Census began in 2005. An iterative and comprehensive process of user consultation, evaluation and prioritisation of user requirements, and qualitative and quantitative question testing has been carried out to inform the decisions on the questions to be included in the 2011 Census.

Information on the health topics listed in this paper is used by both local and central government for resource allocation, the assessment and understanding of health needs and planning and service delivery, as well as policy development and implementation.

This paper outlines the development of the health questions, drawing on evidence from cognitive question testing as well as evidence from the 2007 Census Test, postal tests and other strands of research.

The questions presented below are those for England and Wales that are recommended for the 2011 Census subject to Parliamentary approval.

Figure 1.1 General health – England and Wales (English language version)

13 How is your health in general?

Very good Good Fair Bad Very bad

Figure 1.2 General health – Wales (Welsh language version)

13 Sut mae eich iechyd yn gyffredinol?

Da iawn Da Gweddol Gwael Gwael iawn

Figure 1.3 Long-term illness or disability – England and Wales (English language version)

23 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?

↪ Include problems related to old age

Yes, limited a lot

Yes, limited a little

No

Figure 1.4 Long-term illness or disability – Wales (Welsh language version)

23 A oes gennych broblem iechyd neu anabledd sydd wedi para neu sy'n debygol o bara am o leiaf 12 mis, ac sy'n cyfyngu ar eich gallu i wneud gweithgareddau arferol?

↪ Cynhwyswch broblemau sy'n gysylltiedig â henaint

Oes, yn cyfyngu'n fawr

Oes, yn cyfyngu ychydig

Nac oes

Figure 1.5 Carers - England and Wales (English language version)

14 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

➤ Do not count anything you do as part of your paid employment

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50 or more hours a week

Figure 1.6 Carers – Wales (Welsh language version)

14 A ydych yn gofalu am aelodau o'r teulu, ffrindiau, cymdogion neu eraill, neu'n cynnig unrhyw help neu gefnogaeth i un neu i rai o'r rhain, oherwydd naill ai:

- salwch neu anabledd corfforol/meddyliol hir dymor?
- problemau sy'n gysylltiedig â henaint?

➤ Peidiwch â chyfrif unrhyw beth y byddwch yn derbyn cyflog am ei wneud

Nac ydw

Ydw, 1 - 19 awr yr wythnos

Ydw, 20 - 49 awr yr wythnos

Ydw, 50 neu fwy o oriau'r wythnos

2. Introduction

The next census will take place on 27 March 2011. The proposed topics to be included were announced in the 2011 Census Government White Paper published in December 2008. To access the White Paper and read further information about how the content of the 2011 Census was determined, please refer to the National Statistics website at:

<http://www.ons.gov.uk/census/2011-census/2011-census-questionnaire-content/question-and-content-recommendations-for-2011/index.html>

Question development for the 2011 Census began in 2005. An iterative and comprehensive process of user consultation, evaluation and prioritisation of user requirements and qualitative and quantitative question testing has been carried out to inform the decisions on the questions to be included in the 2011 Census. The questions for England and Wales have been developed through close collaboration with the Welsh Assembly and the census offices of Scotland and Northern Ireland. A key aim of this collaboration is to minimise differences between questionnaires across the UK, though it is recognised that differing circumstances will sometimes require different solutions. A paper on the UK differences in census questions will shortly be available on the National Statistics website.

This paper outlines the development of the health questions for England and Wales, including the Welsh language version. The following health topics are recommended for inclusion in the 2011 Census for England and Wales:

- General health
- Long-term illness or disability
- Carers

The paper briefly outlines the user requirements for each health topic and then describes the development process for each question. The final recommended questions are presented, along with justification of why the questions differ from the 2001 Census and the impact of the change (where applicable).

3. User Requirements

The inclusion of questions in the census must be supported by a clear user requirement for the information. The user consultation process for the 2011 Census began in 2005 with a formal three month general topics consultation. A summary of the consultation responses relating to health can be found at:

<http://www.ons.gov.uk/about/consultations/closed-consultations/consultation-on-2011-census---responses/index.html>.

The health questions outlined in this paper will provide detailed information that will be comparable from local to national level. Importantly it will be possible to cross-classify the health data with information collected from the other questions on the census.

The key user needs for each topic are outlined below.

3.1 General health

A question on general health was first asked in the 2001 Census. Inclusion of a question on general health in the census will help key users such as the Department of Health (DH), the National Public Health Service for Wales (NPHS) and NHS primary care trusts in the allocation of health resources at local and national level. Data on general health has been found to be a strong predictor of the higher utilisation of health service resources.

Data from this question will be used to assess the distribution and extent of health inequalities. DH has a Departmental Strategic Objective (DSO) to deliver 'better health and well being for all'¹. Information on general health will help DH to measure people's general health and assess progress towards better population health and the reduction of health inequalities.

Information from this question will also be used by local authorities in identifying and tackling areas of deprivation. General health status information can be used as a proxy indicator of poverty and can be combined with other variables on the census to build up a picture of an area's deprivation.

3.2 Long-term illness or disability

A long-term illness or disability question has been included in the census since 1991.

Information on long-term illness or disability has been found to be a good indicator of the need for health and social services and data from this question is used by the Department for Health in their formula for funding the 152 primary care trusts (PCT) in England. Furthermore, PCTs then use the information for long-term illness and disability to allocate health resources in their local area. For example, one PCT uses this information to help allocate community nurses in its area.

Similarly Welsh local government and health authorities also use information on the distribution of people with a long-term illness or disability to target health resources and provide health services at a local level in Wales.

¹ More information about the Department of Health's Departmental Strategic Objectives can be found on the website at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085928

Local authorities work closely with health authorities to provide health and social care services. Knowledge of the amount and distribution of people with long-term illness or disability will help these authorities to plan and provide the right amount of care where it is needed.

Central and local government will use this information for policy development and monitoring, in relation to the delivery of healthcare, assessment of progress towards better population health, reduction of health inequalities and improving access to services, such as adult education and leisure facilities. Combined with other information on the census it will also be used to assess housing and transport needs and develop employment and training policies.

Numerical estimates of disability are also important in securing resources especially for disability organisations when they apply for grants from funding organisations. Awarding bodies invariably require statistical evidence of need or likely impact, to make cost effective decisions in the competition for resources.

The number of people with a long-term illness or disability is also used in the Index of Multiple Deprivation² by Communities and Local Government in England and the Welsh Index of Multiple Deprivation³ by Welsh Assembly Government in Wales.

These indices are used to analyse patterns of deprivation, identify areas that would benefit from improvement initiatives and as a tool to determine eligibility for funding.

Responses from the health consultation by users of data on long-term illness or disability, made clear that this question should be worded so that people count themselves as having a disability according to the Disability Discrimination Act 2005 (DDA)⁴ definition of disability⁵.

Users, especially public bodies, want the long-term illness or disability question to count people with disabilities according to the DDA definition, because the act requires public bodies to promote equality of opportunity for disabled people under the Disability Equality Duty (DED)⁶. Knowing the number of people to whom the DDA definition of disability applies will help public bodies in assessing the progress of policies which help to improve equality for disabled people.

A number of respondents to the health consultation also expressed a need for a question on the nature of disability, as well as a long-term illness or disability question. A nature of disability question would allow users to separate out the number of people with a disability from those with an illness. This question would also allow public bodies to better plan their services as different disabilities and illnesses require different services.

Although the results of the consultation demonstrated a user need for a question on nature of disability, a lack of available space on the census questionnaire meant that topics with a greater user need were included ahead of this question. As an

² <http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/?view=Standard>

³ <http://wales.gov.uk/topics/statistics/theme/wimd/?lang=en>

⁴ More information on the Disability Discrimination Act (DDA) can be found on the directgov website at: http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068

⁵ The DDA definition of disability can be found on the directgov website at:

http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001069

⁶ More information is available from the directgov website at:

http://direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_10038105

alternative to a census question, the Life Opportunities Survey⁷, a new survey run by the Office for National Statistics (ONS) in conjunction with the Office for Disability Issues, will include a nature of disability question.

A topic specific consultation on long- term illness or disability was conducted in August 2007 to refine the user requirements for this topic.

This consultation invited users to refine their needs for information on long-term illness or disability from the 2011 Census. They were provided with a list of four alternative options to review and invited to identify their preferred option and provide the reasons for their decision. Of the 49 responses, the majority favoured an option which provided users with a modified 2001 Census question with a reference to the severity and duration of disability.

To ensure that decisions relating to the questions for the census did not disadvantage people with disabilities, ONS commissioned an equality impact assessment for disability. An equality impact assessment provides evidence that 'due regard' is given to the impact of policies and practices on particular communities, or on groups within communities.

A copy of the report, 'Equality Impact Assessment: Disability question development for Census and Integrated Household Survey' is available on the National Statistics website .

3.3 Carers

A question on carers was first included in the 2001 Census. Information on the numbers and distribution of people providing care for family and friends has become increasingly important in recent years.

In 1999 the government launched a national carers strategy, Caring about Carers⁸ with the aim of recognising their important role and to provide more support for carers. This strategy was updated in 2008 with new policies and initiatives to support carers⁹.

In 2000, the Welsh Assembly Government launched its 'Carers Strategy in Wales Implementation Plan'¹⁰. The Strategy has its roots in, and develops, the UK Strategy, Caring about Carers. The Carers Strategy in Wales seeks to meet the legitimate needs of carers for real practical support and assistance across six priority areas:

- Health and social care
- Information provision
- Support
- Young carers
- Carers and employment
- Mental Health Carers Grant Scheme 2007-2008

⁷ Further information on the Life Opportunities Survey can be obtained from the National Statistics website at: http://www.statistics.gov.uk/about/methodology_by_theme/life-opp-survey.asp

⁸ More information about this strategy is available on the Department of Health's website at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006522

⁹ From the publication 'Carers at the heart of 21st-century families and communities', available on the Department of Health's website at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

¹⁰ More information is available from the Welsh Assembly website at: <http://wales.gov.uk/topics/health/socialcare/carers/?lang=en>

There is no particular group of people who provide care for other people. Carers might be relatives, friends, children, older people or people with disabilities. In 2001, there were 5.2 million carers in England and Wales¹¹. Everyone has the potential to become a carer, and it is likely that in the future more and more people will. The number of people aged over 85 (the age group most likely to need care) is set to double over the next 20 years, affecting many more families¹².

Information on the number and distribution of carers is therefore needed by central government to help provide appropriate funding and resources for carers and to develop policies to help carers.

Local authorities and local health authorities also need information on the number and distribution of carers in their area, so they can effectively plan and resource services for carers such as respite care, day centres, adaptations to the home and personal care at home.

In recent years a number of pieces of legislation have been introduced to help give carers new and improved rights. These are¹³:

- The Carers (Recognition and Services) Act 1995
- The Carers and Disabled Children Act 2000
- The Carers (Equal Opportunities) Act 2004
- The Work and Families Act (2006)
- The Children Act 2004 and Childcare Act 2006

Several of these acts give local authorities specific statutory duties to assess the needs and services carers require. Data on the number, distribution and characteristics of carers in their area help local authorities to better plan and meet these duties.

The Department for Work and Pensions (DWP) stated in the consultation that information on carers in the census is 'vital in assessing the employment and income effects of caring, and how state support through Carers Allowance, Income Support and Pension Credit should be directed to this population. This support is worth several billion pounds per annum'. DWP also state that no other source of information is reliable at the local level at which it is required.

The Department for Children, Schools and Families (DCSF) have the lead responsibility for young carers and an interest in the carers of disabled children. They also stated in consultation that the collection of this information is important because the 'only reliable evidence on the true numbers of young carers comes from the census'. DCSF require this information from the 2011 Census to develop national and local policies to support young carers effectively.

¹¹ From the 2001 Census, more information is available from the National Statistics website at: <http://www.statistics.gov.uk/cci/nugget.asp?id=347>

¹² Page 5 of the report listed at footnote 6.

¹³ Taken from the Department of Health website at: http://www.dh.gov.uk/en/SocialCare/Carers/DH_079499

4. Process of question testing

4.1 Qualitative testing

Data Collection Methodology (DCM), within ONS, was commissioned to carry out a programme of cognitive question testing on census questions in English and in Welsh. The English language testing began in February 2005, and the Welsh language testing began in October 2007. The aim of this testing was to develop questions that collect accurate and meaningful information that meet user requirements, minimise the burden on respondents and are designed to conform as closely as possible to best practice of questionnaire design. The testing was split into four main phases:

- Pre-testing for the 2007 Census Test (February 2005 – April 2006)
- Whole Questionnaire Testing for the 2007 Census Test (June 2006 – August 2006)
- Testing for the 2009 Census Rehearsal
 - **Wave 1** (November 2006 to January 2007)
 - **Wave 2** (April to May 2007)
 - **Wave 3** (July to September 2007)
 - **Wave 4** (October and November 2007)
 - **Wave 5** (January to March 2008)
 - **Wave 6** (April to July 2008)
 - **Welsh language testing, Wave 1** (October to November 2007)
 - **Welsh language testing, Wave 2** (June to July 2008)
- Testing for the 2011 Census
 - **Wave 7** (March to April 2009)
 - **Whole questionnaire testing - English language** (June to July 2009)
 - **Whole questionnaire testing - Welsh language** (June to July 2009)

The questions on general health, carers and long-term illness or disability have been tested since the pre-testing for the 2007 Census Test.

4.2 Quantitative testing

4.2.1 Lambeth Postal Test

From June to July 2006, a test of postal enumeration procedures was carried out in the London Borough of Lambeth. Although this test was designed to test aspects of the field operation for the 2011 Census, it allowed the opportunity to analyse and evaluate the performance of the questions. A response rate of 25 per cent was obtained and 366 household questionnaires were returned, giving 787 individual respondents. Some of this data was analysed to help inform the development of the health questions prior to the 2007 Census Test.

4.2.2 2007 Postal Test

The ONS Questionnaire Design and Content team ran a postal test of 10,400 households across England in April 2007. Although the main objective of this test was aimed at testing issues related to questionnaire length, it also provided valuable information on the acceptability and understanding of definitions and questions. This test included questions on general health and carers.

4.2.3 2007 Census Test

A large scale Census Test was carried out covering 100,000 households in England and Wales on 13 May 2007. The test took place in Bath and North East Somerset, Camden, Carmarthenshire, Liverpool and Stoke-on-Trent. This allowed the opportunity to test new and updated questions.

It included questions on general health and long-term illness or disability. A carers question was not tested at this stage as the space on the questionnaire was used to test new and revised questions.

A detailed evaluation of the 2007 Census Test can be found on the National Statistics website at:

<http://www.ons.gov.uk/census/2011-census/2011-census-project/2007-test/index.html>

4.2.4 2008 Postal Test

In July 2008 two postal surveys were carried out, each with a sample of 10,200 households, one across England and the other in Northampton. The main purpose was to test any impact on response rates of including a question on intended length of stay in the UK. The test also allowed valuable analysis to be conducted on the performance of the questions developed for the 2009 Census Rehearsal.

This test included questions on general health, long-term illness or disability and carers.

4.2.5 March 2009 Postal Test

In March 2009, a postal test was conducted with the primary aim of assisting the development of questions relating to the student population. 20,000 questionnaires were sent to areas of England selected for characteristics that were desirable for the purposes of the test.

4.2.6 July 2009 Postal Test

In July 2009, a postal test was conducted with the primary aim of testing the questions relating to ethnicity and identity. 27,000 questionnaires were sent to areas of England selected because their characteristics were suitable for the purposes of the test.

5. Development of the questions

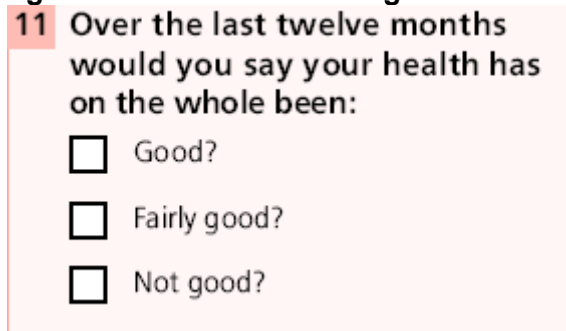
This section provides a detailed description of how each question evolved from the beginning of testing through to the finalisation of the question. It uses evidence gathered from all the strands of testing described in the previous section.

5.1 General health

The question on general health was first asked in the 2001 Census. Evidence from the 'Census 2001 Quality Report for England and Wales'¹⁴ showed that for the 2001 Census, non-response to this question was relatively low at 3.1 per cent and agreement between the answers given in the census and the Census Quality Survey (CQS) was 88.4 per cent. The CQS also identified that some people experienced difficulty in answering the question due to the subjective nature of the question.

The 2001 Census question was based on a three point scale and asked people to recall how their health had been over the last 12 months (Figure 5.1.1).

Figure 5.1.1 – 2001 Census general health question



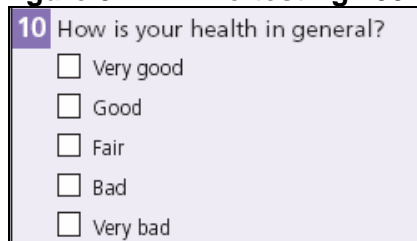
11 Over the last twelve months would you say your health has on the whole been:

- Good?
- Fairly good?
- Not good?

Testing for the general health question began in Wave 1 of pre-testing for the 2007 Census Test. The general health question was changed in order to be harmonised with the question used on three other surveys run by ONS. The General Household Survey, Labour Force Survey and the Opinions (Omnibus) Survey all use a five-point scale response option, without the reference to a time period. This question is also the harmonised standard for Eurostat¹⁵ and has been developed to allow survey results to be compared internationally.

The question used in Wave 1 of pre-testing for the 2007 Census Test can be seen in Figure 5.1.2 below.

Figure 5.1.2 – Pre-testing 2007 Census Test – Wave 1 question



10 How is your health in general?

- Very good
- Good
- Fair
- Bad
- Very bad

¹⁴ 'Census 2001 Quality Report for England and Wales' is available on the National Statistics website at: http://www.statistics.gov.uk/Census2001/proj_qr.asp

¹⁵ Eurostat is the statistical office of the European Union. More information is available on their website at: <http://epp.eurostat.ec.europa.eu/portal/page/portal/eurostat/home/>

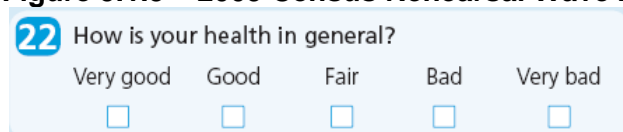
This question was tested in the same format up until Wave 2 of testing for the 2009 Census Rehearsal. During this period of testing, it was found that respondents understood this question to be asking about their health generally, but respondents assessed their health over differing time periods.

Respondents considered a range of health issues when answering the question such as current health, fitness, disability, visiting the doctor, and mental health. While the responses given by respondents are subjective, this is recognised by users of the data on general health.

The general health question tested in the 2007 Census Test appeared to work well. The non-response rate was low at 1.3 per cent and only 0.2 per cent of people provided an invalid multi-ticked response.

From Wave 2 of 2009 Census Rehearsal Testing, the layout was altered, so that the response options were laid out horizontally, whereas they had been vertical in previous phases of testing (Figure 5.1.3). This was in order to save space on the questionnaire and allow room for other questions. While it is preferable to have the response options listed vertically, a horizontal layout was considered to be an acceptable design compromise for a scalar question.

Figure 5.1.3 – 2009 Census Rehearsal Wave 2 question



22 How is your health in general?

Very good	Good	Fair	Bad	Very bad
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During Wave 2 it was found that the new horizontal layout of the responses minimised its impact in relation to other questions. It was found that some respondents only noticed this question by chance and occasionally missed it altogether. This may have been because it was the last question in the left column, on the first page of the individual questions.

In Wave 6, the position of the question in the questionnaire was changed. The question was moved to make room for a filter instruction, for a question on migration. It was located as the first question in the left column of the third page of individual questions.

This version of the question was tested in the 2008 and March 2009 postal tests. Although during Wave 2 it was shown that some respondents had difficulty noticing the question following the change from vertical to horizontal tick boxes, this was not borne out in the results of the 2008 or March 2009 postal tests where only 1.4 and 1.5 per cent of respondents failed to answer this question.

The Welsh language question was also tested in three waves of testing, which produced similar findings to the English question.

The same question as recommended for use in the 2009 Census Rehearsal was also recommended for the 2011 Census.

5.1.1 Final recommended general health question

The questions below are recommended for the 2011 Census subject to approval by Parliament through the legislative process.

Figure 5.1.1.1- Final question for England and Wales (English language version)

13 How is your health in general?

Very good	Good	Fair	Bad	Very bad
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 5.1.1.2 – Final question for Wales (Welsh language version)

13 Sut mae eich iechyd yn gyffredinol?

Da iawn	Da	Gweddol	Gwael	Gwael iawn
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.2 Long-term illness or disability

5.2.1 Measuring disability

Disability can be a difficult concept to measure. The terms used to define disability can be complex and understood differently by different people. Furthermore people's concept of what is a disability can also vary, for example one person with a particular condition may define themselves as disabled where as another person with the same condition would not.

The two most common models for defining disability are the 'medical model' and the 'social model'. They are outlined below, as defined by the Office for Disability Issues (ODI) ¹⁶.

The medical model is sometimes also known as the 'personal model'. This is the traditional view that the inability of disabled people to fully participate in society is a direct result of having a disability, not a result of physical features of society. The individual is 'impaired' and the impairment is the problem to be overcome. This model relies on a strong notion of what is 'normal', thereby emphasising the 'abnormality' of impaired people

The social model begins by defining impairment and disability as follows:

- Impairment is an injury, illness, or congenital condition that causes, or is likely to cause, a long-term effect on appearance and/or limitation of function of the individual.
- Disability is the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

¹⁶ Office for Disability Issues: <http://www.officefordisability.gov.uk/resources/models-of-disability.php>

Impairments and chronic illness often pose real difficulties for disabled people but they are not the main problems. It is the 'barriers' which exist in society that create the main problems. The three main areas of barrier are:

- environment (including inaccessible buildings and services)
- attitudes (stereotyping, discrimination and prejudice)
- organisations which operate inflexible procedures and practices

Government surveys have tended to use different question wording to define disability, so that statistics from them are not necessarily comparable, nor do the statistics necessarily include all people that may be covered by the Disability Discrimination Act (DDA).

In 2006 the Prime Minister set up the Equality Review Panel to carry out an investigation into the causes of persistent discrimination and inequality in British society. In its report¹⁷ the panel reported that:

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

'And the Office for National Statistics (ONS) should be responsible for leading the review and for ensuring data on equalities across government and the devolved administrations meet existing and future need, nationally and locally.'

In response¹⁸ to the Equality Review, ONS recommended that for measuring disability:

'the Office for Disability Issues and Government Equalities Office in partnership with ONS and devolved governments, [should] urgently agree a consistent approach to collecting information on disability, and champion this widely across Government and the wider public sector.'

In 2007, ONS began working with these bodies in order to meet this recommendation and develop a harmonised set of questions for disability based on the DDA definition of disability. These questions could then be used across government with the aim of ensuring a coherent approach to collecting disability data.

Although work on developing harmonised disability questions began in 2007, for the purposes of the census, it was not possible to await the outcome of this research. Questions recommended for inclusion in the census have to be thoroughly tested to ensure that they are both acceptable and understood by the majority of the public. Furthermore it had become clear that there would only be space on the questionnaire for a single question on disability, due to competing demands from higher priority

¹⁷ More information and a copy of the Equalities Report can be found at: <http://archive.cabinetoffice.gov.uk/equalitiesreview/>

¹⁸ More details of the response are available on the National Statistics website at: <http://www.ons.gov.uk/about-statistics/measuring-equality/equality-data-review/index.html>

topics. As a result, developing a disability question for the 2011 Census ran in parallel to the work with ODI to develop a harmonised set of disability questions.

The process for developing a set of harmonised disability questions is further explained on the ODI website at:

<http://www.officefordisability.gov.uk/research/definitions.php>

The questions ODI recommends for inclusion on government surveys to identify the DDA defined disability population are as follows:

1. Do you have any long-standing physical or mental impairment, illness, or disability? 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.
2. Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?
 - Mobility (moving about)
 - Lifting, carrying or moving objects
 - Manual dexterity (using your hands to carry out everyday tasks)
 - Continence (bladder and bowel control)
 - Communication (speech, hearing or eyesight)
 - Memory or ability to concentrate, learn or understand
 - Recognising when you are in physical danger
 - Your physical co-ordination (eg. balance)
 - Other health problem or disability
 - None of these

During the development of a disability question for the census, ODI expressed a concern that the question being developed for the 2011 Census would only be a single question and not two as shown above. ODI also wanted the wording used to be the same as that used in the above questions. However space constraints on the census questionnaire meant that only a single question could be asked and that the wording of this question also had to be limited.

The next section explores the methods taken to develop a single question for the census that is as close as possible to identifying the DDA definition disability population and one that uses terms and definitions that will be understood by the majority of respondents.

5.2.2 Developing a long-term illness or disability question for the census

In the 2001 Census the long-term illness or disability question appeared to work well. The non-response rate was 3.9 per cent and agreement with the Census Quality Survey was 94.0 per cent. Common problems identified in 2001 were that some respondents had difficulty in interpreting the question and their opinions were susceptible to change over a short period of time.

Figure 5.2.1 - 2001 Census long-term illness or disability question

13 Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?

◆ Include problems which are due to old age.

Yes No

Since 2001, the Disability Discrimination Act (DDA) 2005 has come into force. During the consultation process, users expressed a need for this question to measure disability in terms of the definition used in the Act. The Act defines 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’¹⁹.

Therefore much of the testing for this question focuses on changing this question to better reflect the DDA definition of disability (because of the user need to classify the question in this way) and to one that will work on a self-completion questionnaire such as the census.

For Wave 1 of the 2007 Whole Questionnaire Testing, changes were made to the question wording from the 2001 Census question. While the guidance note and the response options remained the same, the question wording was altered slightly so that the term ‘limits daily activities’ was changed to ‘have substantial difficulties’. This is because the word ‘substantial’ is used in the DDA to help define disability and using this wording was therefore felt to be more in line with DDA definition. The question used in Wave 1 of the 2007 Whole Questionnaire Testing is shown below in Figure 5.2.2.

Figure 5.2.2 – 2007 Whole Questionnaire Testing Wave 1 question

11 Does a long-standing health problem or disability mean you have substantial difficulties doing day-to-day activities?

◆ Include problems which are due to old age.

Yes

No

For Wave 2 of the 2007 Whole Questionnaire Testing the response boxes were moved to a horizontal position to save space on the questionnaire.

From these two waves of testing the main issue respondents reported was the complexity of the question. There were reports of respondents simply skim-reading the question, due to its length. Those with lower literacy skills and those who have English as a second language, also reported having difficulty in understanding the question.

It was recommended that further testing be conducted with those who have long-standing illnesses, or need help with day-to-day activities.

In early quantitative testing, a high level of non-response was reported. This was initially seen in the Lambeth postal test with 7.7 per cent of respondents not selecting either response.

¹⁹ Directgov website: http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001069

Possible reasons for this were explored during Wave 1. Some respondents believed that having answered 'No, I do not have a long-standing condition' to the previous question on nature of disability (Figure 5.2.3), they did not need to answer the following long-standing illness or disability question.

Figure 5.2.3 – Lambeth post test and 2007 Census Test question

10 Do you have any of the following long-standing conditions?

- ◆ Include problems which are due to old age.
- ◆ Tick all boxes that apply.
- Deafness or severe hearing impairment
- Blindness or severe visual impairment
- A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying
- A learning difficulty
- A long-standing psychological or emotional condition
- Other, including any long-standing illness
- No, I do not have a long-standing condition

11 Does a long-standing health problem or disability mean you have substantial difficulties doing day-to-day activities?

- ◆ Include problems which are due to old age.
- Yes
- No

The Lambeth test suggested respondents were misinterpreting the health questions as some respondents gave conflicting answers. For example, some respondents selected 'No, I do not have a long-standing condition' in the nature of disability question but then went on to answer 'Yes' to the long-standing illness or disability question.

Further problems with the co-location of these two questions became evident in the 2007 Census Test. Non-response to the long-term illness or disability question was 15.4 per cent. Further analysis of the non-respondents showed that there appeared to be a correlation between those not answering this question and the preceding question on nature of disability.

Of the people who didn't respond to the nature-of disability question, 41.5 per cent also failed to answer the following long-term illness question. For those who answered the nature of disability question as 'No, I do not have a long-standing condition', 17.5 per cent did not answer the long-term illness question. Of those that indicated they had a 'condition' in the nature of illness question, only 4.5 per cent didn't answer the long-term illness question. These differences suggest that some respondents may be viewing the nature of disability and long-term illness questions as a pair and skipping the long-term illness question if they have not already recorded a nature of disability.

The nature of disability question was removed from further testing after Wave 1 of the 2009 Census Rehearsal testing due to competing demands from higher priority

topics (see section 3.2). Had the nature of disability question continued, further testing would have been needed to identify an appropriate order of questions to avoid question non-response.

The long-term illness or disability question was not tested again until Wave 4 (Figure 5.2.4), where the question was redesigned to better meet the DDA definition of disability. In the question wording, the term 'substantial difficulties doing day-to-day activities' was replaced with 'are you limited in your day-to-day activities'. A third response, with a tick-box, was also added, breaking up the 'Yes' response, to offer different degrees of limitation due to a health problem. The term 'long-term' has now also been replaced by a time marker, which asks whether 'a health problem or disability has lasted, or is expected to last, at least 12 months'. The question was also relocated to be after the question on general health.

Figure 5.2.4 2009 Census Rehearsal Testing Wave 4 question

7 Are you limited in your day-to-day activities because of a health problem or disability which has lasted or is expected to last at least 12 months?

◆ Include problems which are due to old age.

Yes, limited substantially

Yes, limited but not substantially

No

There was no further evidence of non-response issues or of conflicting responses after relocation of the question in Wave 4 and the removal from the questionnaire of the nature of disability question.

This question was also tested in the first wave of Welsh language testing (Figure 5.2.5).

Figure 5.2.5 Welsh language testing Wave 1 question

6 A ydych yn cael anhawster wrth wneud gweithgareddau arferol oherwydd problemau iechyd neu anabledd sydd wedi para, neu y disgwylir iddo bara, am o leiaf 12 mis?

◆ Cynhwyswch broblemau sy'n gysylltiedig â henaint.

Ydw, anhawster mawr

Ydw, anhawster ond nid anhawster mawr

Nac ydw

The Welsh language version of this question does not translate literally to correspond to being 'limited' by health problems or a disability, but rather to 'having difficulty' doing day-to-day activities because of health problems or a disability.

Respondents demonstrated an understanding of the time frame involved with this question, and explained that this question was for people with a disability, mobility problems, or other health problems.

For Wave 5 testing (figure 5.2.6) the question contained the same responses and guidance note as Wave 4 but there were some minor changes to the question wording.

Figure 5.2.6 2009 Census Rehearsal Testing Wave 5 question

14 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?

➔ Include problems which are due to old age.

Yes, limited substantially

Yes, limited but not substantially

No

Problems with respondents understanding the differences between 'limited substantially' and 'limited but not substantially' emerged in Wave 5. It was found, that while respondents were able to provide explanations, these were not usually straightforward, and frequently required some thought. The use of the word 'substantially' was preferred by users because it is used in the DDA definition of disability. However as this term was not easily understood by respondents, two additional versions of the question were also tested at this stage, (Figures 5.2.7 and 5.2.8) to see whether some slight wording changes would help respondents to better understand the question. One version used the term 'severely' instead of 'substantially', while the other used a plain English version of the question, replacing 'limited substantially' with 'a lot', and 'limited but not substantially' with 'a little'.

Figure 5.2.7 2009 Census Rehearsal Testing Wave 5 question; alternate version 1.

14 Are you limited in your day-to-day activities because of a health problem or disability which has lasted, or is expected to last at least 12 months?

➔ Include problems which are due to old age.

Yes, limited severely

Yes, limited but not severely

No

Some respondents interpreted 'severely' to mean a much more serious medical condition than 'substantially'. The term 'severely' was however, more easily understood than 'substantially'.

Figure 5.2.8 Census Rehearsal Testing Wave 5 question; alternate version 2.

14 Are you limited in your day-to-day activities because of a health problem or disability which has lasted, or is expected to last at least 12 months?

➔ Include problems which are due to old age.

Yes, a lot

Yes, a little

No

The terms 'a lot' and 'a little' were much easier to understand, with all respondents able to comprehend the question. However, this version was criticised by some respondents who thought the wording was too simplistic and 'childish'.

For Wave 6, the question and guidance note remained unchanged from Wave 5 but there were changes made to the wording of the three responses (figure 5.2.9). The term 'substantially' used after the 'yes' responses in Wave 5, was changed to 'a lot'

and 'a little' for Wave 6. 'Not limited at all' was also added after the 'No' response. These changes were made in order to adopt a plain English approach.

Figure 5.2.9 2009 Census Rehearsal Testing Wave 6 question

14 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?

Include problems which are due to old age

Yes, limited a lot

Yes, limited a little

No, not limited at all

In addition to the Wave 6 question the Wave 5 question was also retested at this stage. When shown both the Wave 6 and Wave 5 version of the question, respondents felt that the response options meant the same thing. All the respondents tested were generally able to understand the Wave 6 version of the question, more so than the Wave 5 version which uses the 'substantially' wording. This version caused some confusion, especially amongst respondents with English as a second language and those of lower literacy levels.

Following Wave 6, the phrase 'not limited at all' was removed from the 'No' response. This was due to the fact that respondents might have health issues, but which have not lasted, or do not expect to last, for 12 months. Some respondents believed that the phrase 'not limited at all' did not reflect this.

At the same time as Wave 6, the second wave of Welsh language testing took place using equivalents of the Wave 6 questions.

Figure 5.2.10 Welsh language testing Wave 2 'substantially' question

14 A oes gennych broblem iechyd neu anabledd sydd wedi para neu sy'n debygol o bara am o leiaf 12 mis, ac sy'n cyfyngu ar eich gallu i wneud gweithgareddau arferol?

Cynhwyswch broblemau sy'n gysylltiedig â henaint

Oes, yn cyfyngu'n sylweddol

Oes, yn cyfyngu, ond nid yn sylweddol

Nac oes

Figure 5.2.11 Welsh language testing Wave 2 'plain English' question

14 A oes gennych broblem iechyd neu anabledd sydd wedi para neu sy'n debygol o bara am o leiaf 12 mis, ac sy'n cyfyngu ar eich gallu i wneud gweithgareddau arferol?

Cynhwyswch broblemau sy'n gysylltiedig â henaint

Oes, yn cyfyngu'n fawr

Oes, yn cyfyngu ychydig

Nac oes

Respondents understood both the question, and considered physical and mental health problems. Also, similar to the findings from the English language testing, respondents tended to tick equivalent response options for both versions of the question. However, a respondent didn't tick 'limited a little' because they felt it was too vague, but did tick 'limited but not substantially'.

As found in the English language testing, respondents tended to prefer the simpler version of the question. Of particular interest was that a couple of respondents did not understand the meaning of 'sylweddol' ('substantially'); either interpreting it to mean 'sylweddoli' (realise), or to mean 'significant'.

The 2008 and March 2009 postal tests also included a question on long-term illness or disability. For each of these tests the Wave 6 version of the question was used. The results of these tests suggested that the question was working well with low non-response rates of 2.5 and 1.8 per cent respectively. Invalid multi-ticked responses were also low at 0.1 per cent for each of the tests.

This question did not undergo any changes for Wave 7 and Whole Questionnaire Testing for the 2011 Census, and was not a priority during testing. Generally no issues were raised for this question.

5.2.3 Final recommended long-term illness or disability question

The questions below are recommended for the 2011 Census subject to approval by Parliament through the legislative process.

Figure 5.2.3.1 - Final question for England and Wales (English language version)

23 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?

Include problems related to old age

Yes, limited a lot

Yes, limited a little

No

Figure 5.2.3.2 - Final question for Wales (Welsh language version)

23 A oes gennych broblem iechyd neu anabledd sydd wedi para neu sy'n debygol o bara am o leiaf 12 mis, ac sy'n cyfyngu ar eich gallu i wneud gweithgareddau arferol?

Cynhwyswch broblemau sy'n gysylltiedig â henaint

Oes, yn cyfyngu'n fawr

Oes, yn cyfyngu ychydig

Nac oes

5.3 Carers

A question on carers was first asked in the 2001 Census (Figure 5.3.1). Evidence from the 'Census 2001 Quality Report for England and Wales' showed that for the 2001 Census, non-response to this question was relatively high at 6.1 per cent but there was a good level of agreement between the answers given in the census and the Census Quality Survey (CQS) at 99.3 per cent.

Figure 5.3.1 – 2001 Census carers question

12 Do you look after, or give any help or support to family members, friends, neighbours or others because of:

- long-term physical or mental ill-health or disability, or
- problems related to old age?

◆ Do *not* count anything you do as part of your paid employment.

◆ ✓ time spent in a typical week.

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50+ hours a week

This question was tested in two waves during the pre-testing for the 2007 Census Test. Some users expressed a requirement to split the first response category from the 2001 Census, 'Yes, 1 – 19 hours a week' into two categories; '1 – 9 hours' and '10 – 19 hours'. This was tested in these waves and the question can be seen in Figure 5.3.2 below.

Figure 5.3.2 – 2007 Whole Questionnaire Testing Wave 1 question

13 Do you look after, or give any help or support to family members, friends, neighbours or others because of:

- long-standing physical or mental ill-health or disability, or
- problems related to old age?

◆ Do not count anything you do as part of your paid employment.

◆ ✓ time spent in a typical week.

No

Yes, 1-9 hours a week

Yes, 10-19 hours a week

Yes, 20 - 49 hours a week

Yes, 50+ hours a week

It was found that respondents generally understood the separate terms in the question and knew what it was asking them for. Respondents also reacted well to the addition of the new tick-box. The only issue respondents raised was with the guidance notes, specifically that it was difficult to differentiate between the different types of bullet points.

Figure 5.3.3 – 2007 Whole Questionnaire Testing Wave 2 question

13 Do you look after, or give any help or support to family members, friends, neighbours or others because of:

- long-standing physical or mental ill-health or disability, or
- problems related to old age?

◆ Do not count anything you do as part of your paid employment.

◆ ✓time spent in a typical week.

No

Yes, 1 - 9 hours a week

Yes, 10 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50+ hours a week

As a result of Wave 1 testing, the first two bullets were made bold to make them stand out more (Figure 5.3.3). In Wave 2 the question was found to work well, however some respondents were concerned about the amount of text and information the question contained, and felt that some of the bullet points were unnecessary.

This question was not asked in the Whole Questionnaire Testing for the 2007 Census Test, nor was it assessed in the Lambeth Test. It was not included in the questionnaire testing until Wave 4 of testing for the 2009 Census Rehearsal (Figure 5.3.4).

Figure 5.3.4 – 2009 Census Rehearsal Testing Wave 4 question

17 Do you look after, or give any help or support to family members, friends, neighbours or others because of:

- long-standing physical or mental ill-health or disability,
- or
- problems related to old age ?

◆ Do not count anything you do as part of your paid employment.

No

Yes, 1 - 9 hours a week

Yes, 10 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50+ hours a week

In Wave 4 the question wording was unchanged. The fourth guidance note, referring to 'time spent in a typical week', had been removed. There was also the addition of 'or' placed before the second guidance note. There were no issues arising from this wave of testing.

Figure 5.3.5 – 2009 Census Rehearsal Testing Wave 5 question

21 Do you look after, or give any help or support to family members, friends, neighbours or others because of:

- long-standing physical or mental ill-health or disability,
- or, problems related to old age?

↻ Do not count anything you do as part of your paid employment.

No

Yes, 1 - 9 hours a week

Yes, 10 - 19 hours a week

Yes, 20 - 34 hours a week

Yes, 35 - 49 hours a week

Yes, 50+ hours a week

For Wave 5, there were two changes. Firstly, the 'or' that was introduced in Wave 4 was removed. Secondly, the 'Yes, 20 – 49 hours a week' response option was split into two; one offering the option of selecting 20 – 34 hours, with the other offering 35 – 49 hours. This breakdown of hours was useful to some users of data on carers as this would help to identify the number of carers who may be eligible for Carers Allowance.

Figure 5.3.6 – 2009 Census Rehearsal Testing Wave 6 question

23 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-standing physical / mental ill-health / disability?
- problems related to old age?

↻ Do not count anything you do as part of your paid employment

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50+ hours a week

For Wave 6 the two additional 'Yes' response options added in Wave 5, were both removed. This was due to competing space demands from a higher priority question.

Overall this question continued to work well in Wave 6, although it was concluded that there was some evidence to suggest that respondents with English as a second language, as well as respondents with lower literacy levels, might find this question cognitively demanding. These respondents sometimes interpreted the question to mean the total amount of time they spend in the company of old or infirm relatives and family members.

The carers question was tested in the 2008 and March 2009 postal tests. The question appeared to work well; there was a 4.5 and 3.7 per cent non-response rate respectively for the two tests and in both tests only 0.1 per cent of people provided an invalid multi-ticked response.

The question was then tested in Wave 7 and Whole Questionnaire Testing for the 2011 Census (in both English and Welsh), and no further issues were raised.

5.3.1 Final recommended carers question

The questions below are recommended for the 2011 Census subject to approval by Parliament through the legislative process.

Figure 5.3.1.1 - Final question for England and Wales (English language version)

14 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

➤ Do not count anything you do as part of your paid employment

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50 or more hours a week

Figure 5.3.1.2 - Final question for Wales (Welsh language version)

14 A ydych yn gofalu am aelodau o'r teulu, ffrindiau, cymdogion neu eraill, neu'n cynnig unrhyw help neu gefnogaeth i un neu i rai o'r rhain, oherwydd naill ai:

- salwch neu anabledd corfforol/meddyliol hir dymor?
- problemau sy'n gysylltiedig â henaint?

➤ Peidiwch â chyfrif unrhyw beth y byddwch yn derbyn cyflog am ei wneud

Nac ydw

Ydw, 1 - 19 awr yr wythnos

Ydw, 20 - 49 awr yr wythnos

Ydw, 50 neu fwy o oriau'r wythnos

6. Justification and impact of changes since 2001

This section provides justification for any changes to the questions since the 2001 Census and explains the effect that these changes might have on the comparability of data.

The changes to the general health question since the 2001 Census have been to change the wording of the question to make it simpler to understand, the removal of the 12 month time frame and changing the response options from a three-point scale to a five-point scale. These changes were made primarily to harmonise the question to those asked in other government surveys (such as the General Household Survey, Labour Force Survey and the Opinions Survey) and international surveys to allow comparisons to be drawn. These surveys all use a question with the same five-point scale and without a reference to a time period.

Data from the 2011 Census general health question may not be directly comparable with results from the 2001 Census.

The question on long-term illness or disability has been reworded from the 2001 Census question to incorporate wording which describes the illness or disability as lasting or expecting to last at least 12 months. The response boxes have been expanded from two to three with the 'yes' response from 2001 changed to 'yes, limited a lot' and 'yes, limited a little'. The primary aim of these changes was to bring the question more into line with the description of disability as defined in the Disability Discrimination Act (DDA) 2005 while still maintaining a 'plain English' wording which is easy for respondents to understand.

As a result the question may not be directly comparable with the 2001 Census, but this question better meets users' needs to assess disability according to the DDA definition.

Since the 2001 Census, only minor changes have been made to the carers question and therefore there should not be any impact on the comparability of data.

To help users compare results from the 2001 and 2011 Censuses, an assessment of the changes to the questions will be made available with the outputs from the 2011 Census.

The questions on long-term illness or disability, general health and carers are all linked and thus should be presented together as a suite of questions. However space constraints on the questionnaire have meant that this has not been possible.

The general health and carers question are co-located on the questionnaire at questions 13 and 14 respectively, but the long-term illness or disability question is located two pages later at question number 23. In the 2001 Census, the equivalent questions were located together at question numbers 11 to 13.

It is not easy to estimate the impact of separating out the questions in this way although testing has not identified any problems with this ordering.

7. Conclusion

Although questions on general health, long-term illness or disability and carers are recommended for inclusion in the 2011 Census, it is recognised that compromises have been made which may mean that the questions do not meet all the requirements set out by data users.

The main factor is the lack of available space on the questionnaire to incorporate all of these requirements. The general health response options are being listed horizontally, rather than the preferred vertical alignment, because of a need for space for other questions.

Only one question on long-term illness or disability is recommended and it will not identify the nature of a person's disability. In addition, the wording of the question has had to be tailored so that is clear to the majority of people, in order to suit a self-completion survey such as the census. However, future data from the Life Opportunities Survey, which includes more than one question on disability, will help to meet more of these user requirements.

Ideally if space had been available, data users would have preferred the carers question to have an additional breakdown of the 'Yes, 20 – 49 hours a week' response category into two options; one offering the option of selecting 20 – 34 hours, with the other offering 35 – 49 hours.

While these compromises have been made to the questions, the results from them will still enable users to make important decisions relating to the allocation of money and resources of public health services and in developing policies for health, carers and disability.