

Scotland's Census 2021 Health Topic Report

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1. Main Points

- Information on health is widely used. There are three separate questions on health that were asked in 2011 Census: general health, long-term health problem or disability, and long-term health conditions.
- Each of these questions provides information on different aspects of population's health.
- In the [Topic Consultation Report](#) (PDF) published in August 2016, NRS proposed to continue to collect information on health in 2021.
- The Topic Consultation has identified strong user need for the information collected on **general health**. No changes were necessary for this question as the data are of a good quality and meets user need.
- The Topic Consultation demonstrated a strong user need for the continued collection of information on **long-term health problem or disability**. No changes were necessary for this question as the data are of a good quality and meets user need.
- The Topic Consultation revealed a strong user need for the continued collection of information on **long-term health conditions**. This question was reviewed for 2021 to consider how to improve the respondent understanding and ease of response, while maintaining continuity of the data.
- Research and analysis support taking the following questions on this subject further at this stage:
 - General health
 - Long-term health problem or disability
 - Long-term health conditions
- The digital first approach for 2021 requires further development and user testing to fully understand the best way to present the questions online to maximise response, minimise respondent burden and ensure good quality data which meets user needs. An on-going programme of question development, focusing on sensitive or complex questions will further inform the specific question wording.

2. Introduction

This topic review sets out the evidence gathered in developing health questions for Scotland's Census 2021.

Question development for the 2021 Census began in 2015. 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 decisions on the questions to be recommended for inclusion in the 2021 Census. More information about [research and preparation](#) and [question development](#) for Scotland's Census 2021 can be found online.

The 2021 Census will be digital first. The Census 2021 questionnaire must gather high quality data that meets user needs. More information about [key elements of the design](#) for 2021 can be found online.

Two frameworks have been published by National Records of Scotland (NRS) to evaluate the effectiveness of [question design for existing, alternative and new questions](#) (PDF) and to evaluate the effectiveness of [question design of tick box response options](#) (PDF).

Questions and their response options are evaluated against five main themes:

Strength of user need

- ✓ Data collected by the census must meet a user need for equality monitoring, policy development, resource allocation and/or service planning and delivery.

Suitability of alternative sources

- ✓ Data collected by the census must meet a user need that cannot be met elsewhere.

Acceptability, clarity and data quality

- ✓ Questions asked in the census must be acceptable to the majority of the public, clear and be designed with minimal respondent burden in order to obtain good data quality that meets user needs.

Comparability

- ✓ Data collected by the census should be comparable over time where possible, and harmonised across the UK where reasonable.

Operational considerations

- ✓ Census questions must be considered as part of the census as a whole, where effective digital and paper design, space and financial constraints must be considered. Additionally, some questions may be required for operational purposes in the process of conducting the census.

The final decision on the content of Scotland's Census 2021 questionnaire will ultimately be made by the Scottish Parliament.

As in previous years, there will be separate censuses conducted by the Office for National Statistics (ONS) in England and Wales, and the Northern Ireland Statistics and Research Agency (NISRA) in Northern Ireland. The three census offices work together to develop a set of questions that, wherever possible and necessary, will deliver harmonised outputs across the UK.

3. Background

Questions on health were introduced in Scotland's Census in 1991, when a question about long-term illness was asked for the first time. In 2001 Scotland's Census also asked a question about general health, and a further health question about long-term health conditions was introduced in 2011 (Figures 1–3).

Figure 1: 2011 general health question, Scotland's Census

2011 Paper Question

19 How is your health in general?

Very good Good Fair Bad Very bad

2011 Online Question

19 How is your health in general?

Very good

Good

Fair

Bad

Very bad

PREVIOUS NEXT

SHOW YOUR ANSWERS

Figure 2: 2011 long-term health problem or disability question, Scotland's Census

2011 Paper Question

21 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

2011 Online Question

21 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 3: 2011 long-term health conditions question, Scotland's Census

2011 Paper Question

20 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?

◆ Tick all that apply.

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (for example, Down's Syndrome)
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
- Physical disability
- Mental health condition
- Long-term illness, disease or condition
- Other condition, please write in

or

No condition

2011 Online Question

20 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? ? ↕

◆ Select all that apply.

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (for example, Down's Syndrome)
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
- Physical disability
- Mental health condition
- Long-term illness, disease or condition
- Other condition, please enter

(maximum 34 characters)

or

No condition

The 2011 Census in Scotland asked a question about general health which included five response options as opposed to the three response options used in 2001 (Figure 4) to provide consistency and comparability across the UK. In addition, the five-point scale allows for further international comparability.

Figure 4: 2001 General Health Question, Scotland's Census

2001 Paper Question

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

Good? Fairly good?

Not good?

2001 Online Question

H7 Over the last twelve months would you say your health has on the whole been:

Good?

Fairly good?

Not good?

The question about general health amended in 2011 is considered not comparable to the question included in 2001. More information about [changes for 2022](#) can be found online.

3.1 Questions in other UK 2011 censuses

Questions on general health and long-term health problem or disability are also asked in England and Wales (Figure 5), and Northern Ireland's censuses. A question on long-term health conditions is included in the census in Northern Ireland (Figure 6).

The question stems and the response options for the two questions (general health and long-term health problem or disability) collected from the three censuses are the same.

The question stem for the long-term health conditions question for Scotland's census and census in Northern Ireland is the same, however, the response options vary to reflect specific user need.

Figure 5: 2011 question set on health, England & Wales

The image shows two screenshots of census questions. The top one is question 23, which asks about day-to-day activities being limited by a health problem or disability lasting at least 12 months. It includes a note to include problems related to old age and three response options: 'Yes, limited a lot', 'Yes, limited a little', and 'No'. The bottom screenshot is question 13, which asks 'How is your health in general?' and provides five response options: 'Very good', 'Good', 'Fair', 'Bad', and 'Very bad'.

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

13 How is your health in general?

Very good Good Fair Bad Very bad

Figure 6: 2011 question set on health, Northern Ireland

22 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

23 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?

↪ Tick all that apply.

Deafness or partial hearing loss

Blindness or partial sight loss

Communication difficulty (a difficulty with speaking or making yourself understood)

A mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)

A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty

An emotional, psychological or mental health condition (such as depression or schizophrenia)

Long-term pain or discomfort

Shortness of breath or difficulty breathing (such as asthma)

Frequent periods of confusion or memory loss

A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy)

Other condition

No condition

24 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"/>

3.2 Alternative Sources

Since 2012, a set of core questions has been used to provide information on the composition, characteristics and attitudes of Scottish households and adults across a number of topic areas through the three largest surveys in Scotland:

- the [Scottish Household Survey](#) (SHS)
- the [Scottish Health Survey](#) (SHeS)
- the [Scottish Crime and Justice Survey](#) (SCJS)

A set of core and harmonised questions is recommended in order to provide comparable estimates across Scotland. Core questions are asked in each survey. More information can be found on the Scottish Government website ([Core Survey Questions](#)). The Scottish Government also produce guidance for [collecting equality information](#), including disability.

Disability and self-assessed health are core survey questions in Scotland. The question on self-assessed general health is the same as the question used in 2011 Census with the same five response options. The core question on disability uses slightly different wording to the question used in 2011 Census ('Does your condition or illness reduce your ability to carry-out day-to-day activities?'). However, the response options broadly collect similar data. The core question on long-term health, on the other hand, asks a similar question to 2011 Census ('Do you have a physical or mental health condition or illness lasting or expected to last 12 months or more?'), but uses 'Yes' and 'No' responses. This is in contrast to the question on long-term health conditions used in the 2011 Census where specific health condition categories were included as response options with an additional response option 'No condition'.

Scottish Household Survey (SHS) and Scottish Health Survey (SHeS) ask similar questions on health, including questions on self-assessed general health, disability, and long-term health conditions. However, the long-term health condition question is only asked if the respondent indicated that they have a health condition lasting or expected to last at least 12 months or more. In addition, both surveys focus on symptoms as opposed to health conditions and the results are available at Local Authority level only.

The data collected by these surveys are not suitable to meet the user needs as expressed through the Topic Consultation (see Section 4.1). The consultation feedback demonstrated that the stakeholders do not support the use of the impairment based model of health as a framework for census data collection, and thus, require information on health conditions rather than symptoms. Further, the data users require the data at small geography level, as well as being able to use these data in combination with other variables for multivariate analysis. This level of detail is only available from census data.

3.3 Findings from 2011 Census

There were no data quality concerns with the questions on general health, and long-term health problem or disability.

The layout and format of the long-term health conditions question showed that it caused confusion for respondents in 2011 Census, as around 350,000 write-in

responses in the 'Other condition' category were included in the collected data. During the processing the majority of these write-in responses were identified as other response option categories. This indicated that people were unsure which tick box response option(s) to select to best describe their health condition(s).

Further development work was carried out to focus on data quality issues identified in 2011, which is detailed in the quality assurance report: [Data quality issues for the long-term health conditions question](#), PDF (2017).

The item non-response rate for the long-term health conditions question in 2011 Census was 15 per cent¹. It was assumed that most people who missed this question generally did so because they had no long-term health conditions but did not respond to 'No condition' tick box. Census 2011 outputs assigned 'No condition' to people who missed answering the long-term health condition question, but answered general health question and long-term health problem or disability question in the way that indicated that they are generally in good health.

Question development for 2021 Census will focus on improvements to the long-term health conditions question and response options to aid respondent understanding.

4. Understanding user need

4.1 Topic Consultation

National Records of Scotland (NRS) invited views on [Scotland's Census 2021 – Topic Consultation](#) (PDF) between 8 October 2015 and 15 January 2016. The consultation was a key step towards understanding what information users will need from the census in 2021, and helped to build strong cases to justify the inclusion of topics. The focus of the consultation was on information required at topic-level, not the detail of the questions that should be asked on the questionnaire.

Following the consultation, NRS worked closely with stakeholders through follow-up events, meetings, focus groups and online surveys to gather more detailed information about data requirements to ensure user needs were understood. Information about these events can be found on our [Get Involved pages](#) online.

There were 49 responses received through the Topic Consultation on the subject of health and unpaid care. A summary of these responses can be found in the [Topic Consultation Report](#) (PDF). In this report NRS proposed to continue to collect information on health in 2021.

Respondents identified the following reasons for requiring information about general health and long-term health problem or disability:

- identifying health and social care service needs
- informing service planning and development
- allocating resources at national and local level
- monitoring and assessing policies on health
- monitoring and assessing health inequalities

The data were used at all geographical levels and many respondents aggregate output areas and datazones to their own customised areas (such as council

¹ More details can be found in the [Scotland's Census 2011 General Report](#).

administrative areas and school catchment areas) and create population sub groups based on health attributes. A key benefit of these questions in the census is the ability to use health data in combination with other census questions as many alternative sources of information do not have the capability for cross-tabulation or are not available at small area level. Continuity with 2011 and/or previous censuses was thought to be important by the majority of users.

In the [Topic Consultation Report](#) (PDF) published in August 2016, NRS proposed to continue to collect information on general health, long-term health problem or disability, and long-term conditions in 2021. The Topic Consultation identified a need to review the detail of the information collected in the long-term health conditions question to ensure it meets user needs in terms of outputs and quality.

4.2 Further Stakeholder Engagement

A [Health and Care Topic Event](#) was held on 24 April 2017. The aim of this event was to further understand user needs. In order to capture the requirements of users who could not attend the event, and to capture further detailed requirements from those who did, a paper (event only) and online survey was provided. This survey, which asked similar questions to the Topic Consultation, was widely promoted through the Scotland's Census newsletter.

The [Health and Care Topic Event](#) primarily focussed on the long-term health conditions question, which asked 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?' in Scotland's Census 2011. Proposed changes to the long-term health conditions question and stakeholders' feedback are outlined in a summary of this event available on the Scotland's Census website: [Health and Care Topic Event Summary Report](#) (PDF).

The feedback from the stakeholders at the [Health and Care Topic Event](#) informed further development of the question on long-term health conditions.

A request of a further sub-division of 'Developmental disorder' category to identify adults with autism and having an autistic spectrum disorder as a separate response option was not supported by a strong user need.

A small number of requests for inclusion of an additional tick box response option for dual sensory loss (for example, deafblind) were expressed during the process of question development. However, no strong evidence of user need has been identified.

Further development focused on improving the question to reduce respondent burden, while taking into account the data user requirements for the data collected at the long-term health conditions question. This included further engagement with stakeholders and testing of the proposed questions.

5. Question testing

2021 Census is digital first. As such, question development for the long-term health conditions question has included design of a question for an online platform to further improve data quality for 2021.

This section provides evidence from the question testing process carried out by NRS in the question development process for Scotland's Census 2021.

Both cognitive testing and quantitative testing processes were used in developing census questions:

- Cognitive testing is a form of in-depth interviewing with a small number of respondents. It aims to provide an insight into the mental processes respondents use when answering questions. This helps to identify if there are any problems with a question or question design and gain an insight into the source of any difficulty respondents are having.
- Quantitative testing is undertaken primarily to identify data quality concerns. NRS included feedback questions in the quantitative testing in order to gather further information on public acceptability and to identify specific difficulties respondents faced if they were unable to answer a question easily.

In 2017 NRS commissioned ScotCen Social Research to conduct cognitive and quantitative testing of selected questions for potential inclusion in Scotland's Census 2021. Information about this testing can be found in the [2017 Cognitive and Quantitative Testing Report](#) (PDF).

5.1 Cognitive testing

During the cognitive testing two versions of the long-term health conditions question were tested in two formats – paper and online:

- version one (the short version) included some examples of the types of condition to consider under 'Learning disability', 'Learning difficulty' and 'Developmental disorder' response options
- version two (the long version) included more detailed definitions of what to include under certain response categories but did not provide example conditions

Version one of the question was based on the version of the question used in 2011 Census. The questions tested are shown below (Figures 7–9).

Following the cognitive testing the text for pop-up prompts of 'More information' under each health condition category in the online version was amended to include the text to clarify that the pop-ups contain examples of health conditions under each category. This was revised to improve accessibility. The amended text was used in the quantitative testing.

Respondents were recruited to ensure diversity in terms of their characteristics that were relevant to the questions tested. Respondents who had health conditions, or were carers of someone with a health condition were recruited using assistance from Alliance Scotland, a national third sector intermediary for a range of health and social care organisations. Over a half of respondents in the final sample reported having one or more health condition.

Figure 7: 2017 Cognitive Testing questions – Paper versions

Paper – version one (short version)

Paper – version two (long version)

16 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

◆ Tick all that apply

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (for example, Down's Syndrome)
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example Autistic Spectrum Disorder or Asperger's Syndrome)
- Physical disability
- Mental health condition
- Long-term illness, disease or condition
- Other condition, please write in

No condition

16 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

◆ Tick all that apply

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate)
- Learning difficulty (a specific learning condition that affects the way you learn and process information)
- Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language)
- Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
- Mental health condition (a condition that affects your emotional, physical and mental wellbeing)
- Long-term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication)
- Other condition, please write in

No condition

Figure 8: 2017 Cognitive Testing questions – Online version one (short version)

Q16A. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

Select **all** that apply.

- Deafness or partial hearing loss**
▶ More Information
- Blindness or partial sight loss**
▶ More Information
- Learning disability** (for example, Down's Syndrome)
▶ More Information
- Learning difficulty** (for example, dyslexia)
▶ More Information
- Developmental disorder** (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
▶ More Information
- Physical disability**
▶ More Information
- Mental health condition**
▶ More Information
- Long term illness, disease or condition**
▶ More Information
- Other condition, please enter:
- No condition

Figure 9: 2017 Cognitive Testing questions – Online version two (long version)

Q16B. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

Select **all** that apply.

- Deafness or partial hearing loss**
▶ More Information
- Blindness or partial sight loss**
▶ More Information
- Learning disability** (a condition that you have had since childhood that affects the way you learn, understand information and communicate)
▶ More Information
- Learning difficulty** (a specific learning condition that affects the way you learn and process information)
▶ More Information
- Developmental disorder** (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language)
▶ More Information
- Physical disability** (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
▶ More information
- Mental health condition** (a condition that affects your emotional, physical and mental wellbeing)
▶ More information
- Long term illness, disease or condition** (a condition that you will have for life which may be managed with treatment or medication)
▶ More information
- Other condition, please enter:

The online version also included help screen pop-ups that respondents could click on where further information and more examples of conditions were provided. An example of these pop-ups is shown in a figure below (Figure 10):

Figure 10: 2017 Cognitive Testing – Example pop-up for the online version

Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language)

Developmental disorder examples:

- Asperger's Syndrome
- Attention deficit disorder
- Attention deficit hyperactivity disorder
- Autistic spectrum disorder
- Emotional learning behaviour
- Emotional learning difficulty
- Global development delay
- Oppositional defiant disorder

Aims of cognitive testing:

- to explore whether the definitions in the long version of the question improve respondents' understanding, and whether that in turn improves the data quality
- to explore whether the longer version of the question reduces the of 'Other condition' response option and the number of write-ins
- to explore whether respondents find the pop-ups in the online version helpful
- to explore whether respondents understand the difference between 'Learning disability', 'Learning difficulty' and 'Developmental disorder'

Key results of cognitive testing:

- Cognitive testing identified general preference by respondents for the long version of the question, as the definitions improved their understanding of the response categories and locating their responses easily.
- While the short version was seen as having a simplified layout, respondents found it more difficult to find the correct category for their response. This resulted in respondents' confusion around which response option to choose and an overuse of the 'Other condition' write-in option. This was corrected when respondents were presented with the long version of the question.
- Respondents found the definitions, particularly in combination with the online pop-ups, helpful. The definitions and the example conditions in online pop-ups for 'Learning disability', 'Learning difficulty' and 'Developmental disorder' helped the respondents to differentiate between the three categories.
- The digital first design incorporated functionality allows for additional guidance in the form of pop-up screens to be included to assist respondents in answering the question on long-term health conditions online. Testing demonstrated that this function improves respondent understanding of the question response options.

Full details of the results of the 2017 Cognitive Testing are available in Annex A.

5.2 Quantitative testing

Following the results of the cognitive testing, the long version (version two above) of the long-term health conditions question was taken forward to quantitative testing. Detail on the methodology of the quantitative testing is available in the [2017 Cognitive and Quantitative Testing Report](#) (PDF). Full details of the results of this testing are available in Annex B.

The key research aim for the quantitative testing phase was to explore whether the long version of the question significantly reduces the number of 'Other condition'

write-ins that are miscoded, or specifically should be included as conditions in other tick box response options

One question on long-term health conditions was included in the individual section of the questionnaire for testing (Figure 11 and Figure 12).

Figure 11: 2017 Quantitative Testing question – Paper version

15 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?
◆ Tick all that apply

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate)
- Learning difficulty (a specific learning condition that affects the way you learn and process information)
- Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language)
- Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
- Mental health condition (a condition that affects your emotional, physical and mental wellbeing)
- Long-term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication)
- Other condition, please write in

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

- No condition

Figure 12: 2017 Quantitative Testing question – Online version

Q15. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

- Select **all** that apply
- Deafness or partial hearing loss**
 - ▶ Deafness or partial hearing loss examples (click here)
- Blindness or partial sight loss**
 - ▶ Blindness or partial sight loss examples (click here)
- Learning disability** (a condition that you have had since childhood that affects the way you learn, understand information and communicate)
 - ▶ Learning disability examples (click here)
- Learning difficulty** (a specific learning condition that affects the way you learn and process information)
 - ▶ Learning difficulty examples (click here)
- Developmental disorder** (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language)
 - ▶ Developmental disorder examples (click here)
- Physical disability** (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
 - ▶ Physical disability examples (click here)
- Mental health condition** (a condition that affects your emotional, physical and mental wellbeing)
 - ▶ Mental health condition examples (click here)
- Long term illness, disease or condition** (a condition that you will have for life which may be managed with treatment or medication)
 - ▶ Long term illness, disease or condition examples (click here)
- Other condition**, please enter:
- No condition**

◀ Previous Stop ■ Next question ▶

Figure 13: Quantitative testing – Online version pop-up screen example

Q15. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

- Select **all** that apply
- Deafness or partial hearing loss**
 - ▼ Deafness or partial hearing loss examples (click here)

Deafness or partial hearing loss examples:

- Deaf
- Deafblind
- Deafened
- Deafness
- Hard of hearing
- Hearing impaired
- Profoundly deaf
- Severely deaf

- ▶ Physical disability examples (click here)
- Mental health condition** (a condition that affects your emotional, physical and mental wellbeing)
 - ▶ Mental health condition examples (click here)
- Long term illness, disease or condition** (a condition that you will have for life which may be managed with treatment or medication)
 - ▶ Long term illness, disease or condition examples (click here)
- Other condition**, please enter:
- No condition**

The question tested included fuller descriptions of the tick box response option categories, and the online version involved additional pop-up screens with extra guidance listing examples of health conditions under each response option category (Figure 13). This version of the question was included in the testing to examine whether these changes are likely to impact upon data quality compared to 2011 question. In particular, the testing aimed to examine the impact on the use of the 'Other conditions' write-in option.

Aims of quantitative testing:

- analyse item non-response as a measure of data quality and acceptability
- analyse invalid responses, specifically invalid combinations, as a measure of data quality
- analyse the use of 'Other condition' write-in option
- analyse the percentage of responses that can potentially be backcoded to other response options as a measure of data quality.

Key results of quantitative testing:

- results of the quantitative testing showed that the distributions by age and sex were largely in proportion with the distributions observed in the 2011 Census
- in total, 90 per cent of respondents provided a valid response to the question on long-term health conditions, and around 10 per cent provided an invalid response
- of those who provided a valid response to the question, over half (around 60 per cent) reported having no health conditions. This compares to 70 per cent of the population reporting having no health conditions in the 2011 Census.
- almost all instances of invalid response from fully completed questionnaires (around 10 per cent of respondents who fully completed the questionnaire) were the result of item non-response, with less than one per cent of invalid responses resulting from invalid combinations. Most instances of item non-response from full completions were from respondents who filled in the paper version of the questionnaire.
- the item non-response of 10 per cent the 2017 testing is broadly comparable to the item non-response in 2011 Census questions and can be used to assess the data quality as a result of the changes to the question. This broad reduction of item-non response rate from 15 per cent in 2011 Census to 10 per cent in 2017 testing is indicative of the revision of the long-term health conditions question had a positive impact on item non-response rate as a measure of data quality.
- around four per cent of respondents who provided a response to the long-term health conditions question have chosen 'Other condition' write-in response option. This compares with around 10 per cent from the 2011 Census. This suggests that the revision of the long-term health conditions question has effectively improved respondents' understanding and, thus, reduced the use of write-in response option.
- the majority of these responses could have been backcoded into a different response category. 'Other condition' responses from the paper mode were more likely to be backcoded compared to responses provided by respondents online.
- in the feedback section of the questionnaire, around two per cent of respondents indicated that they found the long-term health conditions question difficult to answer. However, almost all these respondents provided a valid response.

6. Other considerations – Long-term health conditions question

Consideration was given to amending the wording in the description of the 'Long-term illness, disease or condition' category to include wording as 'a condition that

you may have for life' as opposed to 'a condition you will have for life'. This was suggested in order to assist respondents who might have long-term health conditions that are difficult to estimate a specific timeframe or who might feel uncomfortable describing their long-term condition as a life-long condition.

Cognitive interviews with BSL users as part of development of a set of questions on language were carried out during the British Sign Language Question Testing between April and May 2018. During this testing some respondents commented on their confusion whether they should choose 'Long-term illness, disease or condition' category in addition to 'Deafness or partial hearing loss' tick box option to account for their condition of deafness.

To clarify these types of instances, the wording in the description of the 'Long-term illness, disease or condition' response option category was reviewed and amended to include additional wording of 'not listed above' as follows:

'Long-term illness, disease or condition (a condition, not listed above, that you may have for life which may be managed with treatment or medication)'

The above changes, in particular, the use of word 'may' instead of 'will', and addition of the wording 'not listed above', were presented by NRS to stakeholders who represented a range of health and social care organisations. Basing their views on a previous experience of respondents' needs and understanding as well as understanding of the overall user need, the stakeholders supported these proposed changes.

7. Next steps

Research and analysis support taking the following questions on this subject further at this stage:

- General health
- Long-term health problem or disability
- Long-term health conditions

NRS are continuing question development of a full question set for the 2021 Census and will be considering questionnaire design and respondent burden. The final decision on the content of Scotland's Census 2021 questionnaire will ultimately be made by the Scottish Parliament.

The digital first approach for 2021 requires further development and user testing to fully understand the best way to present the questions online to maximise response, minimise respondent burden and ensure good quality data which meet user needs. An on-going programme of question development, focusing on sensitive or complex questions will further inform the specific question wording.

More information about preparation for Scotland's Census 2021 and details about upcoming events can be found on the [Scotland's Census website](#), by subscribing to the [Scotland's Census newsletter](#) and following us on Twitter [@NatRecordsScot](#).

Annex A: 2017 Cognitive Testing – Long-term health conditions

In 2017 NRS commissioned ScotCen Social Research to conduct cognitive and quantitative testing of selected questions for potential inclusion in Scotland's Census 2021. Information about this testing can be found in the [2017 Cognitive and Quantitative Testing Report](#) (PDF).

1. Questions tested and measurement aims

During the cognitive interviews one question on long-term health conditions was tested. Two different versions of this question were tested on paper:

- Version one (the short version) included some examples of the types of condition to consider under 'Learning disability' 'Learning difficulty' and 'Developmental disorder'.
- Version two (the long version) included more detailed definitions of what to include under certain response categories but did not provide example conditions.

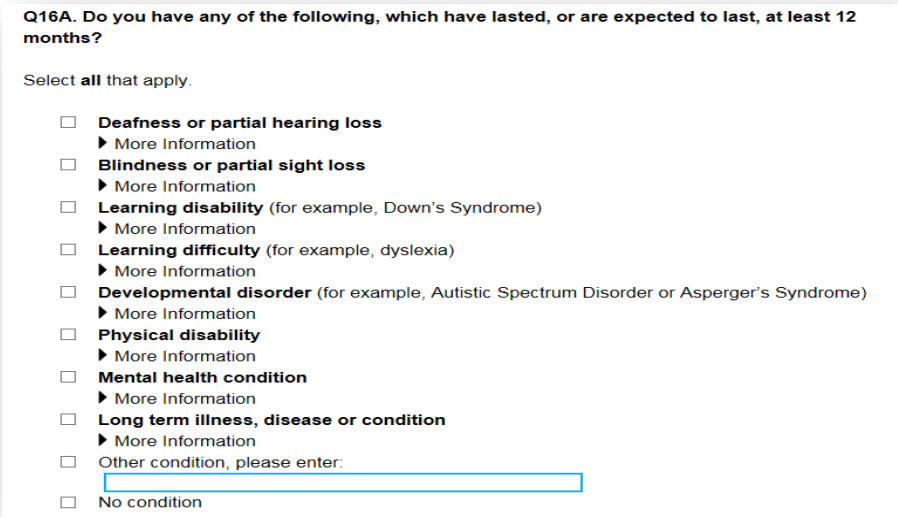
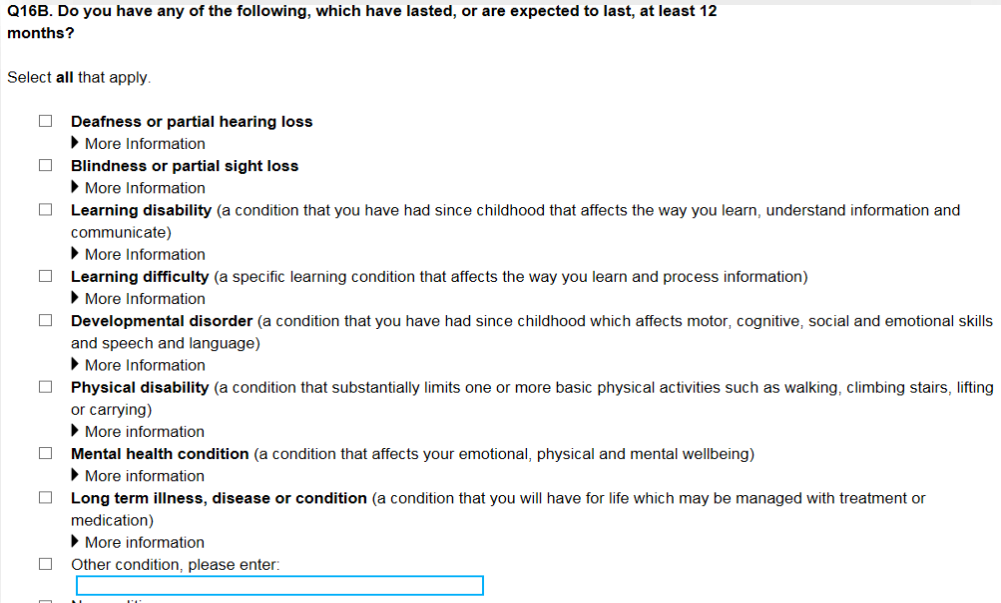
These different paper versions are shown in table A1 below.

Table A1: Paper versions of questions on long-term health conditions

Version one / Short version	Version two/ Long version
<p>Health conditions question paper version 1</p> <p>16 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?</p> <p>◆ Tick all that apply</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss <input type="checkbox"/> Blindness or partial sight loss <input type="checkbox"/> Learning disability (for example, Down's Syndrome) <input type="checkbox"/> Learning difficulty (for example, dyslexia) <input type="checkbox"/> Developmental disorder (for example Autistic Spectrum Disorder or Asperger's Syndrome) <input type="checkbox"/> Physical disability <input type="checkbox"/> Mental health condition <input type="checkbox"/> Long-term illness, disease or condition <input type="checkbox"/> Other condition, please write in <p><input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p><input type="checkbox"/> No condition</p>	<p>Health conditions question paper version 2</p> <p>16 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?</p> <p>◆ Tick all that apply</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss <input type="checkbox"/> Blindness or partial sight loss <input type="checkbox"/> Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate) <input type="checkbox"/> Learning difficulty (a specific learning condition that affects the way you learn and process information) <input type="checkbox"/> Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language) <input type="checkbox"/> Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying) <input type="checkbox"/> Mental health condition (a condition that affects your emotional, physical and mental wellbeing) <input type="checkbox"/> Long-term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication) <input type="checkbox"/> Other condition, please write in <p><input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p><input type="checkbox"/> No condition</p>

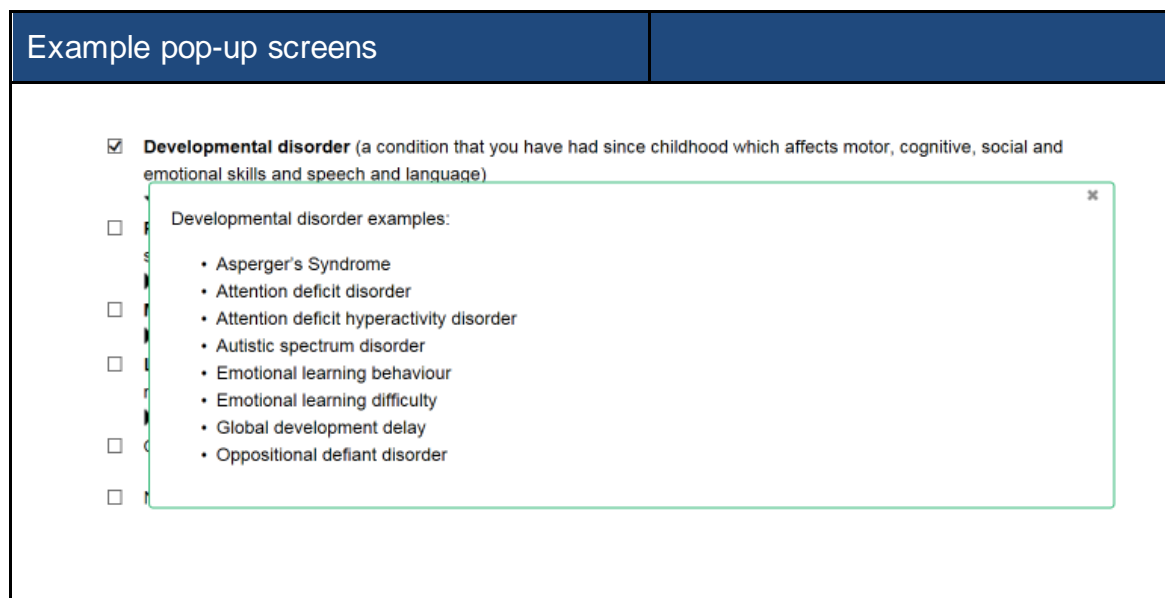
Both versions were also tested online. These different online versions are shown in table A2.

Table A2: Online versions of questions on long-term health conditions

Version one: Short version	
 <p>Q16A. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?</p> <p>Select all that apply.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss ▶ More Information <input type="checkbox"/> Blindness or partial sight loss ▶ More Information <input type="checkbox"/> Learning disability (for example, Down's Syndrome) ▶ More Information <input type="checkbox"/> Learning difficulty (for example, dyslexia) ▶ More Information <input type="checkbox"/> Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome) ▶ More Information <input type="checkbox"/> Physical disability ▶ More Information <input type="checkbox"/> Mental health condition ▶ More Information <input type="checkbox"/> Long term illness, disease or condition ▶ More Information <input type="checkbox"/> Other condition, please enter: [text box] <input type="checkbox"/> No condition 	
Version two: Long version	
 <p>Q16B. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?</p> <p>Select all that apply.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss ▶ More Information <input type="checkbox"/> Blindness or partial sight loss ▶ More Information <input type="checkbox"/> Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate) ▶ More Information <input type="checkbox"/> Learning difficulty (a specific learning condition that affects the way you learn and process information) ▶ More Information <input type="checkbox"/> Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language) ▶ More Information <input type="checkbox"/> Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying) ▶ More information <input type="checkbox"/> Mental health condition (a condition that affects your emotional, physical and mental wellbeing) ▶ More information <input type="checkbox"/> Long term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication) ▶ More information <input type="checkbox"/> Other condition, please enter: [text box] <input type="checkbox"/> No condition 	

The online version also included help screen pop-ups that respondents could click on where further information and more examples were provided. An example of these pop-up screens is shown in table A3.

Table A3: Example pop-up screen for online questions



The aims of testing were to:

- Explore respondents' understanding of the question and how easy or hard the questions are to answer.
- Explore whether respondents found the pop-ups online useful or not.
- Explore whether people noticed and understood the definitions used in the long versions and whether these are useful or not.
- Explore whether there was any preference in response guidance format, i.e. whether people preferred the short versions or the long-versions of response options.
- Explore whether respondents understand the difference between 'Learning disability', 'Learning difficulty' and 'Developmental disorder'.

2. Notes on sampling

In total, twenty respondents who had health conditions were interviewed in order to test the long-term health conditions questions. Many respondents noted having more than one health condition. A breakdown of the types of health conditions are outlined in table A4 below. Alliance Scotland, a third sector intermediary for a range of health and social care organisations, helped with the recruitment of respondents who have health conditions. Alliance Scotland posted an advertisement on their Twitter account and their newsletter to invite respondents with a health condition or who live with someone who has a health condition to take part in an interview. Additionally, the ScotCen Twitter account was used to invite respondents to take part in an interview.

Table A4: Number of respondents with health conditions

Health Condition	Number
Long term illness, disease or condition	11
Deafness or partial hearing loss	4
Physical disability	7
Blindness or partial sight loss	1
Mental health condition	10
Learning disability	2
Other: diabetes type II	1
Developmental disorder	1

3. Coding of response options and ease of responding

All of the respondents in the cognitive interviews said they found the question on health conditions easy to answer during probing. This comment was made for both the paper and online versions.

Respondents said they found the guidance, particularly the online pop-ups, helpful and were able to locate their answers easily. However, despite reports that the questions were easy, some issues were raised regarding the response options and content. It was noted that six respondents changed their answers between the different versions of the questions. This happened in both the paper versions and the online versions. Details of when this occurred and why are summarised in table A5.

Table A5: Examples of respondents changing their answers in different versions of the health questions

Examples – Changing Answers				Reason for changes in response
Paper Version One: Short version	Paper Version Two: Long version	Online Version One: Short version	Online Version Two: Long version	
Physical disability Mental health Long term illness, disease or condition Other: Diabetes	Physical disability Mental health Long term illness, disease or condition Other: Diabetes	Physical disability Mental health Long term illness, disease or condition	Physical disability Mental health Long term illness, disease or condition	Changed to 'Long-term illness, disease or condition' when they realised diabetes was listed under this category in the pop-up guidance online.
Other: Diabetes	Long term illness, disease or condition	Long term illness, disease or condition	Long term illness, disease or condition	Changed to 'Long-term illness, disease or condition' when they read the long version guidance in paper version two (long version) and saw the example of diabetes in the online version.
Other: arthritis	Physical disability	Other: arthritis	Not recorded. At this stage, they said they would not answer the health conditions question due to the sensitivity of the question. They did not have any issues with this particular question or version more than the others tested.	Changed to 'Physical disability' in paper version two (long version) because they said the symptoms listed were similar to their arthritis. Did not use the pop ups and did not see arthritis as an example.

Examples – Changing Answers				Reason for changes in response
Paper Version One: Short version	Paper Version Two: Long version	Online Version One: Short version	Online Version Two: Long version	
Deafness or partial hearing loss Physical disability Other: Arthritis	Deafness or partial hearing loss Physical disability Long term illness, disease or condition	Not recorded	Not recorded	Changed to 'Long term illness, disease or condition' when they read the description of the response option and thought their arthritis would be included in this category.
Blindness or partial sight loss	Blindness or partial sight loss Long-term illness, disease or condition	No condition	No condition	They coded blindness or partial sight loss because they wore glasses but decided not to code this in the online versions. They selected 'Long-term illness, disease or condition' because they were taking medication everyday but said it was not for a long-term health condition.
No condition	No condition	Long-term health condition	Long-term health condition	The participant read the online pop-up for 'Long-term illness, disease or condition' and said " <i>ok, now I would answer differently to this...I wouldn't really have classified a thyroid condition as a long-term condition but that's what I have and it's on the list.</i> "

4. Findings on the online pop-ups

Generally respondents found the pop-ups useful because of the further information provided on the health conditions:

“...that's much better, it's still quite crowded but not as bad...”

There is evidence that the pop-ups helped produce better quality data, in that they encouraged respondents to include conditions that would not have otherwise been reported. For example:

“OK, now I would answer differently to this...I wouldn't really have classified a thyroid condition as a long-term condition but that's what I have and it's on the list....”

The participant above coded 'No condition' in the first two paper versions and changed their response to 'Long term illness, disease or condition' for both the online versions.

The pop-ups also reduced the use of the 'Other condition' option when an existing response option should have been used. For example, one participant stopped recording diabetes under 'Other condition' and started recording it under 'Long term illness, disease or condition' when they noticed diabetes was an example given in the pop-up text.

5. Preference in response guidance

One aim of testing was to explore whether there was any preference in terms of the response guidance provided, i.e. whether people preferred the short versions or the long-versions and whether one version is any better in terms of producing better quality data.

In the short paper version some respondents commented that the simplified layout was easy to understand. However, some respondents, as highlighted above (Table A5), found it difficult to categorise their health condition and this resulted in some miscoding, in particular an overuse of the 'Other condition' category. In paper version two (long version) some respondents found it easier to select a listed response option because of the explanations that follow each of the health conditions. The response options became clearer to respondents and resulted in the correct response. One participant said:

“...having the definitions in has made a difference, as now I know I can tick all three, whereas I wasn't sure on the other version.”

This was reiterated by other respondents who said they preferred version two (long version) because the definitions made it easier to understand the health conditions listed:

“it's got a bit more definition attached to it obviously, that's good, I prefer this one”

However, some respondents commented on the length of version two:

“there's a lot of text there...an awful lot of text. The explanations are better but that's very crowded. Even if they'd spaced it out a bit better or something like that.”

“...there's so much more words, I don't like that there's so many words”.

The advantages and disadvantages for the paper version are outlined in table A6 below.

Table A6: Respondents' views on the advantages/ disadvantages of the short and long versions of the questions on paper

	Version one: short version (Paper)	Version two: Long version (Paper)
Advantages	Simplified version that was easy to read.	Respondents found the explanations helpful. Response options became clearer to respondents. Response options were changed to the correct coding once respondents had read the explanations.
Disadvantages	Some miscoding by respondents, i.e. choosing an incorrect response option for their health condition.	Lengthy and longer to read.

For the online version one (short version) respondents commented on the guidance in the pop-ups being useful. One participant said:

“...that's a good list, extensive.”

Whereas with the second online version (long version) there were cases where respondents thought there was too much information, once you combined the pop-ups and the guidance. This was reiterated by several respondents who commented on the definitions not bringing any additional benefits to the question and, therefore, being redundant:

“I know why you've done that but I wonder if anyone has poor literacy skills...I think this second version has too much information in it.”

However, there were some respondents who thought the extra guidance was helpful in the second version:

“...it makes you more aware of what the condition entails”

“...that's actually better isn't it, as you've got more information on the screen and can dig down further if you want to.”

The preference between the online versions is therefore less clear. The advantages and disadvantages for the online version are outlined in table A7.

Table A7: Respondents' views on the advantages/ disadvantages of the short and long versions of the question online

	Version one: short version (Online)	Version two: Long version (Online)
Advantages	Useful guidance on definitions of health conditions, especially when the health conditions were less common. Respondents thought the layout was clear to read and understand.	Further information if respondents are unsure how to code their response.
Disadvantages		Respondents thought it was too much information. Layout was overcrowded. Overcomplicated – may discourage respondents.

For the paper versions there was a clear indication that version two (long version) guidance was preferable and produced better quality data. The definitions of the health conditions were perceived as being helpful for respondents. Although some respondents commented on the second version being lengthy, the advantages in this case outweigh this disadvantage.

6. Findings on learning disability, learning difficulty and developmental disorder

During interview probing respondents were asked about their understanding of the terms 'Learning disability', 'Learning difficulty' and 'Developmental disorder.'

Respondents sometimes struggled to differentiate the difference between 'Learning disability' and 'Learning difficulty' and also found it difficult to explain 'Developmental disorder.'

In some cases the specific examples of the conditions helped people to distinguish between the categories. In particular, the example conditions named in the short version on paper and the online pop ups. Some respondents said they were not aware of some of the examples provided. Examples of definitions provided by respondents during cognitive interviews are shown in table A8.

Table A8: Understanding of 'Learning Disability, 'Learning Difficulty and 'Developmental disorder'

Understanding of 'Learning Disability'
<ul style="list-style-type: none"> • <i>"...someone with learning disabilities is someone who has got a born disability that affects their ability to process and regurgitate information."</i> • Someone who needs help getting through regular education, for example, dyslexia, Down's syndrome, ADHD. • Someone who is aged <i>"15 but has a mental age of 5 or 6"</i>. • A permanent, congenital difficulty in learning to develop skills, such as speech and language.
Understanding 'Learning Difficulty'
<ul style="list-style-type: none"> • <i>"I would say that those two words [learning difficulty and disability] are merely the same thing but on a different place on the spectrum"</i>. • Someone who is unable to learn on the same level as their peers. • 'Learning difficulty' said a difficulty is not a disability, it's just that you find something difficult – a disability is more something that is affecting the whole child. • One participant thought 'childhood' should be removed from the response guidance – they thought a learning disability could develop later in life.
Understanding of 'Developmental Disorder'
<ul style="list-style-type: none"> • Some respondents were unable to provide a definition of developmental disorders and therefore found the pop-ups/definitions useful. • 'Developmental disorder' this is when a child develops slower than the other children in their age group.

During the testing three respondents were interviewed who had either a learning disability or a developmental disorder or who lived with someone else who did (for example, a partner or child). There was no evidence of misreporting of response options in this group. For example, one participant, who was answering for their partner, had no difficulty selecting developmental disorder in any of the paper or online versions because they were aware of the terms:

"He is autistic so it's quite easy to spot that that falls under developmental disorder and mental health condition"

This was similar for another participant who said they did not use any of the pop-ups because they were aware that Asperger's syndrome (a condition they have) is categorised as a developmental disorder:

"I know Asperger's is classified as a developmental disorder...It's almost a bit of jargon that some of us know, rather than how we would think of ourselves."

They selected 'Developmental disorder' response option for both the online and paper versions.

The final participant, who selected 'Learning difficulty' and 'Development disorder' response options for all the modes, said they had no difficulty finding their answer. There were, therefore, no issues for respondents who had a learning disability or developmental disorder in selecting their response option, although this only applied to a small number of cases. No respondents in the sample reported having, or living with someone with, learning difficulties.

7. Other comments on health condition questions

There were several comments on the general content and guidance following the response options that may be important to consider. These were as follows:

- It was queried whether wearing glasses should be included as partial sight loss. One participant was unsure during the paper versions whether they should select this response option. As noted above, they did select this option ('Blindness or partial sight loss') but changed their response for the online version.
- One participant thought the question was sensitive and said they would hesitate to answer the question if the interviewer was not present. When probed, they suggested a small section explaining why the information was being collected would encourage them to answer.
- It was suggested that the phrase 'a condition you will have for life' should be removed from the response guidance for 'Long term illness, disease or condition' in version two (long version). It was noted that health conditions such as cancer would be expected to fall under this category but these may be treatable and not life-long.
- One participant recommended removing 'self-harm' and 'panic attacks' from the examples of mental health conditions given in the online pop-ups. It was commented that these were symptoms of mental health conditions, not conditions themselves.
- Many respondents thought there were no response options missing from the list and noted the 'Other condition' option if a condition was absent. There were several comments from respondents on what was missing:
 - Post-traumatic Stress Disorder (PTSD) (under 'Mental health condition')
 - Personality disorder (under 'Mental health condition')
 - Genetic disorders

- Auto immune conditions as a separate category (with rheumatoid arthritis as an example)
- Tinnitus (under 'Deafness or partial hearing loss')

8. Summary

- There is some evidence that the long version on the question in the long-term health conditions question produced better quality data during the cognitive interviews in terms of reducing the use of the 'Other condition' write-in category and prompting people to include conditions that they were not otherwise including.
- The online pop-ups with more information were useful to respondents to ensure that they classified their health condition correctly.
- Respondents found it difficult to distinguish between 'Learning disability', 'Learning difficulty' and 'Developmental disorder'. The definitions and the example conditions helped respondents differentiate between the three response options.
- Consideration to the phrase 'a condition you will have for life' should be given in the response guidance for 'Long term illness, disease or condition' in version two (long version).
- Further clarification of 'Blindness or partially sighted' category to exclude problems that are mostly corrected by glasses or contact lenses.
- As some respondents highlighted the sensitivity of this question further explanation to clarify why the census is aiming to collect data on respondents' long-term health conditions would be useful.

Annex B: 2017 Quantitative Testing – Long-term health conditions

In 2017 NRS commissioned ScotCen Social Research to conduct cognitive and quantitative testing of selected questions for potential inclusion in Scotland's Census 2021. Information about this testing can be found in the [2017 Cognitive and Quantitative Testing Report](#) (PDF).

1. Question tested and aims of testing

One question on long-term health conditions was included in the individual section of the questionnaire for testing. The question asked, 'Do you have any of the following, which have lasted, or are expected to last, at least 12 months?'. Whilst a question on long-term health conditions was asked in Scotland's Census 2011, the question and its guidance are currently under review in a bid to improve data quality. The question being tested included enhanced descriptions of each of the health conditions categories, and the online version also featured pop-up boxes that respondents could use to access examples of conditions and symptoms relating to the category of each tick box (Tables B1 – B3).

Table B1: Paper version of question on long-term health conditions

Health conditions 2017 test (paper)	Scottish Census 2011
<p>15 Do you have any of the following, which have lasted, or are expected to last, at least 12 months? ♦ Tick all that apply</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss <input type="checkbox"/> Blindness or partial sight loss <input type="checkbox"/> Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate) <input type="checkbox"/> Learning difficulty (a specific learning condition that affects the way you learn and process information) <input type="checkbox"/> Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language) <input type="checkbox"/> Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying) <input type="checkbox"/> Mental health condition (a condition that affects your emotional, physical and mental wellbeing) <input type="checkbox"/> Long-term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication) <input type="checkbox"/> Other condition, please write in <input type="text"/> <input type="text"/> <input type="checkbox"/> No condition 	<p>20 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? ♦ Tick all that apply.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or partial hearing loss <input type="checkbox"/> Blindness or partial sight loss <input type="checkbox"/> Learning disability (for example, Down's Syndrome) <input type="checkbox"/> Learning difficulty (for example, dyslexia) <input type="checkbox"/> Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome) <input type="checkbox"/> Physical disability <input type="checkbox"/> Mental health condition <input type="checkbox"/> Long-term illness, disease or condition <input type="checkbox"/> Other condition, please write in <input type="text"/> <input type="text"/> <p>or</p> <ul style="list-style-type: none"> <input type="checkbox"/> No condition

Table B2: Online version of question on long-term health conditions

Health conditions 2017 test (online)
<p>Q15. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?</p> <ul style="list-style-type: none"> ▪ Select all that apply <input type="checkbox"/> Deafness or partial hearing loss ▶ Deafness or partial hearing loss examples (click here) <input type="checkbox"/> Blindness or partial sight loss ▶ Blindness or partial sight loss examples (click here) <input type="checkbox"/> Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate) ▶ Learning disability examples (click here) <input type="checkbox"/> Learning difficulty (a specific learning condition that affects the way you learn and process information) ▶ Learning difficulty examples (click here) <input type="checkbox"/> Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills and speech and language) ▶ Developmental disorder examples (click here) <input type="checkbox"/> Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying) ▶ Physical disability examples (click here) <input type="checkbox"/> Mental health condition (a condition that affects your emotional, physical and mental wellbeing) ▶ Mental health condition examples (click here) <input type="checkbox"/> Long term illness, disease or condition (a condition that you will have for life which may be managed with treatment or medication) ▶ Long term illness, disease or condition examples (click here) <input type="checkbox"/> Other condition, please enter: <input style="width: 300px; height: 15px;" type="text"/> <input type="checkbox"/> No condition <p style="text-align: center;"> <input type="button" value="◀ Previous"/> <input type="button" value="Stop ■"/> <input type="button" value="Next question ▶"/> </p>

Table B3: Example pop-up screen for online questions

Pop-up screen example 2017 test (online)

Q15. Do you have any of the following, which have lasted, or are expected to last, at least 12 months?

- Select **all** that apply
- Deafness or partial hearing loss**
 - ▼ Deafness or partial hearing loss examples (click here)

Deafness or partial hearing loss examples:

- Deaf
- Deafblind
- Deafened
- Deafness
- Hard of hearing
- Hearing impaired
- Profoundly deaf
- Severely deaf

- Physical disability examples** (click here)
- Mental health condition** (a condition that affects your emotional, physical and mental wellbeing)
 - ▶ Mental health condition examples (click here)
- Long term illness, disease or condition** (a condition that you will have for life which may be managed with treatment or medication)
 - ▶ Long term illness, disease or condition examples (click here)
- Other condition**, please enter:
- No condition**

The aims of testing this question were to:

- look at the distribution of responses;
- look at an uptake of 'Other condition' write-in category rates as a measure of data quality;
- analyse item non-response rates as a measure of data quality and acceptability;
- analyse invalid responses, specifically invalid combinations, as a measure of data quality; and
- analyse the percentage of potentially backcodeable responses as a measure of data quality.

2. Health Conditions Distribution

In total, 90 per cent of respondents provided a valid response to the question on long-term health conditions, and around 10 per cent provided an invalid response. Almost all invalid responses from full completions were attributable to item non-response.

Of those who provided a valid response to the question, over half (around 60 per cent) reported having no health conditions. The most commonly selected response

was 'Long-term illness, disease or condition' (selected by around 21 per cent of respondents), followed by 'Mental health condition' (selected by around 11 per cent), 'Physical disability' (around 10 per cent), and 'Deafness or partial hearing loss' (around nine per cent). Roughly four per cent of respondents selected the response option 'Other condition'. Proportions citing the remaining health conditions ranged from roughly one to two per cent.

Table B4: Valid weighted response to each health condition (2017 test)

		Yes	Weighted base
Health conditions	Deafness or partial hearing loss	9%	1,288
	Blindness or partial sight loss	2%	1,288
	Learning disability	1%	1,288
	Learning difficulty	1%	1,288
	Developmental disorder	1%	1,288
	Physical disability	10%	1,288
	Mental health condition	11%	1,288
	Long-term illness, disease or condition	21%	1,288
	Other condition	4%	1,288
	No condition	60%	1,288
	One or more condition	40%	1,288

As mentioned above, in the 2017 test around 60 per cent of the valid responses were from respondents who reported having no long-term health conditions. This compares to 70 per cent of the population reporting having no long-term health conditions in the 2011 Census (Table B5).

Table B5: 2011 Census data on long-term health conditions

	2011 Census	2011 Census, proportion of total
All people	5,295,403	100%
No condition	3,710,676	70%
One or more condition	1,584,727	30%
Each long-term health condition as a proportion of total population		
	2011 Census	2011 Census, proportion of total
Deafness or partial hearing loss	350,954	7%
Blindness or partial sight loss	125,660	2%
Learning disability	26,349	1%
Learning difficulty	106,154	2%
Developmental disorder	31,712	1%
Physical disability	355,182	7%
Mental health condition	232,943	4%
Other condition and Long-term illness, disease or condition	988,430	19%
Total number of long-term health conditions reported in 2011 Census		
Total conditions		2,217,384

Health conditions by mode

Distributions of valid responses to the long-term health conditions question were evenly split across modes, with around half of respondents answering online and on paper (around 54 per cent and 46 per cent respectively).

Of respondents who reported having a long-term illness, disease or condition, around 48 per cent completed the online questionnaire and around 52 per cent completed the paper version. Of those who reported having a mental health condition, around 64 per cent completed the online questionnaire while 36 per cent completed the paper version.

Around 39 per cent of respondents who reported having a physical disability completed the online questionnaire with the remainder completing the paper version. While around 33 per cent of those reporting deafness or partial hearing loss completed the online questionnaire with the remainder completing the paper version.

Of those reporting no health conditions, 53 per cent completed the online questionnaire while 47 per cent completed the paper version.

Base sizes amongst other groups were too small to analyse any association between health condition and mode.

Table B6: Health conditions by mode (as a percentage based on weighted estimates of total valid responses)

		Mode		
		Number of responses - Online	Number of responses - Paper	Total
Health conditions	Deafness or partial hearing loss	33%	67%	100%
	Blindness or partial sight loss	22%	78%	100%
	Learning disability	32%	68%	100%
	Learning difficulty	66%	34%	100%
	Developmental disorder	80%	20%	100%
	Physical disability	39%	61%	100%
	Mental health condition	64%	36%	100%
	Long-term illness, disease or condition	48%	52%	100%
	Other condition	45%	55%	100%
	No condition	59%	41%	100%
	One or more conditions	47%	53%	100%
	Total valid responses	54%	46%	100%

Health conditions by age

Around 30 per cent of valid responses came from those aged 16-34, while around 32 per cent came from those aged 35-54. Around 15 per cent of valid responses were given by those aged 55-64, with the remaining 22 per cent being given by those aged 65 and over. This distribution of responses by age is largely in proportion with the overall proportion of the age groups of the total responses.

A higher proportion of those who reported either a long-term illness, disease or condition, a physical difficulty, or deafness or partial hearing loss were over the age of 65. Forty per cent of those who stated they had a long-term illness, disease or condition fell into the 65 and over age group, while the corresponding figures for those who had physical difficulty and deafness or partial hearing loss were 49 per cent and 64 per cent respectively.

A higher proportion of those who reported having a mental health condition were aged between 16-34 (44 per cent) and 35-54 (35 per cent). Similarly, a higher proportion of those who reported having no long-term health conditions came from

younger age groups, with around 38 per cent of those aged between 16-34 and 35-54 who described themselves as having no long-term health conditions.

It should be noted that none of the above findings have been tested for significance.

Table B7: Health conditions by age as a percentage based on weighted estimates of total valid responses

		All people					
		16-34	35-54	55-64	65+	Total valid responses	
Health conditions	Deafness or partial hearing loss	2%	16%	18%	64%	100%	
	Blindness or partial sight loss	0%	15%	4%	80%	100%	
	Learning disability	21%	61%	13%	6%	100%	
	Learning difficulty	77%	20%	4%	0%	100%	
	Developmental disorder	80%	15%	0%	4%	100%	
	Physical disability	9%	20%	22%	49%	100%	
	Mental health condition	44%	35%	15%	6%	100%	
	Long-term illness, disease or condition	11%	26%	23%	40%	100%	
	Other condition	10%	25%	15%	50%	100%	
		No condition	38%	38%	14%	11%	100%
		One or more conditions	19%	25%	18%	38%	100%
	Total valid responses	30%	32%	15%	22%	100%	

Table B8: Health conditions by age from the 2017 test (as a percentage, based on weighted estimates of total valid responses) vs. 2011 Census

	All people					
	16-34		35-64		65 and over	
	2017 Test	2011 Census	2017 Test	2011 Census	2017 Test	2011 Census
No condition	38%	38%	52%	51%	11%	11%
One or more conditions	19%	14%	43%	47%	38%	39%
Total valid responses	30%	30%	47%	50%	22%	20%

Overall, the distribution of those with no conditions and those with one or more conditions, by age, was found to be similar in the 2017 test to the 2011 Census.

3. Invalid responses to long-term health conditions question

All types of invalid response

If a participant did not answer any questions beyond the Marital Status Question their questionnaire was classified as partially completed. At all questions beyond Marital Status Question, a partial completion was treated as a questionnaire drop out and distinct from item non-response.

Invalid responses accounted for around 13 per cent of total responses to the long-term health conditions question, with around two per cent attributable to partial completions and therefore indicative of questionnaire drop out, as opposed to invalid response to the long-term health conditions question. Almost all instances of invalid response from fully complete questionnaires (around 10 per cent of full completions) were the result of item non-response, with less than one per cent of invalid responses resulting from invalid combinations.

All types of invalid response by mode

Almost all instances of invalid response from full completions were attributable to item non-response. In total, there were 143 instances of item non-response at the long-term health conditions question. Most instances of item non-response from full completions were the result of the paper version of the questionnaire (135 cases, compared with just eight cases from the online questionnaire).

Table B9: Invalid long-term health conditions by mode (unweighted counts)²

	Mode		
	Number of responses - Online	Number of responses - Paper	Total
Item non response – full completions	8	135	143
Item non-response – partial completions	34	0	34
Invalid multi-tick – paper only, single tick questions			
Invalid combination	0	6	6
Routing error			
Total invalid responses	42	141	183
Not applicable			
Total valid responses	603	668	1271
Total responses	645	809	1454

² Partial completions are excluded from the analysis of this question and treated as questionnaire drop out.

All types of invalid responses by age

Item non-response from full completions to the long-term health conditions question seems to be associated with age. As shown in table B10, item non-response from this type of completion is highest amongst those aged 55 and over (86 cases) and lowest amongst those aged 16-34 (14 cases). Invalid combinations, that is, where a participant selected 'No health condition' and a valid type of health condition in combination, were also only present amongst the oldest age group (six cases in the aged group 55 or over).

It should be noted that these findings have not been tested for significance.

Table B10: Invalid health condition by age (unweighted counts)

	Age			Total valid responses	Total invalid responses	Total responses
	16-34	35-54	55 or over			
Item non response – full completions	14	40	86	140	3	143
Item non-response – partial completions	1	0	4	5	29	34
Invalid multi-tick – paper only, single tick questions						
Invalid combination	0	0	6	6	0	6
Routing error						
Total invalid responses	15	40	96	151	32	183
Not applicable						
Total valid responses	133	338	797	1,268	3	1,271
Total responses	148	378	893	1,419	35	1,454

Item non-response only³

Given that almost all invalid responses were item non-response, the findings discussed above in relation to invalid responses hold true for item non-response only.

While the question included in the 2017 testing is not directly comparable to previous census questions it is nonetheless noteworthy to look at item non-response as a means of assessing what might happen to this measure of data quality as a result of the changes. The fact that item non-response was around 10 per cent in 2017, compared with around 15 per cent in the 2011 Census could be an indication that something about the revision to the long-term health conditions question has reduced item non-response and had a positive impact on this marker of data quality.

³ Note that item non-response to the 2017 Quantitative Testing and item non-response to the 2011 Census are not directly comparable as there was no questionnaire drop-out or partial completion rate estimated for the 2011 Census, which was primarily a paper questionnaire.

4. Back-coding

Around four per cent⁴ of respondents who provided a response to the long-term health conditions question reported having an “Other condition”. Almost all of those who selected this option both ticked the option and wrote in a health condition – only one participant ticked ‘Other condition’ response option and did not provide a write-in response.

In total, around 79 per cent (52 cases, out of a total of 66 cases) of those who ticked and wrote in a response to ‘Other condition’ could have been backcoded. All but one of these cases were backcoded either into ‘Long term illness, disease or condition’, or another health condition the participant had already selected in combination with ‘Other condition’. There was one case of ‘Other condition’ being backcoded into ‘Physical disability’.

As shown in table B11, ‘Other condition’ written responses from the paper mode were more likely to be back-codable than those provided by respondents responding online (92 per cent of paper write-in responses, compared with 61 per cent of write-in responses provided online).

Table B11: Back-coding health conditions by mode (unweighted counts)

	Mode		
	Number of responses - Online	Number of responses - Paper	Total
Total Write-ins	28	38	66
Total Re-codable	17	35	52
% Re-codable	61%	92%	79%

⁴ Weighted percentage

Table B12: Back-coding by health conditions and by mode (unweighted counts)

		Unweighted count		
		Original	Backcoded	Total
Health condition	Deafness or partial hearing loss	173	0	173
	Blindness or partial sight loss	43	0	43
	Learning disability	9	0	9
	Learning difficulty	8	0	8
	Developmental disorder	4	0	4
	Physical disability	156	1	157
	Mental health condition	97	0	97
	Long term illness, disease or condition	351	39	390
	Other	67	52	119
	No health condition	665		665
	Other: No write-in	1	0	1
	Total valid responses	1,271		1,271
	Invalid responses	183		183
	Total responses	1,454		1,454

5. Feedback

When asked 'Did you find any of the following questions difficult to answer: Q15. Health conditions' only two per cent of respondents indicated that they did find the long-term health conditions question difficult to answer. Around three per cent of respondents did not respond to the feedback question at all, while 98 per cent responded about other questions.

Of the 27 respondents who expressed having an issue with the long-term health conditions question, almost all (25) provided a valid response.