# Scotland's Census 2021
# Health and Care Topic Event Summary

## May 2017

**Table of Contents**

# 1. Introduction

## 1.1 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 document presented the initial views from NRS on the topics under consideration for collection in the census in 2021, with the aim of encouraging discussion and to help build strong cases to justify the inclusion of topics. The consultation was a first step towards understanding what information users will need. 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.

In total, 113 responses were received to the consultation; 91 of these were from organisations and 22 were from individuals. On 15 February 2016, NRS published the responses of those organisations and individuals who had indicated they were content for us to do so. These responses can be viewed on the Citizen Space website. On 15 August 2016, NRS published the Topic Consultation Report (PDF). This report presented an overview of the evaluation process used to assess Topic Consultation responses and outlined NRS's response to the consultation, updated view on topics under consideration for collection in Scotland's Census 2021 and NRS's intended next steps.

NRS received a strong response from users on a range of topics, some of which have not been included in Scotland's Census before. In the introduction to the consultation document, we said:

"Changes to the content of the questionnaire will be considered to address:

- where questions didn't work well in 2011, particularly where there were issues with data quality and/or they didn't support users' requirements for outputs,
- new or emerging policy requirements that cannot be addressed through the use of alternative sources,
- changes in international guidelines (e.g. around the labour market topic) and in legislation."

The consultation was a key step towards understanding what is needed from the census in 2021. In order to develop the question set that will be recommended for inclusion in the census questionnaire, NRS will work with users and undertake research, question testing and consideration of acceptable burden. The final decision on the content of Scotland's Census 2021 questionnaire will ultimately be made by the Scottish Parliament, likely in late 2019.

As in previous years, there will be separate censuses in England & Wales and Northern Ireland and the three census offices will work together to develop a set of questions that, wherever possible and necessary, deliver harmonised outputs across the UK.

Consultations on the content for the 2021 Censuses in England & Wales and Northern Ireland also took place last year. On 23 May 2016, the Office for National Statistics (ONS) published their response to the consultation for England & Wales[1]. The Northern Ireland Statistics and Research Agency (NISRA) published their response to the consultation for Northern Ireland later on 30 August 2016[2].

1.2     Following the Topic Consultation

In the Topic Consultation, NRS outlined the next steps for each topic or sub-topic where question changes or new questions may be required. For Health and Care this included further discussion with users in light of requests which were made for additional information to be collected and to better understand the exact nature of user need.

We recognised that it was vital to ensure that our follow-up discussions included a wide range of users. Respondents to the Topic Consultation who indicated that they were happy to be contacted by NRS about Health and Care were invited to attend a Topic Consultation follow-up event on 24 April 2017.

The event was also widely promoted through the Scotland's Census newsletter which has a distribution list of around 2,000 contacts and by the @NatRecordsScot Twitter feed.

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 materials from the Health and Care Topic Event held on 24 April 2017 are available on the Scotland's Census website.

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. The 2021 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.

At the Health and Care Topic Event on 24 April 2017, NRS gave some background to the questions asked about health and care in Scotland's Census, and through a series of activities asked stakeholders for their feedback and thoughts about the type of information they need to collect (Section 3: Conditions or symptoms) from the Long-term Health Conditions Question, why they need the information (Section 4:

---

[1] 'The 2021 Census – Assessment of initial user requirements on content for England and Wales: response to consultation' 2021 Census topic consultation - Office for National Statistics
[2] 'Assessment of the responses received – Response to Consultation' 2021 Census Topic consultation – Northern Ireland Statistics and Research Agency

User requirements for 2021) and for their feedback and comments on six possible question options for the Long-term Health Conditions Question in Scotland's Census 2021 (Section 5: Alternative Long-term Health Conditions Question designs for 2021).

This report summarises the further discussion with users from the Health and Care Topic Event and the responses gathered through the paper and online survey for the census topic Health and Care.

## 2.      2011 Long-term Health Conditions Question

The Long-term Health Conditions Question, shown in Figure 1, was first introduced in Scotland's Census in 2011 after strong evidence of user demand for the data was collected in the 2007 Topic Consultation.   A list of eight specific conditions categories were included in the response options for the question, along with 'other condition' (with a write in option) and 'no condition'.

**Figure 1: Scotland's Census 2011 Long-term Health Condition Question**



The format and the response options of the 2011 question caused considerable confusion for respondents to the 2011 Census, evidenced by around 330,000 write-

in responses in the 'other condition' category, indicating that people were unsure which response(s) to select to best describe their condition(s). Over half a million individual conditions or symptoms were identified from the write-in responses, from which approximately 1500 unique conditions were identified.

Strong support to continue to collect information on long term health conditions was identified in the 2021 Topic Consultation. This information is used by local government and public bodies for service planning and provisions, the development of social care policies and equality monitoring.

The 2021 Topic Consultation identified some user need for further breakdown of conditions, for example having separate tick-box response options for Down's Syndrome and a breakdown of mental health conditions. This would give a better idea of the number of people in Scotland with this condition which would help policy makers and care provides to provide applicable and essential services to the individual communities.


## 3.    Conditions or symptoms

3.1    Introduction

Stakeholders at the Health and Care Topic Event took part in an exercise to identify and group symptoms and conditions into response categories similar to those in the 2011 question, and were asked to consider whether data on conditions or symptoms is of more value to meet their data needs. This section presents the category groupings created at the event and summarises feedback from attendees around the collection of symptoms and conditions.

3.2    Grouping conditions and symptoms into the 2011 response categories

Each table group of attendees at the Health and Care Topic Event was provided with a template of Table 1 containing only the category headings: 'deafness or partial hearing loss', 'blindness or partial sight loss', 'learning disability'. 'learning difficulty', 'developmental disorder', 'physical disability', and 'other condition'. The groups were asked to enter examples of conditions and symptoms that should be grouped into these categories, the combined results of this exercise are shown in Table 1.

Stakeholders discussed the difference between conditions and symptoms, whether the examples they provided were symptoms or conditions, and what information they need. Some found it hard to place some conditions into Table 1 (such as Autism) and some required another category such as terminal illness, which has been added as a category in Table 1.

**Table 1: Symptoms and conditions grouped by stakeholders into 2011 Long-term Health Conditions Question style categories**

| | |
|---|---|
| **Deafness or partial hearing loss**<br>• Deaf<br>• Deafblind<br>• Deafened<br>• Hard of Hearing | **Blindness or partial sight loss**<br>• Glaucoma |
| **Learning disability**<br>• Autism | **Learning Difficulty**<br>• Autism<br>• Developmental delay |
| **Developmental Disorder**<br>• Autism | **Physical disability**<br>• COPD |
| **Mental Health condition**<br>• Suicidal<br>• Self-harm<br>• Depression | **Other Condition**<br>• Acute Coronary Syndrome (ACS)<br>• Dementia<br>• COPD<br>• Celiac disease<br>• Eating disorders<br>• Cancer |
| **Terminal illnesses**<br>• Cancer | |

As can be seen above, there are questions surrounding categorising some conditions such as Autism which can fit into at least three different categories. The individuals perception of what Autism is and the effects of Autism mean this condition may be categorised differently according to the individual responding.

Comments made by stakeholders at the event suggested that examples given in the guidance next to the response in 2011 may have made respondents struggle to determine where their condition should fit. For example, respondents with a general learning disability diagnosis when provided with the 2011 response option with guidance: 'Learning disability (for example, Downs Syndrome)', may have thought it was only for those with Downs Syndrome. This was evidenced by around 400 written responses of 'learning disability' (stating the degree of the condition i.e. mild, moderate, severe and profound). There was evidence for similar problems in other categories, for example 'Developmental disorder (for example Autistic Spectrum Disorder or Asperger's Syndrome)', where 'ADHD' had around 2,600 entries in the 'Other condition' text box.

There was a discussion around how to support respondents in answering this question. Some concern was expressed around capturing different responses if the

respondent answers the question or their support worker or guardian answers. Stakeholders also discussed particular difficulties in identifying the correct response category for some conditions, including neuropathic pain, and questioned how someone would define dementia.

It was also pointed out that the term deafblind is not related to someone who is Deaf and Blind. This term describes someone who has a severe impairment of both hearing and vision.

## 4.     User requirements for 2021

### 4.1     Introduction

At the Health and Care Topic Event NRS introduced the categories being used to prioritise questions, question design and question content for Scotland's Census 2021. This information is included in the slides for the Health and Care Topic Event, available online. The 2021 Topic Consultation identified a strong user need for continuing to collect this data and a need to review the detail of the information collected in the Long-term Health Conditions Question to ensure it meets user needs. In order to capture more detail about what data is essential to meet user need, stakeholders at the event were asked to outline why they need to collect this information from the 2021 Census. This section summarises the user needs identified at the event, and comments from attendees about their need for data on long-term health conditions.

## 5.     User requirements for 2021

Stakeholders were asked to list specific ways in which they would use data on long-term health conditions, and to group these into NRS's five prioritisation pillars: strength of user need; lack of alternative sources; acceptability, clarity and data quality; comparability; and operational considerations. The grouped needs identified, and comments about user need that were provided as part of this exercise are listed in Table 2.

As captured in the 2021 Topic Consultation, a range of uses for the data were identified by stakeholders at the event and respondents to the event survey. With the emergence of new Government strategies appearing before 2021, and disability legislation, it is clear to see how important this question is to many stakeholder groups. Census is often the key source of evidence for long term health conditions, and strong user need for certain response categories was expressed in order for stakeholders to meet legislative and Scottish Government commitments.

In addition, stakeholders at the event strongly favoured a need for comparability with 2011 Census data over comparability with other surveys.

**Table 2: User requirements and comments provided by stakeholders at the Health and Care Topic Event and in the related online survey**

| |
|---|
| **Strength of user needs**<br>• *"Used for what gets counted as part of the economy eg. Unpaid carers, and the impacts on the economy. Should be in next UN rules about measuring economies: caring is very important in that"*<br>• *"SCLD: SG partner in delivering 'Keys for life' -> equality monitoring via mainstreaming, Legislative needs"*<br>• *"Implementation of Scottish Autism Strategy requires solid data. Census can be a part of this"* |
| **Lack of alternative sources**<br>• *"Carers Survey (SG) covers carers in contact with LA's (in line with carers act) BUT excludes a wide range of unpaid and other carers"*<br>• *"Estimates range massively on Learning Disability population from ~ 26,000 through to 180,000. This is a broad range to be working in"*<br>• *"Information not gathered on autistic adults who do not receive social work support"*<br>• *"Deafness Question – no other sources of data. Not gathered in health. Not everyone linked to social care"* |
| **Acceptability, clarity and data quality**<br>• *"There is a need for autism spectrum disorder to be included in its own right as a standalone option"* |
| **Comparability**<br>• *"Comparable across UK communities for carers"*<br>• *"Useful to understand in experience in service provision across UK. BUT prevalence comparability not the highest priority concern."*<br>• *"Comparability with 2011 data is high priority."*<br>• *"Key feature of the census is because of wide scope it offers opportunities for cross-tabs that surveys never can"*<br>• *"The previous question is not worth anything. Because the question doesn't mean anything"* (referring to the General Health Question, which asks 'How is your health in general?') |
| **Operational Consideration**<br>• *"What is the financial cost of not knowing how many people have a hearing loss across the spectrum of deafness in Scotland – especially with an aging population?"* |

**6. Alternative Long-term Health Conditions Question designs for 2021**

6.1    Introduction

NRS are developing a Long-term Health Conditions Question that is easier to understand and reduces respondent burden. At the Health and Care Topic Event, NRS presented six alternative Long-term Health Conditions Question options and asked stakeholders for comments and feedback on the following:

- Are the questions being asked in a way that captures the user need?
- What other ways could we ask it to capture the information needed by our users?
- Are there enough response categories to capture the required information?
- What are people's understanding of disabilities, long term conditions and illnesses
- People's use of terminology over the year to be addressed yearly
- Are we using acceptable terminology to retain comparability between census statistics

Stakeholders were also asked to list pros and cons for each question design. The following sections summarise these responses captured at the event for each alternative question option.

6.2    Option 1: Continue to use a 2011-style question

Due to the number of text responses in the 2011 Census, Option 1 is to continue to use the 2011 response options but consider eliminating the text box for 'Other condition'. The 2011 Long-term Health Conditions Question asked in Northern Ireland did not include a text box for 'other' response category.

Eliminating the text box would reduce coding burden, however, there is a risk that respondents may not answer the question if they are unsure which response category to tick for their condition. In this case, the detailed information on conditions required by users may not be captured.

Alternative Question Option 1 is shown in Figure 2, and the Health and Care Topic Event attendees list of pros and cons for this question is shown in Table 3.

**Figure 2: Alternative Long-term Health Conditions Question Option 1**

> 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
>
> ☐ Other condition
>
> **or**
>
> ☐ No condition

**Table 3: Alternative Question Option 1: Stakeholder Pros and Cons**

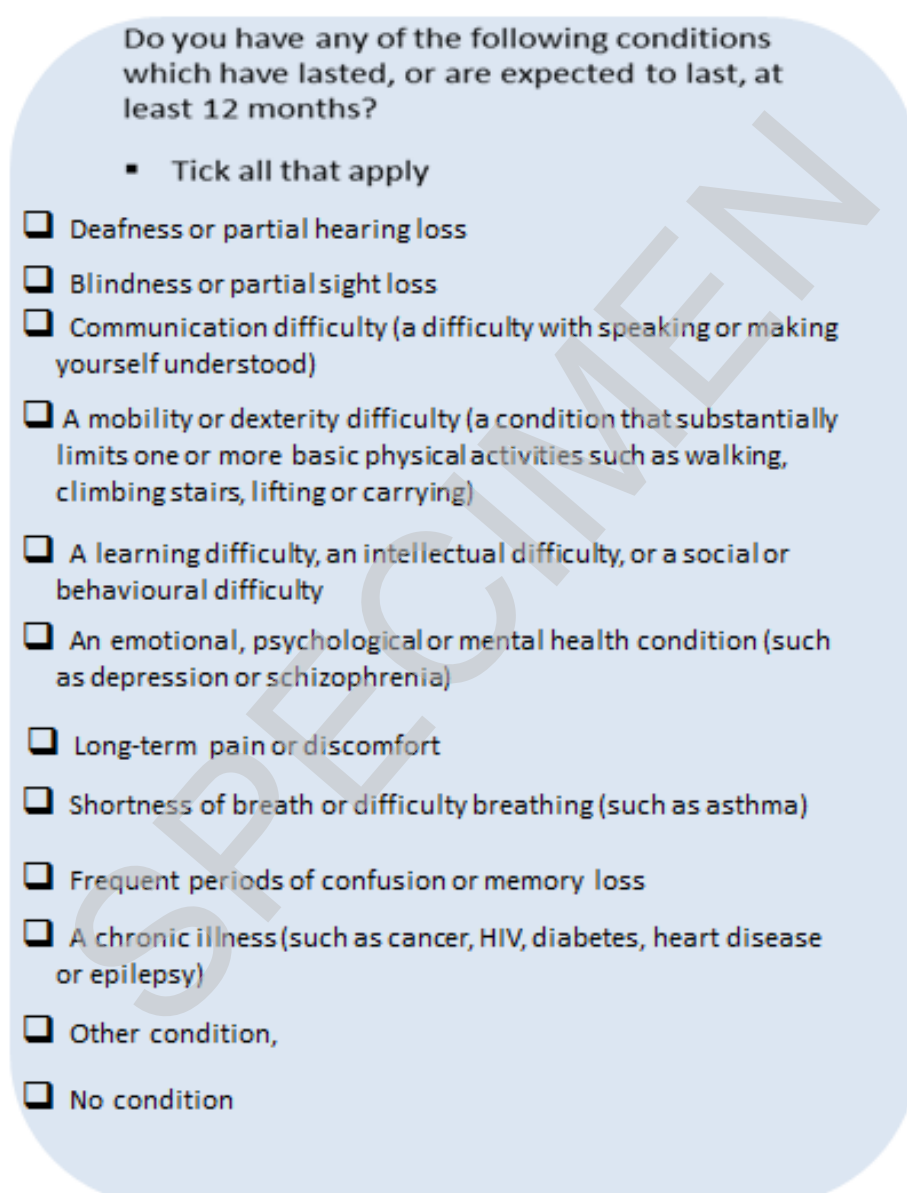| Pros | Cons |
|---|---|
| • *"Comparable with 2011"*<br>• *"Concise question means people more likely to complete"* | • *"No write in box"*<br>• *"Learning Disability population in census "*<br>• *"2011 too low to be very useful – issues with self-identification "* |

An additional point was made in relation to the specified length the condition lasted (12 months). Some respondents, for example those with a recently diagnosed condition may not know whether their condition will last for 12 months. There was some concern that respondents may have selected 'No condition' because they were unsure of how long their condition would last. One example of this would be cancer. If a respondents cancer is not diagnosed as terminal, the respondent may not know whether the cancer would last for a period of 12 months or not. For this reason, some members of the group felt it would be better to remove the 12 month criteria from the question.

Some stakeholders felt the word 'condition' in the question was not an accurate description, and felt some respondents were confused by the terminology. There were mixed views as to whether the question was about disabilities or health conditions, thus the wording of the question needed to reflect this.

6.3    Option 2: A 2011 Northern Ireland style question

NRS reviewed a range of similar long-term health condition questions from censuses around the world, and decided that the long term health question included in the Northern Ireland 2011 Census would be worth further investigation. This option is shown in Figure 3.

**Figure 3: Alternative Long-term Health Conditions Question Option 2**

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

NRS are working with the Northern Ireland Statistics Research Agency (NISRA) in planning for the 2021 Census, and using a Northern Ireland style question may enable closer harmonisation with Northern Ireland for 2021. However, some key conditions are merged in the Northern Ireland style question. In particular, data for those on the autistic spectrum would not be available and this was a key requirement identified in The Spring 2007 Census consultation and The Scottish Strategy for Autism.

England and Wales did not include a long-term health conditions question in their 2011 census and have no plans to include it in 2021.

The pros and cons identified by stakeholders at the Health and Care Topic Event for replacing the Scotland's Census 2011 question with the Northern Ireland's Census 2011 question are listed in Table 4.

**Table 4: Alternative Question Option 2: Stakeholder Pros and Cons**

| Pros | Cons |
|---|---|
| • *"No write in box, which would eliminate the additional conditional and reduce the additional coding."* <br> • *"More detailed guidelines on some of the response categories"* <br> • *"Long-term illness, disease and condition has been split into 4 response categories which makes it easier to understand"* <br> • *"The addition of the communication difficulty "* <br> • *"Harmonisation would enable comparable analysis between Scotland and Northern Ireland"* <br> • *If there was a text box to note diagnosed conditions, the question would need info, but also symptoms"* | • *"No option to identify conditions not included in response guidelines"* <br> • *"Needs more guidelines include against each response category"* <br> • *"Condensed question which includes learning difficulty, intellectual disability and social or behaviour difficulty"* <br> • *"The communication difficulty could overlap other conditions which may mean it gets counted twice such as someone who has had a stroke"* ( a long term illness), *"would also have speech problems as well as mobility problems "* <br> • *"It is not 100% comparable with the Scotland's 2011 Census question due to the groupings. Both data would need to include derived variables to address this difference"* <br> • *"Can't ascertain conditions such as Autism -> doesn't provide the information needed. Same applies to Learning Disabilities"* <br> • *What does dexterity difficulty mean – maybe change terminology"* <br> • *"What does frequent periods mean?"* <br> • *"No direct comparability with 2011 physical condition ?"* <br> • *"Communication difficulty – speaking* |

| | *or making yourself understood?"* <br> • *"Communication need? Two way process"* |
| --- | --- |

Organisations such as Autism Scotland, Scottish Learning Disability Observatory (SLDO) and Scottish Commission for Learning Disabilities (SCLD), require data on specific types of conditions such as how many people in Scotland have Down's Syndrome and how many adults are autistic. Data about these key conditions are not available from other sources, thus, having this data in the census is crucial for them. The way this question is designed at the moment, means data which answers these specific questions cannot be collected, but instead gives an estimate on total numbers.

6.4     Option 3: A combination of Scotland and Northern Ireland 2011 questions

Another option is to combine the Scotland and Northern Ireland 2011 questions, as shown in Figure 4. This option has additional response categories and contains some of the more detailed response categories from the Northern Ireland 2011 question. The Northern Ireland 2011 question response category 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty' has been split into three response categories similar to those in the Scotland's Census 2011 question: 'Learning disability (for example, Down's Syndrome)', 'Learning difficulty (for example, dyslexia)' and 'Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome'.

The categories in Option 3 could be grouped to provide data comparable with the 2011 questions for both Scotland and Northern Ireland. However, a particular disadvantage with this option is that it is very long and there are space constraints on the paper questionnaire. The pros and cons identified by stakeholders at the Health and Care Topic Event for question Option 3 are listed in Table 5.

This question option was thought to be a bit too confusing by most stakeholders, because of the increased number of response categories. The stakeholders did however, prefer the inclusion of the three Scotland's Census 2011 response categories for learning disability, learning difficulty and developmental disorder, and felt this would be more useful for their needs.

**Figure 4: Alternative Long-term Health Conditions Question Option 3**

> 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)
>
> ☐ Learning disability (for example, Down's Syndrome)
>
> ☐ Learning difficulty (for example, dyslexia)
>
> ☐ Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
>
> ☐ A mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
>
> ☐ 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

**Table 5: Alternative Question Option 3: Stakeholder Pros and Cons**

| Pros | Cons |
|---|---|
| • *"Greater disagg"* [dissagregation] *"BUT for Learning Disability same scope for people to identify differently - doesn't necessarily identify all Learning Disability population"*<br>• *"Ideally stand-alone question for Autism especially for adults where there is no alternative data source"* | • *"No text box"*<br>• *"If there was a separate question on communication we wouldn't need this response on here"*<br>• *"Nesting brackets too confusing"* |

6.5    Option 4: Option 3 with additional response guidance

Option 4, shown in Figure 5, includes additional guidance for the response options included in Option 3 (Figure 4). This guidance gives more examples of conditions that fit into these response categories to aid respondents in identifying the response option they should select. As with Option 3, a particular disadvantage to this option is space constraints on the paper questionnaire. The pros and cons identified by stakeholders at the Health and Care Topic Event for question Option 4 are listed in Table 6.

**Figure 5: Alternative Long-term Health Conditions Question Option 4**



**Table 6: Alternative Question Option 4: Stakeholder Pros and Cons**

| Pros | Cons |
|---|---|
| | • *"Nowhere to identify conditions"* <br> • *"Issues with where conditions are included – may be contentious"* <br> • *"Question too long"* <br> • *"Query about Dyspraxia and whether it should be classified as a learning difficulty or a learning disability"* |

As with Option 3, stakeholders were put off by the length of the question and the volume of text. This option was the least favoured option.

There was also a question about which response category dyspraxia should be included in: learning disability, learning difficulty, or developmental disorder.

6.6    Option 5: Online version of Option 1 including additional guidance

Option 5, shown in Figure 6, explores a way of listing all the common conditions which could fit into each category to provide respondents with more guidance online. In this online option, lists of conditions and symptoms could 'pop up' to indicate which conditions should be in which category. This is a possible option online only, because there is not enough room to incorporate additional lists within the paper questionnaire. However, this additional information would be made publically available through the public assistance helpline and online.

This option uses the Scotland's Census 2011 response categories, and as such would provide the same detail as Option 1 (Figure 2). This additional guidance may decrease the non-response rate online.

One drawback to this option is that some conditions or symptoms may appear in more than one response category. The lists provided in Figure 6 are an example of this style only, and the final lists would need to be validated by an external source.

Stakeholders at the Health and Care Topic event provided little feedback on this option, except to agree that it removed clutter, which was identified as problematic in Option 4 (Figure 5), as shown in Table 6.

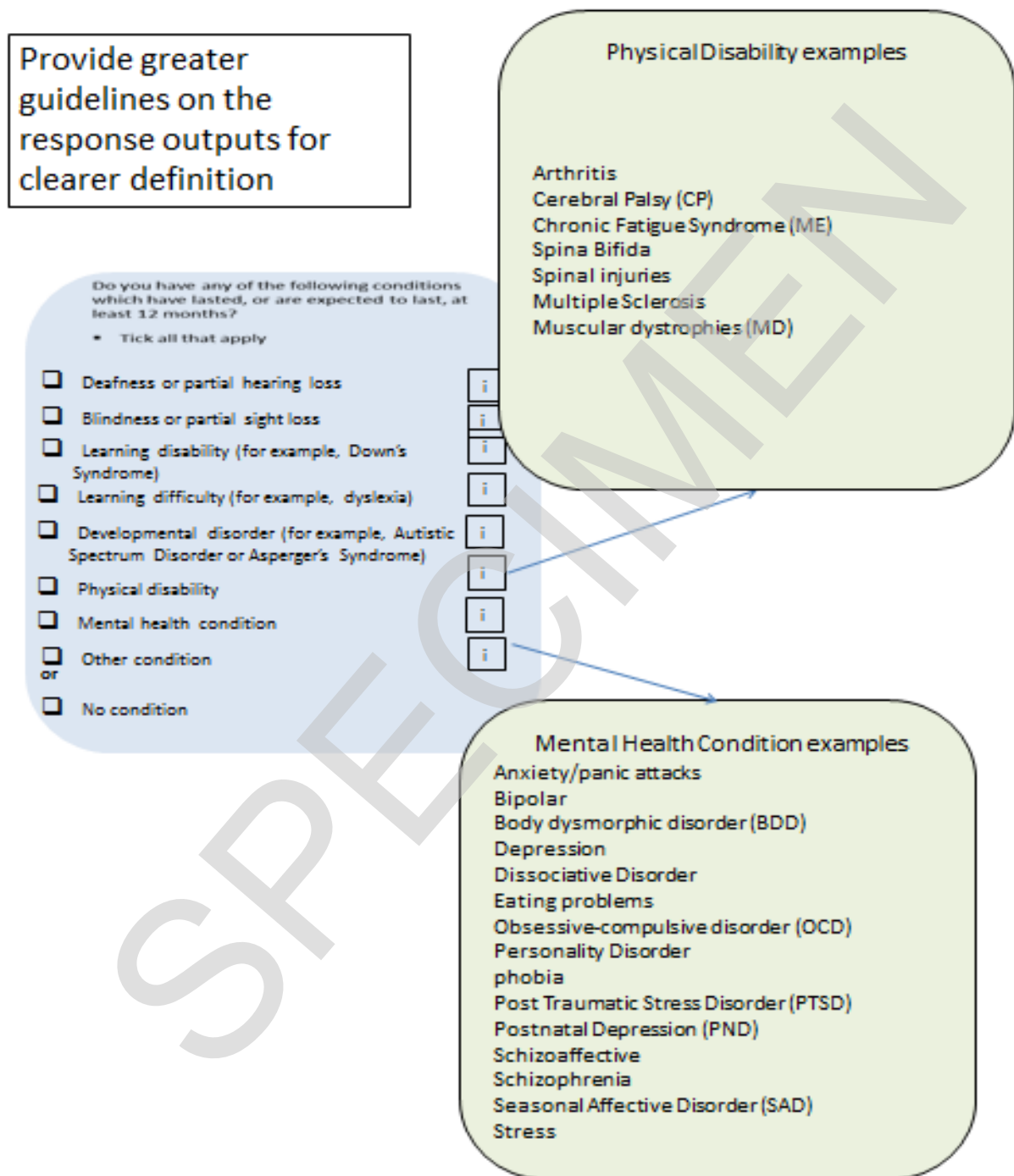**Figure 6: Alternative Long-term Health Conditions Question Option 5 – Online Only**

Provide greater guidelines on the response outputs for clearer definition

Physical Disability examples

Arthritis
Cerebral Palsy (CP)
Chronic Fatigue Syndrome (ME)
Spina Bifida
Spinal injuries
Multiple Sclerosis
Muscular dystrophies (MD)

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 ⓘ
☐ Other condition ⓘ

or

☐ No condition

Mental Health Condition examples
Anxiety/panic attacks
Bipolar
Body dysmorphic disorder (BDD)
Depression
Dissociative Disorder
Eating problems
Obsessive-compulsive disorder (OCD)
Personality Disorder
phobia
Post Traumatic Stress Disorder (PTSD)
Postnatal Depression (PND)
Schizoaffective
Schizophrenia
Seasonal Affective Disorder (SAD)
Stress

**Table 7: Alternative Question Option 5: Stakeholder Pros and Cons**

| Pros | Cons |
|------|------|
| • *"Removes clutter from option 4"* | |

6.7     Option 6: Online version of Option 1 with additional subcategory tick-boxes

This sixth option (Figure 7) is similar to Option 5 (Figure 6), but instead of being a pop up information screen, the detailed list of conditions or symptoms is a subcategory list of tick-box response options.

This option would fulfil the needs of the stakeholders who expressed a need for condition specific data to be available. However, this option would have a higher coding burden for NRS, and comparison with paper questionnaires would only be available at the high level response categories (the detailed responses would not be available for the whole population of Scotland).

The pros and cons identified by stakeholders at the Health and Care Topic Event for question Option 6 are listed in Table 8.

The majority of stakeholders were positive about the additional information that could be captured using Option 6, and expressed that they would make greater use of this data. In particular, organisations including Down's Syndrome Scotland, National Autistic Society, Scottish Commission for Learning Disability and Scottish Council on Deafness felt this would be useful in order to create better estimates of the numbers of children and adults in Scotland with certain conditions.

In addition, stakeholders agreed that the response categories were simpler, easier to use and easier to interpret, which may reduce respondent burden.

**Figure 7: Alternative Long-term Health Conditions Question Option 6 – Online Only**

Provide sub-outputs on the response outputs for clearer definition

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

❑ Other condition

or

❑ No condition

**Physical Disability**

Tick **ALL** that apply
❑ Arthritis
❑ Cerebral Palsy (CP)
❑ Chronic Fatigue Syndrome (ME)
❑ Spina Bifida
❑ Spinal injuries
❑ Multiple Sclerosis
❑ Muscular dystrophies (MD)
❑ Other

**Mental Health Condition examples**

Tick **ALL** that apply

❑ Anxiety/panic attacks
❑ Bipolar
❑ Body dysmorphic disorder (BDD)
❑ Depression
❑ Dissociative Disorder
❑ Eating problems
❑ Obsessive-compulsive disorder (OCD)
❑ Personality Disorder
❑ phobia
❑ Post Traumatic Stress Disorder (PTSD)
❑ Postnatal Depression (PND)
❑ Schizoaffective
❑ Schizophrenia
❑ Seasonal Affective Disorder (SAD)
❑ Stress
❑ Other

**Table 8: Alternative Question Option 6: Stakeholder Pros and Cons**

| Pro's | Con's |
|---|---|
| • *"Includes identification of conditions - makes data usable for stakeholder groups"*<br>• *"Looks less confusing than the longer list of symptoms"*<br>• *"Only want [condition] in one place – but careful thought about where they go"*<br>• *"Captures most people so will cut down on text responses"*<br>• *"Most viable option for data"*<br>• *"If expanding question, need 4 pillars of deafness question to be asked. Not enough room in 2011"* | • *"Careful thought needed for where conditions are placed"*<br>• *"Ideally want a write in box in each pop-up from an inclusion perspective"*<br>• *"Should include childhood mental health conditions"* |

6.8    Summary

This activity was met with a lot of enthusiasm and ideas to improve the question both for the Census team, the respondents and Stakeholders needs. Although there was not a final decision made on the day, it informed the Census team of any additional information need on the question and what did and did not work.

With this information, the census team were able to present four out of the six options at the Scottish Learning Disability Observatory Conference 2017 for additional stakeholder feedback.


## 7.    Next steps

NRS are continuing to engage with stakeholders in planning for Scotland's Census 2021. NRS will be updating users on progress as this process continues.

More information 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.