Office for National Statistics

ONS Census Transformation Programme

The 2021 Census

Assessment of initial user requirements on content for England and Wales

Health topic report

May 2016

Contents

1. Introduction

In June 2015 the Office for National Statistics (ONS) published the public consultation document 'The 2021 Census initial view on content for England and Wales'[1]. This discussed the initial views of ONS regarding the potential inclusion of current (2011) and additional topics in the 2021 Census. The public consultation was open from 4 June 2015 to 27 August 2015 and aimed to promote discussion and encourage the development of strong cases for topics users wanted to be included in the 2021 Census. The focus was on information required from the 2021 Census, not the detailed questions that could be asked on the questionnaire.

ONS received 1,095 responses to the consultation; 279 of these were from organisations and 816 were from individuals. Of all consultation respondents, 331 answered at least one question on the 'Health' topic.

There are two sub-topics within the 'Health' topic; general health and long-term illness or disability. Additionally, the user consultation generated a request by users to add three new sub-topics to the census in 2021. These were mental health, health conditions, and factors affecting health. These additional sub-topics have also been evaluated using the evaluation criteria.

Based on the evidence given by users, sub-topics were evaluated using the criteria detailed in the consultation document using a standardised method. The criteria are listed in table 1 below. The criteria largely reflect those used in the 2011 Census topic consultation and have undergone expert review within ONS and via the Census Advisory Groups for use in the 2021 Census topic consultation. More detail on the scoring methodology is available in section 2 of the document 'The 2021 Census - Assessment of initial user requirements on content for England & Wales: Response to consultation'[2].

[1] https://www.ons.gov.uk/census/censustransformationprogramme/consultations/the2021censusinitialviewoncontentforenglandandwales

[2] https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/assessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf

Table 1 Evaluation criteria

1. User requirement	2. Other consideration
• Purpose • Small geographies or populations • Alternative sources • Multivariate analysis • Comparability beyond England and Wales • Continuity with previous censuses	• Data quality • Public acceptability • Respondent burden • Financial concerns • Questionnaire mode
	3. Operational requirement • Maximising coverage or population bases • Coding of derived variables and adjustment for non-response • Routing and validation

This report provides ONS's updated view based on our evaluation of user responses against these evaluation criteria.

2. Background

The 2011 Census asked for information on general health, and long-term illness or disability.

General health is a self-assessment of a person's health-related well-being. It is a fundamental component of the healthy life expectancy summary measure of population health, which is used in the public health outcomes framework in England as a high level outcome indicator to monitor health improvement at local authority level and the inequality in health status between population sub-groups exposed to greater and lesser levels of deprivation. A question on general health was first included in the 2001 Census using a three point scale; but in the 2011 Census, the question was replaced with more detailed response categories using a five point scale[3].

Limitations in performing normal day-to-day activities, or activity restriction, is a measure of disability. A person is disabled under the Equality Act 2010 if he/she has a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on his/her ability to do normal daily activities.

- 'substantial' is more than minor or trivial, eg it takes much longer than it usually would to complete a daily task like getting dressed

- 'long-term' means 12 months or more

A question on long-term health problem associated with limitation in activity was first included in the 1991 Census and also collected in 2001; however, in the 2011 Census, the question differed by using three plain English response categories which reflected extent of limitation.

The topic consultation for the 2021 Census asked users about the current need for data about the extent of limitation of activities by long-term health conditions or illnesses in the light of the changes to public policy and to definitions of disabilty introduced by the Equality Act 2010.

This led to ONS's initial view on this topic, as published in the consultation document 'The 2021 Census: Initial view on content for England and Wales' being as shown in table 2 below.

[3] The five categories for general health in the 2011 Census were 'Very good', 'Good', 'Fair', 'Bad', 'Very Bad'

Table 2 Initial view of ONS

Sub-topic detail	Initial view	Collected in 2011?
General health	Collect	Yes
Long-term health problem or disability	Further information required	Yes
Mental health	N/A – proposed new sub-topic	No
Health conditions	N/A – proposed new sub-topic	No
Factors affecting health	N/A – proposed new sub-topic	No

3. Summary of consultation responses

Table 3 presents the number of responses by type of respondent and organisational sector. The organisations that responded to this topic are listed by sector in Annex A.

Table 3 Health - number of responses by type of respondent and organisational sector

Type of respondent	Total responses	
	N	% total responses
Individual	**178**	**54**
Organisation (all sectors)	**153**	**46**
Sector		% organisation responses
- Government department/public body	15	10
- Local authority	90	59
- Health organisation	4	3
- Housing	2	1
- Academic / research	8	5
- Charity and voluntary	17	11
- Commercial	7	5
- Genealogist/family historian	1	1
- Other	9	6
Total responses	**331**	**100**

Note: Percentages might not add to 100% due to rounding.
Note: An organisation may have submitted more than one response.

The quotes below are used to illustrate how respondents use information from the census about health. These provide additional context to the evaluation.

Respondents across government discussed the importance of having sound evidence to underpin health policy.

> **Department of Health (DH):** "*The Census offers unique and significant value in supporting a range of health organisations and a range of health-related purposes. The main value is in providing information for small areas or small sub-groups of the population, where those areas and populations are small enough to be meaningful to individual commissioners and providers of health and social care. That information is vital for the detailed planning of activities, by increasing knowledge about the composition and characteristics of the population. The value is increased through consistency over time and through comparability with national data*."

The provision of data on health and disability status at small area level enables inequalities to be assessed within local authorities and is used with other census topics. This is a useful extension to the evidence base to inform health policy on tackling inequalities in health through improving the health of all people, but focusing particularly on reducing inequalities for the poorest. Such data is not available from surveys.

> **Health Statistics User Group (HSUG):** "*Data on both general health and long-term conditions are widely used at small area level and there would a substantial impact on public health and research if the data on long term conditions were not collected in the 2021 Census. Information about health is used for a number of purposes. Levels of general health and long-term health problems or disabilities are both key metrics of the health of the population, at both a whole population level and for specific population sub-groups. The ability to look at the health of different population sub-groups (eg age/gender, ethnicity, employment status, educational levels, tenure types etc) is key to examining the level and scale of health inequalities within and between geographical areas within the UK."*

Joint Strategic Needs Assessment (JSNA) is a recurring process of assembling information about an area's health and social care needs using diverse information sources, multi-sectoral expertise and coordination of actions which aim to meet health needs efficiently and effectively, thereby improving health and reducing health inequality.

> **East Riding of Yorkshire Council:** "*We use both sub-topics in this section for small area analysis (such as LSOA and electoral ward level) as a way of highlighting areas of poor health and disability. This helps inform initiatives such as the Pharmaceutical Needs Assessment (PNA), JSNA and ongoing Public Health commissioning support work, in the form of profiles and other documents. At present we prefer to use census derived measures of health due to the completeness of the information, rather than those provided by the other smaller national surveys, such as Health Survey for England."*

Public Sector organisations are subject to a general Equality Duty and specific equality duties which cover the protected characteristics included under the Equality Act 2010.

Respondents told us about their duties under the Equality Act 2010.

> **Tower Hamlets Council:** "*Without detailed information on both topics (general health and long-term disability), the Council's ability to meet, and monitor its duties under the…2010 Equality Act would be significantly limited."*

> **East Riding of Yorkshire Council:** "*These areas are used to help the Council meet its duties under the Equality act 2010, especially with equality impact assessments. The information is also used as part of a wider look at the demographics of the East Riding and how access to services reflects these demographics."*

There were some suggestions for additional health sub-topics, including mental health, health conditions and factors affecting health.

4. Evaluation

The following sections show the scores allocated to each sub-topic by individual criterion based on the evidence given by users. The criteria largely reflect those used in 2011, but have undergone expert review within ONS and via the Census Advisory Groups. The document 'The 2021 Census - Assessment of initial user requirements on content for England and Wales: Response to consultation'[4] gives details on the scoring methodology including:

- 'user requirements criteria', including a description of relative weights, are described in section 2.1 of the document. Note that, in the following tables, the overall score is weighted and is not the sum of the scores for individual criteria

- 'other considerations' are described in section 2.2 of the document. These will predominately be used in conjunction with the user requirement score to steer the development of the census questionnaire and the production of administrative data research outputs

- 'operational requirements' are described in section 2.3, of the document. ONS has operational uses for some of the data collected in the census, of which the most important is maximising coverage of the 2021 Census. Each sub-topic is categorised as being of maximum, moderate or minimum importance in relation to operational requirements.

4.1 User requirements – general health

Table 4 User requirement score by criterion – general health

Criterion	Score	Evidence
Weighted Overall Score	**82.5**	**High user need**
Purpose	8	Central government use general health data for policy and informing resource allocation. The Department of Health (DH) told us that: *"Policy and operational work is likely to increase the need for such information over the coming decade. It is difficult to predict the precise way in which policies and operational practices will affect the demand for information over a time horizon of ten years. However, we can be sure that continued financial pressure will remain and that there will be a continued need to ensure financial allocations are as well-informed as they can be."* Department for Culture, Media and Sport (DCMS) said: *"DCMS has responsibility for organisations which deliver*

[4] https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/assessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf

		services to a range of individuals, including sport, arts and broadband delivery. Having an understanding of the health of individuals in local areas improves the ability to target services that are appropriate to the local community." General health data is used by local government to guide and support public health spending, resource allocation and planning, policy development, funding bids and JSNAs. Sandwell Public Health said: *"The health topic questions within the census have been used … as a basis for policy documents, strategies, funding bids and to direct service provision. The data informs the whole of the public health work stream and is used extensively within the work of the Health and Wellbeing Board and the Public Health lifestyle programme. Recently the census health data has specifically been utilised within the Joint Health and Wellbeing Strategy, Community Offer scheme and Better Care Fund, as well as within Joint Strategic Needs Assessments*..." Users from local government gave evidence that they used general health data for public health work. For example, Caerphilly County Borough Council told us that: *"Information on the health status of our residents is vital in ensuring that we understand the health issues that they are experiencing and enables us to target resources effectively."*
Small geographies or populations	9	Respondents stated a need for sufficiently small geographical areas (including OAs) to undertake general health profiling and service planning. The Department for Culture, Media and Sport (DCMS) said: *"Information about health for small geographies is required, in order to identify areas where more resources are required. This would enable resources to be allocated to specific areas based on 'general health' or 'long-term health and disability'. As many of these policies are delivered at a local level this is particularly important."* Evidence was given of a need for general health data for small geographies, based on the clustering of pockets of poor health. Gloucestershire County Council told us that: "*We look for small areas with poor health to target our Public Health outreach services, including health trainers, weight loss*

		on referrals, and NHS health checks." Evidence for general health data on small populations was also presented. The Equality and Human Rights Commission told us: "*The Commission's statutory remit requires us to carry out a review of equality and human rights in Great Britain every five years.* *Evidence papers prepared for the 2015 review make use of census data on general health within the health domain. Using census data has allowed us to measure the levels of bad health for small population groups, such as Gypsies and travellers."* Data for minority ethnic groups is also used to better understand their health service needs and inform service provision and equalities monitoring. Tower Hamlets Council said: "*The census is one of the few data sources that can provide detailed health information about the borough's different ethnic minority and migrant populations. We use this information to build profiles of different population groups to help understand need, and consequently, to inform commissioning and delivery of service. The information is also used to inform equalities monitoring on service access and take up, which enables the Council to monitor our obligations under the Equality Act 2010."*
Alternative sources	6	Respondents quoted a range of alternative sources, which overall lack the small geographical and small population detail that the census provides. Public Health Wales NHS Trust stated: *"Alternative sources include the LFS, the Welsh Health Survey and the National Survey for Wales. However, none of these can provide robust information at sub-local authority level."* Manchester City Council told us: *"ONS births and mortality data, ONS Vital Statistics (VS) tables, Hospital activity datasets (SUS), Disease registers data from primary care via Quality and Outcomes Framework (QOF). These data are used in combination with the Census in order to produce local area profiles and Health Needs Assessments etc. However none of the alternative sources of information provide a 'like for like' replacement for census data in terms of being able to assess patterns of poor general health and limiting long term illness/disability in small*

		geographic areas or for specific population groups." Cyngor Sir Ceredigion/Ceredigion County Council explained that: "*There are no other sources of information for this general health of the population against age and other data for small areas."*
Multivariate analysis	9	There was evidence of multivariate analysis with a wide range of topics to highlight health inequalities and guide service planning. Hywel Dda University Health Board told us that: *"We use the information produced by Public Health Wales along with other topics to demonstrate associations between health and other factors such as, proxies for income (e.g. NS-SEC, housing tenure, car ownership), housing, education, and ethnicity. This aids our understanding of variations in health, health inequalities and health needs. This in turn assists the health board with service planning, needs assessment and policy formulation."* Sheffield City Council discussed: *"Producing a more detailed profile (age, gender, ethnicity) of people based on health, and to identify possible inequalities (eg labour market) that might be an issue in the city."*
Comparability beyond England and Wales	9	Respondents stated that they compare across the countries of the UK with some evidence of international comparisons. The Health Statistics User Group (HSUG) said: *"It is important to have comparability across the UK for comparisons between countries of the UK and to produce UK data for international comparisons."* Manchester City Council stated: *"We have used census data as part of a piece of large scale research that is designed to explore the relationship between socio-economic circumstances and mortality across three comparable post-industrial UK cities, namely Manchester, Liverpool and Glasgow. We have also used census data as the basis for benchmarking health spending and outcomes in Manchester with that in other similarly sized areas or areas with similar population profiles."* Hywel Dda University Health Board told us that: *"There are only limited sources of directly comparable*

		information about health across UK nations. Comparison between nations and regions adds context and value to the analysis we produce. The health board can then use this to learn from others and share good practice."
Continuity with previous censuses	9	Comparing 2011 Census general health data with previous censuses allows monitoring of health inequalities which helps to inform future policy. For example, Manchester City Council said: *"We have used comparisons from previous censuses for health to help us evaluate change over time in order to make decisions about policy and monitor change against historic benchmarks in order to look at the success of area based interventions. The ability to look back several decades is important because of the delayed impact of some public health interventions on key health outcomes."* Tower Hamlets Council told us that: *"Trend data inform demand modelling work, allow us to evaluate progress on issues around health inequalities between groups, and help shape policy priorities*."
Weighted Overall Score	**82.5**	**High user need**

4.2 Other considerations – general health

Table 5 ONS assessment of impact by criterion – general health

Criterion	Operational impact	Justification
Impact on data quality	Medium	There were some concerns around data quality due to the subjective nature of the general health question. The response rate was 98.4% and agreement rate between the 2011 Census and the Census Quality Survey (CQS) was 68.2%. The CQS report identified potential reasons for disagreements between the CQS and the census - 'The 1999 CQS and testing of the 2011 questionnaire found that although respondents were able to understand the question, its subjective nature meant that the answer given depended on how the respondent felt at the time the question was asked. In addition it is possible that by the time of the CQS survey interview, respondents might have changed their perception of their health or could not remember how their health was at the time of the census. Social desirability bias[5] might also affect the CQS responses to this question as the respondent might not report the true answer to the interviewer as they might feel embarrassed or want to portray themselves in a particular way to the interviewer.'[6]
Impact on public acceptability	Low	A question on general health has been asked on the census since 2001. ONS does not anticipate any impact arising from public acceptability concerns.
Impact on respondent burden	Low	There was some demand for online help from people who responded online indicating that some respondents were unsure how to answer the question.
Impact on financial concerns	Low	The response to this sub-topic did not require manual coding or complex processing.
Impact on questionnaire mode	Low	This question displayed well online and on the 2011 Census paper questionnaire.

4.3 Operational requirements – general health

Minimum operational requirement

There is minimal census operational requirement to collect data on this sub-topic.

[5] ONS The application of alternative modes of data collection in UK Government social surveys: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/method-quality/general-methodology/data-collection-methodology/reports-and-publications/alternative-modes-of-data-collection/index.html

[6] http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/2011-census-user-guide/quality-and-methods/assessing-accuracy-of-responses--census-quality-survey-/index.html

4.4 User requirements – long-term health problem or disability

Table 6 User requirement score by criterion – long-term health problem or disability

Criterion	Score	Evidence
Weighted Overall Score	**87.5**	**High user need**
Purpose	9	Long-term health problem or disability data were used by central and local government to target areas and groups for public health spending, resource allocation and planning. The Department for Work and Pensions (DWP) told us: *"The census is the only data source which provides measures of local authority level long-term health condition and disability prevalence and local authority-level prevalence of sub-groups within this (eg. Black and Minority Ethnic disabled people). This data has been key in development of strategy related to health and disability employment, notably highlighting geographical variations and the need for localised policy/delivery responses tailored to the needs of local areas, as opposed to national… "* Welsh Government said: *"This is used in the Welsh Index of Multiple Deprivation as part of the health domain. If it were not available the health domain would only consist of low birth-weight and cancer incidence indicators therefore would not capture an overall indicator of limiting long-term illness or disability which applies to the whole population. This would lead to a weaker index of multiple deprivation and impact on the quality of decisions eg resource allocation."* Evidence from other organisations included for example, the Health Statistics User Group (HSUG) who told us: *"For the Public Health function the long term illness and disability question from the census provides local information for the JSNA and other Health Needs Assessment processes, to enable the measurement and monitoring of our vulnerable populations with a view to planning and commissioning appropriate services."*
Small geographies or	10	Respondents provided evidence of using long-term health problem data at output area level to feed into policy development

populations		and service planning. For example, the City of London Corporation said the data is: "*Utilised by aggregating Output Areas into zones which equate to housing estates eg Golden Lane and Barbican which are neighgouring estates of different population profiles. This enables policy development and services to be focused upon the relevant population characteristics of the estates."* Coventry City Council said: *"We have used this data recently to re-organise the geographical structure of Health Visitor Teams - placing more staff in areas where long-term health problems or disability is greater... Because there is no substitute indicator for long-term health problem or disability at small geographies, we would not be able to identify the extent of health inequalities in the City."* HR Wallingford, an independent civil engineering and environmental hydraulics organisation, from the commercial sector, told us: "*We use output areas because our target geography is 100 metre by 100 metre grid cells… If only a coarser geography was available we wouldn't be able to identify a small area with highly vulnerable residents that would benefit greatly from a flood defence scheme for example... In the calculation of flood risks to people, all residents would be treated equally in terms of mobility. So flood risk strategies couldn't take into account that particular vulnerability."* The Department for Work and Pensions (DWP) said: "*The census is the only data source which provides measures of local authority-level long-term health condition and disability prevalence and local authority-level prevalence of sub-groups within this (e.g. Black and Minority Ethnic disabled people). ...it is likely we will be developing further trials to test approaches to help reduce the risk of people with long term health conditions or disabilities falling out of work and/or remaining out of work…. The risk of not having the census data is that trials may not be able to account for local variations, thereby reducing their ability to consider the role/impacts of geographical variations in determining which policy or delivery initiatives do/do not work."*
Alternative sources	6	Alternative sources identified do not generally provide data for small geographies and small populations. Welsh Government said:

		"*Health and Disability data are available from the Welsh Health Survey, National Survey for Wales as well as from other surveys such as the Annual Population Survey. However they only provide robust estimates at local authority level, do not provide small area data nor the ability to analyse data for small population groups.*" Kent County Council stated: "*We look at data from the Annual Population Survey about disability but this only covers part of the population and as a sample survey does not give us an accurate picture, particularly at district level and data is not available at any lower geographical level. We use benefits data from the DWP and while data is available to LSOA level the variables are limited at smaller geographies and the claimant data can only show us those people who meet the health criteria set for each benefit. It is therefore only a partial count of people with health problems or disability.*" Haringey Council told us that: "*We use benefit claimant data but that doesn't include the people with disabilities and do not claim.*"
Multivariate analysis	9	Central and local government users use long term health problem and disability data with a wide range of sub-topics to identify and understand associations to inform service planning and delivery. The Department for Work and Pensions (DWP) said: "*We have used information about long-term health problems or disability alongside information relating to employment, general health, education, transport, social care, income and demographics. This is part of understanding the drivers of health disability and employment outcomes…*" Coventry City Council told us that: "*… we are able to see differentials in long-term health problem or disability vs Country of Birth and create specific services appropriate for people born in those places. This supports our ability to ensure we meet the Authority's duties under the the Equality Act 2010.*"
Comparability beyond England and Wales	9	Respondents from local authorities stated that they compare long term health problem data across the countries of the UK. For example, Swansea Council told us:

		"To ensure that detailed information on health within communities, and health-related deprivation, is available on a consistent basis from local to national levels within the UK. For benchmarking local data to national levels / averages, together with enabling comparisons with other local authorities in Wales and similar UK LAs. This analysis all ultimately contributes to local service planning and resource allocation."
Continuity with previous censuses	9	Comparisons with previous censuses were made to assess whether areas were in need of targeting if the number of people there reported a long-term health problem or disability. For example, the London Borough of Hackney stated: "*Comparisons have been used to examine trends in general health and also in disability, this informs decisions about funding and policy. Consistency in definition and method means that this data is particularly useful for looking at long term trends"* This evidence highlights the requirement in continuity over time as a result of the time lag between intervention and public health outcome. Manchester City Council said: "*We have used comparisons from previous censuses for Health to help us evaluate change over time in order to make decisions about policy and monitor change against historic benchmarks in order to look at the success of area based interventions. The ability to look back several decades is important because of the delayed impact of some public health interventions on key health outcomes."*
Weighted Overall Score	**87.5**	**High user need**

4.5 Other considerations – long-term health problem or disability

Table 7 ONS assessment of impact by criterion – long-term health problem or disability

Criterion	Operational impact	Justification
Impact on data quality	Low	There were some concerns around data quality due to low rates of agreement with the Census Quality Survey (CQS). The response rate was 96.8 per cent and agreement rate between the 2011 Census and the CQS was 88.9 per cent. The CQS report[7] identified potential reasons for disagreements between the CQS and the census - 'The 1999 CQS and testing of the 2011 questionnaire found that although respondents were able to understand the question, they interpreted it differently depending on how the respondent felt at the time the question was asked, meaning there was a degree of subjectivity involved. Another reason for differences might be recall as it is possible that by the time of the CQS interview, respondents" perception of their health had changed.'
Impact on public acceptability	Low	A question on long-term health problem or disability has been asked on the census since 1991. ONS does not anticipate any impact arising from public acceptability concerns.
Impact on respondent burden	Medium	The respondent had to read a long question on long term health problem or disability with an additional instruction.
Impact on financial concerns	Low	The response to this sub-topic did not require manual coding or complex processing.
Impact on questionnaire mode	Low	This question displayed well online and on the paper questionnaire.

4.6 Operational requirements – long-term health problem or disability

Minimum operational requirement

There is minimal census operational requirement to collect data on this sub-topic.

[7] http://webarchive.nationalarchives.gov.uk/20160105160709/http:/ons.gov.uk/ons/guide-method/census/2011/census-data/2011-census-user-guide/quality-and-methods/assessing-accuracy-of-responses--census-quality-survey-/index.html

4.7 User requirements – mental health

Requests were received for additional data on mental health conditions, both from respondents working in mental health, and from those who wish to use it as an indicator of social isolation. These responses were evaluated to see if there was a case for their inclusion in the 2021 Census. Questions on health conditions were included in both Scotland and Northern Ireland in the 2011 Census , which included an option for mental health conditions (described in the Northern Irish census as "an emotional, psychological or mental health condition (such as depression or schizophrenia)").

Table 8 User requirement score by criterion – mental health

Criterion	Score	Evidence
Weighted Overall Score	**55**	**Low user need**
Purpose	7	There was evidence that mental health data are needed for local government resource allocation and non-governmental service planning. The Mental Health Foundation said: *"If a strong standalone question on mental health was included in the 2021 census, we could assess changes over time and seek whether other determinants are correlated with mental health, which would be invaluable information for the development of public policy and to identify areas where more research needs to take place."* The London Borough of Havering told us: *"...Councils have a statutory obligation to provide services for people with a physical disability, learning disability or mental health need. These vulnerable groups are often socially isolated within their communities and it is not until they have reached breaking point that they access our services. Without accurate information on social isolation, our services are only able to provide reactive safeguarding interventions. The Council also has specific duties to provide appropriate housing and leisure facilities, by not being able to identify those in the borough who are socially isolated we are unable to ensure that the needs of our residents are best met- for examples that sufficient provision is made for leisure in a certain ward where social isolation is high."*
Small geographies or populations	7	Respondents told us that they needed mental health data at borough and ward level. For example: The London Borough of Havering said: *"We would need our topic broken down into wards so that*

		more targeted resourcing can be done by our local authority. This would also allow us to analyse any arising trends between ward deprivation, demographics and social isolation which would inform our commissioning strategies." Respondents explained the importance of mental health data by ethnic group and armed forces veterans. For example, the consolidated response from The Royal British Legion, ABF The Soldier's Charity, Blesma The Limbless Veterans, Forces in Mind Trust, Help for Heroes, RAF Benevolent Fund, and SSAFA told us: "*The NHS currently has ten centres of excellence in Armed Forces mental health around the country, whether these centres are located in the right areas is crucial as to whether they are effective and a credible intervention into tackling need. … Rates of Post Traumatic Stress Disorder (PTSD) amongst the veteran community remain roughly comparable with the general population…, however there is an increased risk amongst sub sets of the population such as reservists and those who have seen active combat. It is vital that effective commissioning recognises the unique scale and nature of the local ex-service community's profile. The accurate population data that the 2021 Census can provide will therefore be invaluable in strategic planning and assessments."*
Alternative sources	5	Respondents told us about survey and administrative data sources that only partially meet their needs. Mental Health Foundation explained: "*In England, we can use the psychiatric morbidity survey gathers information on the populations mental health, but because it doesn't capture information on the other areas captured in the census…it does not give a sufficient picture of the positive and negative determinants of mental health. However in Wales, there is not alternative source of information, as the psychiatric morbidity survey is no longer collected here..."* The Health Statistics User Group (HSUG) stated: " *It can be indirectly estimated for example from prescribing data although not all medication for mental health issues is used for this purpose (ie some are also used in pain management) and not all people with mental health issues access the medical services or use medication. It can be directly estimated from sample surveys, but not at the population level."*

Multivariate analysis	5	Respondents gave evidence of a need for the ability to undertake multivariate analysis with mental health data in order to explore outcomes for specific groups and target future interventions appropriately. Mental Health Foundation told us that: "*As an organisation, we focus on prevention by targeting the social determinants of health. This involves looking for trends involving poor mental health and education, income, sex, ethnicity and other determinants of health*."
Comparability beyond England and Wales	5	Respondents told us about the importance of UK wide comparability in order to monitor outcomes. For example, the Mental Health Foundation told us: "*Our organisation covers England, N.Ireland, Scotland and Wales so it is important for information on mental health and wellbeing be captured in all nations so we can compare results and follow positive and negative national trends*." the Health Statistics User Group (HSUG) stated: "*It is important to have comparability across the UK for comparisons between countries of the UK and to produce UK data for international comparisons. Owing to the increasing interest in wellbeing and mental health the introduction of a question on mental health is important. A question was introduced for both Scotland and Northern Ireland in the 2011 Census"*
Continuity with previous censuses	0	Since information on mental health has not been collected on the census no comparisons with previous censuses would be possible if a question was to be included in the 2021 Census.
Weighted Overall Score	**55**	**Low user need**

4.8 Other considerations and operational requirements – mental health

Questions on this sub-topic were not asked in the 2011 Census, therefore there are no 2011 Census data to assess against the ONS considerations evaluation criteria and no operational requirement to collect this information. If development of questions on this sub-topic were to be taken forward, ONS would integrate consideration of these criteria into the development process.

4.9 User requirements – health conditions

Respondents requested additional sub-topics related to a range of health conditions and/or disability types. These were scored collectively to determine whether there was a case for their inclusion in the 2021 Census.

Table 9 User requirement score by criterion – health conditions

Criterion	Score	Evidence
Weighted Overall Score	**52**	**Low user need**
Purpose	6	There was evidence of a need for health conditions data by government and non-government organisations. The Older People's Commissioner for Wales said: *"…Ensuring that the Census reflects the key issues for older people… is important in measuring progress, and how services are addressing some of the key generational challenges facing older people in Wales, such as dementia, falls prevention and lonelienss and social isolation. Data and evidence of this kind will help determine whether we are moving towards an outcomes-focused approach supported by the integration and prevention agendas."* Habinteg Housing Association told us that: *"A question which determined whether anyone in the household used a wheelchair could produce an important source of information about wheelchair user numbers based on a cross-population sample….The data would be useful for planning housing and other aspects of the built environment as well as supporting the development of evidence-based policy by a wide range of service providers and others, employment providers and others."* The charity, Marie Curie stated: "*Currently we have no data on how many people regard themselves as living with a terminal illness. This might, of course, be very different from the number who actually are living with a terminal illness. Knowing the numbers of people who think they are living with a terminal illness would enable us to plan use of resources better, better inform what resources are needed and enable us to see where the greater weight of support is needed."*
Small geographies or populations	7	Local authorities gave examples of using census data to underpin analysis on the variation of certain health conditions between small areas. For example,

		Warrington Borough Council stated: "*We calculate many health statistics, including … prevalence of various lifestyle behaviours, prevalence of various diseases/conditions, and many other measures. From this we can compare one geographical area with another in order to target interventions and services, and to identify which are the areas with greatest need on which to focus limited resources. NB We look at many health issues at a ward level*." Royal Borough of Kingston upon Thames said: *" One project set up to deliver Kingston's Dementia Strategy 2015-20 used census indicators including age and gender (in combination with ethnicity and the provision of unpaid care) at LSOA and LA levels to estimate the geographical spread of older people and the profile of carers caring for dementia patients in Kingston and to monitor the project's coverage"* There was evidence for small populations data on health conditions for housing and building planning. For example, Habinteg Housing Association said that: "*A question which determined whether anyone in the household used a wheelchair could produce an important source of information about wheelchair user numbers based on a cross-population sample. This result would be more robust than current sources. Although the population of wheelchair users would be much smaller than the number of disabled people as a whole, it is, on the other hand, a precise question capable of producing very useful data. The data would be useful for planning housing and other aspects of the built environment as well as supporting the development of evidence-based policy by a wide range of service providers and others, employment providers and others*."
Alternative sources	5	There is evidence that alternative sources (including administrative data) exist. Marie Curie said: "*Currently we have no data on how many people regard themselves as living with a terminal illness... a wide range of health episode data, surveys such as VOICES, individual pieces of academic research, international data on outcomes etc."* Local authorities sometimes use online tools combining information from multiple sources to estimate prevelance of health conditions.

		Shropshire Council Intelligence and Research Team stated: *"Websites such as POPPI and PANSI[8] are frequently used by commissioners as they hold the sub-national population projections and use them as a basis for estimating key vulnerable population groups (i.e. learning disability / dementia)"*
Multivariate analysis	5	Respondents gave evidence on the use of health conditions data for multivariate analysis. A charity, Health Deafinitions, stated that they would analyse health conditions of those stating their main language as British Sign Language (BSL): "*Due to the differential incidence and prevalence of health conditions among D/deaf people, locally and regionally in South Yorkshire it would be helpful to have accurate numbers of BSL users. This would enable us to correlate BSL users with different health conditions, in different localities, and according to differences in age, sex, ethnicity, and other characteristics. This information would, in turn, allow us to identify the different needs of D/deaf people, the need for targeted interventions, and the kinds of information that we could/should prepare for D/deaf people to meet their needs for accessible information.* " Marie Curie said: *"matching the new data on terminal illness with topics such as household income/sex/sexual identity/numbers of people in a household/caring etc."*
Comparability beyond England and Wales	5	Users provided us with limited evidence of the need for UK comparability. Habinteg Housing Association stated: *"By having comparable information for the UK and similar socio-economic policy makers would be able to assess the impact of different kinds of housing and design standards on different populations of disabled people, specifically (in this case) wheelchair users."*
Continuity with previous censuses	0	Since information on health conditions has not been collected previously on the census no comparisons would be possible were a question to be included in the 2021 Census.
Weighted Overall Score	**52**	**Low user need**

[8] Projecting Older People Population Information (POPPI - http://www.poppi.org.uk/) and Protecting Adult Needs and Service Information (PANSI - http://www.pansi.org.uk/)

4.10 Other considerations and operational requirements – health conditions

Questions on this sub-topic were not asked in the 2011 Census, therefore there are no 2011 Census data to assess against the ONS considerations evaluation criteria and no operational requirement to collect this information. If development of questions on this sub-topic were to be taken forward, ONS would integrate consideration of these criteria into the development process.

4.11 User requirements – factors affecting health

Requests for this sub-topic covered a range of factors that affect health – obesity, smoking and exercise as well as general wellbeing. In the past these have sometimes been modelled from censuses using data from social surveys. They have not, however, been previously collected through a combined single question on a UK census.

Table 10 User needs scores by criterion – factors affecting health

Criterion	Score	Evidence
Weighted Overall Score	**50.5**	**Low user need.**
Purpose	7	The evidence provided outlined the use of data on factors affecting health to inform central government spend and also to inform local government resource allocation and service planning. For example, the Department for Culture, Media and Sport (DCMS) said: *"Obesity is an issue that is becoming increasingly problematic in the UK and a lack of action will have huge consequences for costs for the health and wellbeing of the nation and the NHS budget. A lack of data means it is difficult to deliver policies in the areas which most need them, including healthy eating campaigns, encouraging people to get more active and preparing health services for the impact of higher levels of obesity and the related issues that leads to."* An individual, Stephen Patterson, told us that: *"Smoking is one of the major public health problems nationally… Data on smoking from the Census would enhance the data used at present to support existing anti-smoking interventions and would probably make those interventions more effective..."* Department of Health requested: "*information on key behavioural determinants of health such as smoking, which has been raised by the Advisory Committee on Resource Allocation as having significant potential value."*

Small geographies or populations	5	Users gave evidence of a need for data on factors affecting health at small geographic level to target interventions. DCMS told us that: "*Currently, DCMS does not use information on obesity at small geographies as there are no suitable data sources. If a question on obesity was included in the 2021 Census, it would enable identification of obesity at small geographies. This could then help to inform policy delivery (including sport delivery by DCMS and ALBs) and resource allocation (particularly for NHS), to ensure that the areas that require support can receive it."* An individual, Stephen Patterson, also said: " *A lot of data on smoking are available in the Public Health England Tobacco Control Profiles. However, the lowest level at which these data are available is local authority district. There is a need for data of good quality on prevalence of smoking at small-area level in England and Wales. These data would be used in describing the health of the local population and for targeting anti-smoking interventions."*
Alternative sources	6	There was evidence that surveys and other alternative sources exist but do not meet user need as they are not available at the small geography level needed by users. The Department for Culture, Media and Sport (DCMS) told us: "*Without information from the census, Health Survey England provides the best alternative source of information. The impact of using this source rather than the census is that it cannot provide the information at small geographies and therefore is unable to support the provision of services at that level."*
Multivariate analysis	5	Respondents told us that they needed to undertake multivariate analysis with the data. DCMS said: "*If a question about obesity is included in the 2021 Census, it could be used alongside many other topics to understand the characteristics of this group of the population and therefore support targeting and appropriate measures for specific groups. Causes of obesity are likely to vary depending on a number of factors which would be seen from census responses (e.g. employment, education, disability, age)."*

		An individual, Stephen Patterson, said: *"Studies of smoking prevalence usually describe variations by age, sex, ethnic group and social class."*
Comparability beyond England and Wales	3	There was limited evidence of use at UK level, with some reference to regional/national comparsion. The Department for Culture, Media and Sport (DCMS) said: "*The majority of health and sport policy are devolved, therefore while comparability would be beneficial it is not essential."*
Continuity with previous censuses	0	Since information on factors affecting health has not been collected on the census no comparisons would be possible were a question to be included in the 2021 Census.
Weighted Overall Score	**50.5**	**Low user need.**

4.12 Other considerations and operational requirements – factors affecting health

Questions on this sub-topic were not asked in the 2011 Census, therefore there are no 2011 Census data to assess against the ONS considerations evaluation criteria and no operational requirement to collect this information. If development of questions on this sub-topic were to be taken forward, ONS would integrate consideration of these criteria into the development process.

5. Updated view

The following tables give the updated views of ONS at the sub-topic level and the justification for these.

Table 11 Updated View

Sub-topic Detail	Initial View	Updated View	Justification
General health	Collect	Collect	The consultation showed that users in central and local government and working in public health need to measure the general level of public health in their specific areas and how it varies across socio-demographic groups and geographical areas. It is important for local strategies, especially Joint Strategic Needs Assessments (JSNAs), and also for specific health improvement actions. Users gave clear evidence of using the data to the smallest geographic levels, in combination with other census sub-topics, in comparison with other parts of the UK, and over time. Concerns surrounding operational impact are generally low.
Long-term health problem or disability	Further information required	Collect	Evidence from the consultation showed that users in central government, local government and health organisations use data on long-term health problems and disabilities. Data are important for local strategies, especially Joint Strategic Needs Assessments (JSNAs), and also for specific interventions. Users gave clear evidence of using the data to the smallest geographic levels, in combination with other census sub-topics, in comparison with other parts of the UK, and over time. Concerns surrounding operational impact are generally low.
Mental health	N/A	Do not collect	Respondents provided evidence of potential use for local government resource allocation and non-governmental service planning. However, user need is not sufficient to include ahead of other topics.
Health conditions	N/A	Do not collect	Respondents gave evidence of potential use for non-governmental service planning and/or policy monitoring. However, user need is not sufficient to include ahead of other topics.
Factors affecting health	N/A	Do not collect	Respondents provided evidence of potential use for supporting central government spend and local government resource allocation and service planning. However, user need is not sufficient to include ahead of other topics.

6. Equality implications of ONS's updated view

The Equality Act 2010 and associated public sector equality duty require public bodies to work towards eliminating discrimination and promoting equality of opportunity with regard to nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. These requirements are reinforced by secondary legislation in both England and Wales[9] as well as by the Equality Objectives published recently by the Welsh Government which seek to address the key equality challenges faced in Wales and to support progress towards the well-being goals in the Well-being of Future Generations (Wales) Act 2015.

The proposals made for the 2021 Census content will consider identified 'User requirements' for data alongside other factors such as 'Other considerations' and 'Operational requirements' specified in our evaluation criteria. In addition, it will be important to take account of the impact of any decisions that we may make on equality. Impacts can be:

- positive - actively promote equality of opportunity for one or more groups, or improve equal opportunities/relations between groups
- adverse or negative - cause disadvantage or exclusion (any such impact must be justified, eliminated, minimised or counter-balanced by other measures)
- neutral - have no notable consequences for any group

Collection of information about general health will continue in the 2021 Census and the question is expected to remain unchanged. Poor health is thought to correlate with a number of protected characteristics, such as age, sex, and race/ethnicity, and can therefore be used by public bodies for equalities monitoring. ONS will work to maintain the quality of data on this sub-topic, to allow this function to continue.

The continued inclusion of a disability question in the 2011 Census helped enable organisations to fulfil the requirements of the public sector Equality Duty, contained within the Equality Act 2010, by providing information on this protected characteristic. It was intended that the outputs from the disability question asked on the 2011 Census would enable benchmarking with other official disability datasets and that the development of the questions would assist ONS, the Office for Disibility Issues (ODI) and UK government departments to agree on a harmonised definition of disability that could be applied in key administrative and survey data sources. Outputs from disability data that identified social barriers would help organisations in all business sectors to remove or minimise the impact of the barriers. The disability question would provide data about the needs and requirements of disabled people in diverse communities and across age groups. Responses to the consultation confirmed that census data on disability has been used for these purposes.

The next steps for this topic, discussed below, take into account the identified equality implications. As research and stakeholder engagement continues, if further equality implications emerge, these will be considered and mitigated where necessary.

[9] *The Equality Act 2010 (Specific Duties) Regulations 2011 and The Equality Act 2010 (Statutory Duties) (Wales) Regulations 2011.*

7. Next steps

For the 2021 Census, ONS does not intend to change the questions on the 'Health' topic. ONS intends to continue to measure disability in line with national guidelines, currently set by the Equalities Act 2010. However, there is scope to review question guidance, formats or their exact wording in order to improve data quality or reduce the burden placed on respondents.

These activities will be sufficiently progressed to provide a clear proposal for the 2021 Census questionnaire which will be included in the Census White Paper in 2018 before the questions are submitted to Parliament for approval in 2019.

Annex A: List of organisations that responded, by sector

This list includes organisations that responded to at least one consultation question, or discussed collection of data, on the 'Health' topic. If multiple responses were received from an organisation the name only appears once.

Government department/public body

College of Arms
Department for Communities and Local Government (DCLG)
Department for Culture, Media and Sport (DCMS)
Department for Environment, Food and Rural Affairs (DEFRA)
Department for Transport (DfT)
Department for Work and Pensions (DWP)
Department of Health (DH)
Equality and Human Rights Commission (EHRC)
Health & Social Care Information Centre (HSCIC)
High Speed Two Limited
National Assembly for Wales
Office for National Statistics (ONS)
Sport England
Welsh Government

Local authority

Arun District Council
Association of North East Councils
Aylesbury Vale District Council
Barnsley Metropolitan Borough Council
Bedford Borough Council
Birmingham City Council
Blaby District Council
Blackburn with Darwen Borough Council
Blackpool Council
Bolton Council
Bournemouth Borough Council
Brent Council
Bristol City Council
Bury Metropolitan Borough Council
Caerphilly County Borough Council
Carmarthenshire County Council
Cheshire East Council
Cheshire West and Chester
Chesterfield Borough Council
City of Bradford Metropolitan District Council
City of London Corporation
Colchester Borough Council

Cornwall Council
Coventry City Council
Cumbria County Council
Cyngor Sir Ceredigion/Ceredigion County Council
Derbyshire County Council
Devon County Council - Public Health
Dudley Metropolitan Borough Council
Durham County Council
East Riding of Yorkshire Council
East Sussex County Council
Essex County Council
Gateshead Council
Gedling Borough Council
Gloucestershire County Council
Greater London Authority
Gwynedd Council
Haringey Council
Hertfordshire County Council
Horsham District Council
Kent County Council
Knowsley Metropolitan Borough Council
Lancashire County Council
London Borough of Bexley
London Borough of Camden
London Borough of Hackney
London Borough of Harrow
London Borough of Havering
London Borough of Hounslow
Manchester City Council
Merton Council
Mole Valley District Council
Newcastle City Council
North York Moors National Park Authority
North Yorkshire County Council
Northampton Borough Council
Northumberland County Council
Oldham Council
Oxfordshire County Council
Powys County Council
Reigate & Banstead Borough Council
Royal Borough of Kensington and Chelsea
Royal Borough of Kingston upon Thames
Salford City Council
Sandwell Public Health
Sheffield City Council

Shropshire Council – Intelligence and Research Team
Snowdonia National Park
Somerset County Council
South Norfolk District Council
Southend-on-Sea Borough Council
St Helens Council
Suffolk County Council
Surrey County Council
Swansea Council
Tameside Council
Tower Hamlets Council
Uttlesford District Council
Walsall Council
Waltham Forest Council
Warrington Borough Council
Warwickshire Observatory
West Suffolk Councils - St Edmundsbury Borough Council and Forest Heath District Council
Westminster City Council
Wookey Parish Council
Worcestershire County Council
Wychavon District Council
Wycombe District Council

Health organisation
Cardiff and Vale University Health Board
Hywel Dda University Health Board
Public Health Wales National Health Service Trust
West Midlands Public Health Information Group

Housing
Habinteg Housing Association
Yarlington Housing Group

Academic/research
British Sociological Association
Centre for Longitudinal Study Information and User Support (CeLSIUS)
Economic History Society
Economic Social Research Council (ESRC) & Medical Research Council (MRC)
Gloucestershire House Histories
Imperial College London – Small Area Health Statistics Unit
Leeds Beckett University – Institute for Health and Wellbeing - Centre for Men's Health
University of York - Centre for Housing Policy

Charity and voluntary
Cardiff Cycling Campaign

Chwarae Teg
Discrimination Law Association
Family and Childcare Trust
Friends, Families and Travellers
Irish in Britain
Marie Curie
Mental Health Foundation
Muslim Council of Britain
National Association of British Arabs
Older Lesbian, Gay, Bisexual and Trans Association (OLGA)
Royal Town Planning Institute
Shelter
The Royal British Legion
The Salvation Army
The Vegan Society
Consolidated response: The Royal British Legion, ABF The Soldier's Charity, Blesma The Limbless Veterans, Forces in Mind Trust, Help for Heroes, RAF Benevolent Fund, and SSAFA

Commercial
CACI Ltd
Demographics User Group (DUG)
First UK Bus
HR Wallingford
Infusion Research
Operational Research in Health Ltd (ORH Ltd)
Sainsbury's

Genealogist/family historian
Tasmanian Family History Society Inc.

Other
Academy of Social Sciences
Emergency Planning Society - West Midlands Branch
Health Statistics User Group (HSUG)
Market Research Society (MRS) and MRS Census & Geodemographics Group
New Economy
Older People's Commissioner for Wales
Royal Geographical Society with the Institute of British Geographers (IBG)
Spaced
Tees Valley Unlimited

RPT 15 TPC