



# ONS Census Transformation Programme

The 2021 Census

Assessment of initial user requirements on content for England and Wales

Carers topic report

May 2016

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## 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'. 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 262 answered at least one question on the 'Carers' topic.

The carers topic has a single sub-topic, 'amount of unpaid care provided'.

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'<sup>2</sup>.

#### Table 1 Evaluation criteria

#### 1. User requirement

- Purpose
- Small geographies or populations
- · Alternative sources
- Multivariate analysis
- Comparability beyond England and Wales
- Continuity with previous censuses

#### 2. Other consideration

- 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.

<sup>&</sup>lt;sup>1</sup> https://www.ons.gov.uk/census/censustransformationprogramme/consultations/ the2021censusinitialviewoncontentforenglandandwales

<sup>&</sup>lt;sup>2</sup> <a href="https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/gasessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf">https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/gasessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf</a>

## 2. Background

In the 2011 Census we defined a person as a provider of unpaid care if they looked after or gave any help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. This sub-topic was first collected in the 2001 Census and then again in 2011, enabling users to look at the increases in the 'carer' population, and its implications for specific groups such as young carers aged 5 to 17.

Since the 2011 Census, the Care Act 2014 has come into force in England. This legislation requires local authorities to assess support needs of carers if the person they are caring for lives in that local authority. In Wales, The Social Services and Well-being (Wales) Act 2014 also requires local authorities to look at and assess the needs of carers. ONS therefore asked 'unpaid care' data users to help us understand changing requirements for data, in light of this new legislation.

The ONS' initial view on 'amount of unpaid care provided', as published in the consultation document 'The 2021 Census: Initial view on content for England and Wales' is shown in table 2 below.

Table 2 Initial view of ONS

Topic detail	Initial view	Collected in 2011?
Amount of unpaid care provided	Collect	Yes

## 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 Carers topic - number of responses by type of respondent

Type of respondent	Total responses	
	N	% total responses
Individual	152	58
Organisation (all sectors)	110	42
Sector - Government department/public body - Local authority - Health organisation - Housing - Academic / research - Charity and voluntary - Commercial - Genealogist/family historian - Other	9 71 3 1 4 13 3 1 5	% organisation responses 8 65 3 1 4 12 3 1
Total responses	262	100

Note: Percentages might not add to 100% due to rounding.

Note: An organisation may have submitted more than one response.

The provision of unpaid care is subject to national-level policies, and carers are eligible in some cases to receive particular benefits and services. Central government users therefore make use of the census data on this topic.

**Department of Health (DH):** "Similarly, unpaid care makes a vital contribution to the health and wellbeing of the nation. There is a need to plan for adequate support to carers. The information is not only important for resource allocation, service design and planning, but also for inequalities analysis."

**Welsh Government:** "We assign funding to support the implementation of the Carers Strategy Measure (Wales) 2010. Knowing the number of carers in the total population has enabled us to bid for future additional funding to support transition from the measure to the Social Services and Well-being (Wales) Act 2014."

Respondents giving examples of how carers' data are used predominantly came from local authorities. They highlighted two key kinds of activities:

Firstly using census data to underpin long-term strategies and plans, especially Joint Strategic Needs Assessments (JSNAs). For example:

**Oldham Council:** "Carers data will typically be used at a high level to inform funding and strategy of our services for carers, and at a small area level to look at service need locally, and plan local provision. It will form part of our JSNA and be important in the decision-making of our health and well-being board, and our public health team."

Secondly, a number of local authority respondents highlighted the services that they provide to unpaid carers, and in particular to understand the numbers of carers who may be eligible to receive an assessment under the new legislation.

**Tower Hamlets Council:** "Going forward, these data will become even more important given the Council's new duties under the 2014 Care Act. From 2015, the Council has a legal duty to support carers so Census data will be central to informing assessments of future demand for services, and the anticipated increase in demand for carer assessments."

**East Riding of Yorkshire Council:** "Our support ranges from Carer Relief services, Emergency Cover; short breaks and other social and practical hands on support (e.g. a range of Activity groups; gardeners; home cleaning services; Passport to Leisure services etc) that will enable a carer to continue in their caring role and have a good quality of life themselves."

A number of respondents discussed the difficulty in measuring a phenomenon which is widespread and largely invisible to local authorities.

**Caerphilly County Borough Council:** "This information is important as unpaid carers are often invisible within the general population. The Census is the only available source for this information. It is used to identify young people who may be providing care for parents or siblings, which may mean that they have additional needs. It is also used to identify adults who may be providing care for elderly parents or other relatives, to ensure that services are available such as respite etc."

While there were few concerns raised with the data quality of this sub-topic, several respondents requested questions to measure other aspects of caring, in addition to the amount of unpaid care provided. Two English local authorities put forward a case that they would be better able to meet the provisions of the Care Act if census data showed what kind of relationships existed between carers and care recipients:

**Cornwall Council:** "The Care Act brings with it enhanced local and national government responsibilities for carers. The census data helps in the identification of carers and where the Council may not be meeting its duties. Given the enhanced responsibilities it would also be helpful if the Carers question could be broken down and separated between neighbours and friends and family; the former of which is more likely to be voluntary."

**London Borough of Hackney:** "This information is also used to inform provisions within the Care Act and our responsibility to assess the support needs of carers. Additional information on whether the person the carer is caring for within the LA, and whether the care is provided through a voluntary organisation (linking with the proposed question on volunteering) would be helpful"

However, there was no widespread support for any one alternative sub-topic.

## 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 & Wales: Response to consultation' 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 - amount of unpaid care provided

Table 4 User requirement score by criterion

Criterion	Score	Evidence High user need	
Weighted Overall Score	81		
Purpose	8	Respondents gave a clear message that numbers of unpaid carers by local authority have underpinned work to provide new services required by the 2014 Care Act, and services for unpaid carers in general. Both local and central government respondents used unpaid care data from the census to deliver a range of adult social care and carer support services. The Department for Work and Pensions (DWP) told us:  "The information is also used in forecasting future demand for carers benefit, particularly given the pressures of the ageing population and increasing care requirements. The information is also employed in measuring the value of informal care and benefits it brings to the government."	
		<ul> <li>The Equality and Human Rights Commission (EHRC) stated:</li> <li>"The Commission uses census data on carers to identify level of caring for different population groups. These data are particularly important for providing data on children and young people providing unpaid care, as surveys on the topic are usually aimed at adult carers."</li> <li>An example of using unpaid care data for local resource allocation came from East Riding of Yorkshire Council:</li> </ul>	

<sup>&</sup>lt;sup>3</sup> <a href="https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/assessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf">https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/2021censustopicconsultation/assessmentofinitialuserrequirementsoncontentforenglandandwalesresponsetoconsultation.pdf</a>

Criterion	Score	Evidence		
		"These figures enable us to estimate an indicative amount of resource allocation and in 2014/15 alone the Council spent approximately £990,000 on a variety of support and services to Carers."		
		Local authority users also mentioned using data for policy and planning and moving to new arrangements under the Care Act 2014, for example Lancashire County Council told us:		
		"Unpaid care data is only available from the census and is therefore very valuable. It was used to anticipate the impact of the Social Care Act on the county council, as it brought a new duty to assess carers' needs in addition to those who are cared for. It was also used to strengthen the case for additional funding to deliver this new duty."		
Small geographies or populations	8	There was evidence of use by local authorities who gave specific examples of LSOA-level uses; and several respondents identified small populations in particular - young carers and the elderly. The 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" "Census information on age is also used in combination with the provision of unpaid care to identify young carers as part of the Joint Strategic Needs Assessment core dataset"		
		Cyngor Sir Ceredigion/Ceredigion County Council also stated that:		
		"The main sub-groups we would identify are children providing care and the elderly and very elderly carers all of whom will require especial programmes of support."		
		Southend-on-Sea Borough Council added to that by saying:		
		"However, it will need this to be collected at Lower LSOA level to enable us to identify the prevalence in small areas allowing more effective targeting of resources."		
Alternative sources	9	A majority of respondents stated there were no reliable alternative sources from which to acquire data on unpaid care.		
		Department for Work and Pensions (DWP) said:		
		"The Family Resources Survey is the next best source, but must be quality assured against the census. The use of the FRS alone would make certain analysis impossible due to small sample sizes."		
		Welsh Government stated:		
		"There are questions about carers in Wales in the Welsh Health Survey and in the National Survey for Wales. The data is unlikely to be reliable below the national level."		
		Salford City Council mentioned:		
		"No other data source relating to carers picks up this information, closest we have are the people registered with the Carers Centre. There		

Criterion	Score	Evidence		
		are currently 5500 people registered and therefore census provides us with information that there are approximately 18000 carers not currently in receipt of services."		
		Sheffield City Council stated:		
		"Even with census information it is hard to get an accurate picture, due to the number of 'hidden carers' but it is a good start. Without this information, estimates about carers and where they live would be largely guesswork"		
		In particular there was a lack of alternative sources on young carers. Equality and Human Rights Commission (EHRC) mentioned:		
		"The Commission used data from the Survey of Carers in Households in a briefing in 2013, however this only covers adult carers in England."		
		Bournemouth City Council also said:		
		"There is not an alternative source on young carers."		
Multivariate analysis	7	The evidence highlighted by respondents underlined a broad need to profile carers and understand future needs, by using carers with age and different combinations of ethnicity, health, labour market and housing information. Local authorities using census data on unpaid carers often require multivariate data on other characteristics to profile carers and understand their need for other social care services for example, Southend-on-Sea Borough Council use ethnicity, age, employment status, housing and health in conjunction with information on carers into the needs of their carer population.		
		There is a need for central government to understand how the proportions of carers vary by the protected characteristics in the Equalities Act. The Equality and Human Rights Commission (EHRC) stated:		
		"Information on carers is needed for comparison between different groups of people who share protected characteristics as identified within the Equality Act 2010 and by NS-SEC classes. These topics are listed below. This allows us to compare different groups within the population."  New Economy also said:		
		"Carer information is used in combination with other topics to assess scale of need. For instance carers in overcrowded households or carers with no hours of employment or carers who themselves may be elderly."		
Comparability beyond England and Wales	8	While local authorities had little need for comparability, respondents with a UK or GB remit pointed to devolution of policy leading to a greater need for comparability to understand the effectiveness of different policies. The Department for Work and Pensions (DWP) said:		
		"The UK Government need to be able to make comparisons across regions, particularly when addressing policy questions on devolution of powers. Work on devolution policy will be ever more important in the future. We are involved in developing UK wide policy and our organisational remit is UK wide and requires this information."		

Criterion	Score	Evidence	
		British Sociological Association said:  "The support for those in need of care and for care givers varies across the UK especially as between Scotland and England and Wales and we need to be able to explore these differences as well as regional and local differences."	
Continuity with previous censuses	9	Several respondents stated that an ageing population and the changing nature of unpaid care - for example more people providing the highest amount of unpaid care - means that comparisons between 2001 and 2011 were particularly important.  Warwickshire Observatory said:  "Without time comparison we would not have been able to identify changes in patterns of unpaid care. In Warwickshire we identified a trend for carers caring for longer which in turn this could be highlighted to decision and policy makers."  Oxfordshire County Council also said:  "Data on unpaid care has been of particular use to ongoing work to investigate changes in future demand for adult social care, and programmes to expand the carer workforce to cope with anticipated demand."	
Weighted Overall Score	81	High user need	

## 4.2 Other considerations - amount of unpaid care provided

Table 5 ONS assessment of impact by criterion

Criterion	Operational impact	Justification	
Impact on data quality	Medium	The agreement rate between the 2011 Census and the 2011 Census Quality Survey (CQS) for this question was 90.9%. The response rate was 96.5%. The CQS stated that some people did not realise that the type of care they provided should have been included or that the amount of care they provided varied which made it difficult to quantify the number of hours provided per week. In Scotland there was some evidence that respondents misunderstood the questions and gave the hours they were cared for rather than hours of care they provided.	
Impact on public acceptability	Low	Asking for information on this sub-topic was considered to be publically acceptable.	

Criterion	Operational impact	Justification	
Impact on respondent burden	Medium	The respondent had to read question text and some instruction on what to include regarding why they were providing care. 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 Low This questionnaire mode		This question displayed well online and on the paper questionnaire .	

## 4.3 Operational requirements - amount of unpaid care provided

## Minimum operational requirement

There is no census operational requirement to collect data on this topic.

# 5. Updated view

The following table gives the updated view of ONS at the sub-topic level and the justification for this.

**Table 6 Updated view** 

Sub-topic	Initial	Updated	Justification
detail	view	view	
Amount of unpaid care provided	Collect	Collect	Evidence from local and central government users showed that data on the amount of unpaid care are important for making strategic decisions, and for planning specific services. This has particularly been the case with the advent of new legislation, particularly the 2014 Care Act.  The updated view remains to collect this data, and explore the possibility of improving the guidance to this question.

## 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<sup>4</sup> 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

Although not a protected characteristic, provision of unpaid care is a sub-topic with links to other protected characteristics such as age and gender. An analysis of 2011 results identified an increased number of <u>carers aged 5 to 17</u>. Differences have also been shown between men and women in the 2011 Census, with analysis of <u>women aged 50 to 64</u> being most likely to provide unpaid care, affecting their participation in the labour market. The 2011 Census results also highlighted differences in provision of unpaid care between <u>ethnic groups</u>.

Some respondents to the topic consultation referred to the equalities monitoring that they undertook using data on carers. Respondents use the data to profile the characteristics of carers, and in particular to assess potential health inequalities between carers and non-carers. Continuing to collect data on provision of unpaid care will continue to enable related research and equalities monitoring.

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.

<sup>&</sup>lt;sup>4</sup> 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 question on 'amount of unpaid care provided'. However, there is scope to review the question guidance in order to both improve data quality and 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 'Education' topic. If multiple responses were received from an organisation the name only appears once.

## **Government department/public body**

College of Arms Health & Social Care Information Centre (HSCIC)

Department for Work and Pensions (**DWP**) National Assembly for Wales

Department of Health (**DH**) Office for National Statistics (**ONS**)

Equality and Human Rights Commission (EHRC) Welsh Government

## **Local authority**

Arun District Council Gateshead Council

Barnsley Metropolitan Borough Council Gedling Borough Council

Bedford Borough Council Gloucestershire County Council

Birmingham City Council Greater London Authority

Blaby District Council Gwynedd Council
Blackpool Council Haringey Council

Bournemouth Borough Council Hertfordshire County Council

Bristol City Council Kent County Council

Caerphilly County Borough Council Knowsley Metropolitan Borough Council

Carmarthenshire County Council

Cheshire West and Chester Council

Chesterfield Borough Council

London Borough of Camden

City of Bradford Metropolitan District Council London Borough of Hackney

City of London Corporation London Borough of Harrow

Cornwall Council London Borough of Havering

Cumbria County Council London Borough of Hounslow

Cyngor Sir Ceredigion/Ceredigion Manchester City Council
County Council Mole Valley District Council

Derbyshire County Council Newcastle City Council

Devon County Council - Public Health North York Moors National Park Authority

Dudley Metropolitan Borough Council

North Yorkshire County Council

Durham County Council

East Riding of Yorkshire Council

Oldham Council

East Sussex County Council Oxfordshire County Council

Essex County Council Powys County Council

## Local authority (continued)

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

Somerset County Council

Southend-on-Sea Borough Council

St Helens Council

**Surrey County Council** 

Tameside Council

**Tower Hamlets Council** 

**Uttlesford District Council** 

Waltham Forest Council

Warrington Borough Council

Warwickshire Observatory

West Sussex County Council

Westminster City 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

## Housing

**Yarlington Housing Group** 

#### **Academic/research**

**British Sociological Association** 

Centre for Longitudinal Study Information and

User Support (**CeLSIUS**)

**Economic History Society** 

University of York - Centre for Housing Policy

#### **Charity and voluntary**

Chwarae Teg

Discrimination Law Association

Family and Childcare Trust

Friends, Families and Travellers

Irish in Britain

Mental Health Foundation

Muslim Council of Britain

National Association of British Arabs

Older Lesbian, Gay, Bisexual and Trans

Association (OLGA)

Shelter

The Salvation Army

The Vegan Society

#### **Commercial**

**CACI Ltd** 

First UK Bus

Operational Research in Health Ltd (ORH Ltd)

## **Genealogist/family historian**

Tasmanian Family History Society Inc.

#### **Other**

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