

CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Consultation on 2011 Census Topics

Carers UK's response to the Office for National Statistics consultation document August 2005

About Carers UK

Carers UK is the leading organisation representing the views and interests of the six million carers in the UK who care for their frail, disabled or chronically ill partners, relatives or friends. Carers UK is an organisation of carers, run by carers, for carers. We have a membership of carers and over 80 Branches, run by carers, throughout the UK. Carers UK have offices in Northern Ireland, Scotland, Wales, Manchester and a UK office in London.

Carers UK is a campaigning organisation and has been since it was established nearly 40 years ago. We continue to seek change for carers so that they are able to access the same opportunities in life as others. We aim to raise awareness of carers' issues and seek changes in the law and practical support to prevent carers from poverty, having their health and well-being affected by caring and by not having a choice about whether or not to take on a caring role.

1. Why is the information required?

Comparative data and measuring impact of demographic change

The 2001 Census was the first Census to include a question on carers. The 2011 Census will therefore provide the first ever opportunity for comparative data on changes in the caring population over a 10 year period.

It is Carers UK's view that it is essential to include a question in the 2011 Census to measure the impact of an ageing population on the number and nature of carers. Demographic analysis carried out for Carers UK by the University of York has predicted that the ageing population is likely to result in an increase in the number of carers from 6 to 9 million by 2037.

It is essential that an accurate comparative measure exists to measure the impact of this change, and the resultant impact on, for example, carers' own health, and the number of carers in employment. Information on the change in the numbers of carers will also be important at local level, in the planning of services for carers and services that impact on carers. In order to facilitate accurate data on change over time it is important that the same question is included in the 2011 Census.

The Census data will also serve as the most effective measure of the impact of government policies on a range of issues affecting carers, including carers' health and carers' access to employment.

Evidence of how the 2001 Census has contributed to policy development

The 2001 Census information on carers has helped clearly identify key policy issues affecting carers and resulted in the development of policy initiatives as a result of these findings.

For example, the evidence supplied on carers' health and carers and employment has already helped initiate new policy solutions. Carers issues generally have risen to the top of the political agenda, with the passage of the Carers (Equal Opportunities) Act 2004, the formation of a new All Party Parliamentary Group for Carers and the inclusion of carers in numerous other policy initiatives. It is Carers UK's view that the evidence from the 2001 Census has contributed to these initiatives. Inclusion of a question in the 2011 Census would allow for a comparative analysis to measure the effectiveness of these new policies.

Health

Research from the General Household Survey, Carers UK and other carers organisations had indicated for a long time that there was a link between caring and carers' health. However, the argument had been made against this that carers poor health could be attributed to the fact that carers tended to be older. For example, the National Carers Strategy states that "the evidence on whether carers suffer proportionately more health problems than other people of the same age is not conclusive. Physical injuries in particular become more common as people get older and a large proportion of carers are over 60."

Evidence from the 2001 Census has for the first time provided the opportunity of comparison of carers and non-carers health across age ranges. This has clearly demonstrated that those caring 50 hours a week or more were twice as likely to report poor health as the non-carer population and that this was true across all age-ranges. This has established once and for all the negative impact caring can have on carers' health.

The 2001 Census evidence on carers health has proved an essential tool in arguing for better support for carers from health professionals and has already generated policy solutions, including a recent announcement that carers have been added to the list of at-risk groups to receive influenza vaccinations and a continuation of the Carer's Grant in England for at least another 3 years. The Carer's Grant is paid to provide flexible breaks services for carers and other services to support them in their caring role.

2. Why is this information required for small population groups

and/or small geographies?

The 2001 Census data has proven an invaluable source of information for local authorities, health services and other service providers at local level. The detailed breakdown on numbers of carers in each local area for example enables local authorities to measure the effectiveness of their carers services and identify the number of 'hidden' carers in their area.

Local health authorities have also used the data in planning of their services and localised Census data has helped raise professional awareness on the number of carers. As mentioned above, the findings of the 2001 Census have clearly identified carers as an at-risk group and local health authorities will benefit from updated information on the numbers (and health) of carers at local level.

Accurate data on the numbers of carers will also prove important for a range of local authority departments. Under the Carers (Equal Opportunities) Act 2004 any local authority department in England can be asked to include carers in their strategic planning, this could include transport, housing, education authorities. Accurate data on the numbers of carers will facilitate better planning across all of these sections of government.

Carers UK is in regular contact with a network of 800 carers organisations and Carers UK branches across the UK, who have told us that the Census information has proved useful on a local level in raising awareness and providing better understanding of carers issues. This has helped bring about changes in information provision, service delivery and support for carers at a local level.

Having accurate localised data has also helped raise awareness of carers issues, as local information has helped generate local media coverage. Carers UK have seen a marked increase in local media coverage thanks in part to the availability of local information on numbers of carers. In turn this media coverage has alerted hidden carers to recognize their role as carers and subsequently their right to access benefits/information/ support and services.

3. What assessment of alternative source of information has been carried out? What would be the impact of using the next best alternative?

It is likely that the General Household Survey 2010 will include a question on carers. However, the nature of the GHS is that it is a projected figure based on a sample, and previous GHSs have varied in their estimation of numbers of carers rising from 6.1 million in 1985 to 6.8 million in 1990, then falling to 5.7 million in 1995 and rising again to 6.8 million in 2000.

It is important that a more reliable figure is attained in order to compare change in the number of carers over time. The Census figure is much more reliable

because it is a survey of all households in the UK. Consequently any change in the number of carers over time identified by the Census will be reliable and cannot be dismissed as a statistical blip.

An accurate measure of changes in the number of carers is absolutely essential to feed into a range of government policies. Changes in the numbers of carers will have implications for the NHS, social services, the workforce and benefits system and to measure the effectiveness of existing government policies.

Though the NHS National Programme for Information Technology (NPfIT) will by 2011 provide data on health conditions and treatments it is important that for the 2011 Census a question on carers is included as a measure of the accuracy and effectiveness of the NPfIT system. Carers who call our information line frequently report that their role is overlooked by NHS professionals and it is likely that the majority of caring roles will not be identified by the NPfIT system. A question on carers in the 2011 Census will provide a useful measure of the effectiveness of the new system in identifying carers.

While the information provided by the NPfIT system will be important, it will only provide a partial picture. The Census will collect information about carers that will impact on a broad range of policy areas. The role carers play in the workforce will become increasingly important with an ageing population and the Census will provide crucial information on the numbers of carers also in paid employment.

4. Which other topics, if any, are required for multivariate analyses together with this topic?

Health

As discussed in question 1, analysis of the 2001 Census showed that those caring for 50 hours a week or more were twice as likely to report poor health as the non-carer population, and the difference was consistent across age ranges. This has clearly identified carers as an at risk group that needs to be targeted by the health service and supported by local authorities.

It is important that data on carers' health is collected in the 2011 Census, to measure the impact of policy initiatives introduced since 2001 in combating carers' poor health.

Ethnicity

Evidence from the 2001 Census has already identified particular ethnic groups where incidence of caring is high. Demographic trends suggest that there will be ageing populations amongst several of these ethnic minority communities and it is important to measure the impact of this on the numbers of carers. This will

have significant implications for the provision of information and services to these communities.

Age

It is important to have a breakdown of the numbers of carers across age ranges. As mentioned above, the number of carers is expected to rise due to the impact of an ageing population. It is important to collect data on which particular age-groups are affected by this increase in caring. This will have important implications in terms of developing social policy, for example in providing up-to-date information on the numbers of carers of working age, which has economic and workforce implications.

Work

With an ageing population and declining working population, the role carers play in the workforce will be of increasing importance. The 2001 census identified 3 million carers who combine caring with paid employment. However, with the number of carers expected to increase due to the ageing population, it is important to measure how this increase impacts on the working population.

It will also measure the effectiveness of an expected new right to request flexible working (expected to be included in the Parental Rights Bill later this year) and the Carers (Equal Opportunities) Act 2004, under which all Carer's Assessments in England and Wales must cover whether the carer works, or wishes to work.

Income

If a question on income is included in the 2011 Census, then multivariate analysis of this data will prove an invaluable source of information on the income of carers. The best available research, based on relatively small samples, clearly demonstrates that carers are at risk of poverty.

However, as was previously the case with carers' health, the limited scale of existing research data has meant that carers have not been targeted as a priority group for social exclusion and poverty policies.

Carers UK anticipate that evidence on carers' income levels would identify carers as an at risk group for poverty and would therefore serve as a driver for policy solutions.

5. Why is it important that this information is available for the UK as a whole?

The 2001 Census identified differences in rates of care across the UK and it is important to measure any changes to these differentials over time. The 2001 Census identified several areas where the numbers of carers are

disproportionately high, many of these being in areas of social deprivation. It will be important to measure any change in the geographic spread of carers.

Many of the policy areas discussed above are the responsibility of the developments of the devolved parliaments and assemblies. It is essential therefore that the devolved parliaments and assemblies have accurate and detailed data on the number of carers and the data would also provide the opportunity to measure the effectiveness of policies that have been enacted in each of the nations in the UK.

6. Will this information ensure continuity with previous Censuses?

As mentioned above including the question in the 2011 Census will provide the first opportunity to compare changes in Census data over time, which will measure the impact of an ageing population on the numbers of carers.