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Introduction

This document relates to the Survey of Adult Carers in England (SACE); a biennial national survey, conducted by Councils with Adult Social Services Responsibilities (CASSRs), which covers carers aged 18 or over, caring for a person aged 18 or over. In 2016-17 the eligible population changed to include those carers who have not been assessed or reviewed during the previous 12 months. Under the Care Act (2014) councils have a duty to ensure relevant information and advice are made available. This provides a clear rationale for including carers who were not assessed or reviewed during the year but who the local authority reports are receiving support. The survey seeks carers' opinions on a number of topics that are considered to be indicative of a balanced life alongside their caring role.

The SACE was developed in consultation with the Social Services User Survey Group (SSUSG) which includes Department of Health and Social Care (DHSC) policy leads, DHSC and NHS Digital statisticians, council representatives, the Care Quality Commission (CQC) and researchers from the Personal Social Services Research Unit (PSSRU). SSUSG reports to the National Data Collections Programme Board, which reports to the Data and Outcomes Board (DOB). DOB is co-chaired by the Association of Directors of Adult Social Services (ADASS) in England and the Department of Health and Social Care. The survey has DHSC and ADASS approval.

In 2009-10, a pilot survey\(^1\) was run in which councils were asked to volunteer to take part; 90 councils agreed to do this. The findings from the pilot survey were used to develop the first mandatory survey (2012-13).

In 2010-11, the Adult Social Care Survey (ASCS), which is a survey of users of adult social care services, was reviewed\(^2\) by the Office for National Statistics Methodology Advisory Service and a response\(^3\) to this review was provided in collaboration with SSUSG. The SACE shares much of the methodology of the ASCS; recommendations and suggestions in the ONS report were implemented in the SACE where appropriate.

The SACE has received favourable ethical opinion from the Social Care Research Ethics Committee (SC-REC)\(^4\), which operates within the framework of the National Research Ethics Service.

This survey has no direct relationship to the 2009-10 Survey of Carers in Households (SCH)\(^5\). The SCH questionnaire had a considerably greater number of questions and, rather than being conducted largely by post, used face-to-face interviews. The survey sample for the SCH was selected via a short screening questionnaire at addresses which were randomly selected rather than being selected from council records.

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\(^5\) [http://content.digital.nhs.uk/pubs/carersurvey0910](http://content.digital.nhs.uk/pubs/carersurvey0910)
Business Case and Relevance

The September 2018 letter\textsuperscript{6} from NHS Digital to CASSR contacts informed CASSRs that they should undertake a survey of carers. The survey is also listed on the Ministry of Housing, Communities and Local Government single data list\textsuperscript{7} as one of the data returns councils are required to submit under current arrangements. Carers are a key policy area.

In 2018 the government published their carers action plan\textsuperscript{8}, which was based around the following themes:

- Services and systems that work for carers
- Employment and financial wellbeing
- Supporting young carers
- Recognising and supporting carers in the wider community and society
- Building research and evidence to improve outcomes for carers

The Care Act 2014\textsuperscript{10} gives carers new rights to support and puts them on an equal basis with the people they are caring for. It allows for provisions such as simplifying carers’ assessments, giving carers a legal right to support if they are eligible and setting the minimum level at which carers become eligible for support.

Initially piloted in 2009-10, the survey provides information on carers’ experiences of the services they received and whether these services improved carers’ ability to care and live a life outside this role. The survey contributes to monitoring the impact of the national carers’ strategy.

The survey is the most significant pool of personal outcome information for carers receiving support from CASSRs. It is an important resource for accounting for what has been achieved for local carers, supporting local services for carers, and enabling local authorities to make better choices about support for carers. It investigates whether services received by carers have helped them in their caring role and their life outside of caring, and seeks their perception of services provided to the person in receipt of care.

The main purpose of the survey is to provide assured, benchmarked local data on outcomes to support local services in considering ways of improving outcomes in a very challenging financial climate. The survey is constructed so that an individual outcome can be disaggregated into constituent groups. This means that, as well as providing an overall quality of life index, the survey provides intelligence on whether specific groups experience better outcomes, whether services are meeting all outcome needs, and in time, the value added by social services.

\textsuperscript{6} https://digital.nhs.uk/binaries/content/assets/website-assets/data-and-information/data-collections/september-letter-2018--final.docx
\textsuperscript{7} The single data list, which lists all the datasets that local government must submit to central government, can be accessed at: https://www.gov.uk/government/publications/single-data-list
\textsuperscript{10} http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm
Data from the survey questions are used to populate five of the measures from the ASCOF. These are:

- **1D**: Carer-reported quality of life (Q7-12).
- **1I2**: The proportion of carers who reported that they had as much social contact as they would like (Q11).
- **3B**: Overall satisfaction of carers with social services (Q4).
- **3C**: The proportion of carers who report they have been included or consulted in discussions about the person they care for (Q18).
- **3D2**: The proportion of carers who find it easy to find information about support (Q16).


More uses of the survey are given in the Data Quality Statement which is available alongside the publication: https://digital.nhs.uk/pubs/psscarersurvey1819.
Overview of Methodology

Councils are asked to send questionnaires to a random sample of carers who are:
- aged 18 or over
- caring for someone aged 18 or over
- recorded within the last three rows of the Short and Long Term Support (SALT) return on carers provided support during the year (i.e. excluding the first row, carers aged under 18).

The sample frame therefore contains all carers aged 18 and over who either received “support direct to carer” or “no direct support to carer”, irrespective of whether their cared-for person received respite care.

Councils select a date between 1 June and 30 September to extract the list of carers (the eligible population).

NHS Digital provides councils with detailed survey guidance and with survey materials such as questionnaires, forms and letters. There are large-print and translated versions of the materials. The questionnaires are also provided as an interview script so that carers who request an interview can participate in the survey.

The model questionnaires and interview scripts are generic and contain sections that are customised by councils. Councils may include additional questions or free-text boxes for local research purposes; any proposals to do so are subject to NHS Digital approval.

The survey uses data from a sample of carers to make inferences (or estimates) about the whole population. These estimates are subject to a degree of uncertainty that can be expressed as a margin of error. The margin of error of an estimate is related to the proportion of the population that responds to the survey; as this proportion increases, the margin of error decreases. Therefore, the margin of error can be reduced by increasing the survey sample size and/or response rate. Councils are required to select a sample such that the survey results have a margin of error of less than five percentage points.

The selected sample is checked for carers who should not be sent a survey, for example if the person has stopped being a carer, the carer or the cared-for person has died, or if the carer has been hospitalised or is involved in an open safeguarding alert or investigation. In addition, a survey is not sent if the carer is in active dispute with the council and it is felt that sending them a questionnaire could be perceived as being unduly provocative or insensitive. Carers removed from the sample for any of these reasons are replaced with other randomly selected eligible carers.

The recommended fieldwork period is during October and November. The survey is conducted mainly using a postal questionnaire. Councils can use a face-to-face or telephone interview if requested by the carer. In 2018–19, two councils also piloted the use of an online survey.

One reminder letter is sent to each non-respondent. The returned questionnaires are then coded onto the data return and the resulting datasets are returned to NHS Digital for validation and analysis.

Further information about the SACE, such as the guidance document (which contains more detail about the survey process) and the survey materials (including the model

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11 SALT measure LTS003 table la
Comparisons with the 2009-10 pilot survey

The carers’ survey was first piloted on a voluntary basis in 2009-10, when 90 out of 152 councils (59 per cent) participated. There were 58 questions in the pilot, some of which were optional.


We do not recommend making comparisons between the 2009-10 pilot survey and the results for later surveys, for the following reasons:

1. Only 90 councils out of a possible 152 undertook the pilot survey and not all of them provided responses to all of the questions.
2. The response rate in 2012-13 was 46 per cent, compared with 40 per cent for the pilot survey. Initial comparisons suggest the profile of characteristics of respondents (e.g. age and condition of the person cared for) was broadly similar between surveys.
3. The sampling frame for the 2009-10 survey included carers who were known to the cared for person by association i.e. they were in receipt of services from the council. This was not the case for the 2012-13 and 2014-15 samples where the carer had either been receiving services or been assessed for suitability for services from the council. 41 of the 90 councils that took part in 2009-10 survey included carers known by association; this equates to 19 per cent of the total responses received.
4. The ordering of questions and their position within a questionnaire can also have an impact on the way in which people respond to a survey.

However, should you wish to review the 2009-10 scores alongside 2012-13 scores for identical questions, a time series analysis is available in Appendix D of the 2012-13 Final Report, available at https://webarchive.nationalarchives.gov.uk/20180328134643/http://digital.nhs.uk/catalogue/PUB12630.
Calculating Margin of Error, Confidence Interval and Standard Error

A standard formula for the calculation of a margin of error for the estimate of a proportion $p$ from a sample survey is:

$$1.96 \times \sqrt{\frac{p(1-p)}{n} \left( \frac{N-n}{N} \right)}$$

where:

$p$ is the sample proportion
$n$ is the sample size achieved (number of useable responses)
$N$ is the size of the eligible population.

This formula includes the finite population correction factor and assumes $n$ is reasonably large.
Example
Council A has 11,600 eligible service users and sent questionnaires to 1,100, of which 452 were returned by users.

The responses received to the question ‘Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?’ were:

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
</tr>
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<tbody>
<tr>
<td>I feel clean and am able to present myself the way I like</td>
<td>206</td>
</tr>
<tr>
<td>I feel adequately clean and presentable</td>
<td>161</td>
</tr>
<tr>
<td>I feel less than adequately clean or presentable</td>
<td>22</td>
</tr>
<tr>
<td>I don’t feel at all clean or presentable</td>
<td>3</td>
</tr>
<tr>
<td>Responded to survey but not this question</td>
<td>60</td>
</tr>
</tbody>
</table>

\[ n = 452 - 60 = 392 \]

\[ p = \frac{206}{392} \approx 0.526 \]

\[ N = 11,600 \]

Substituting the above values of \( p \), \( n \) and \( N \) into the formula, the margin of error for \( p \) is calculated as:

\[
1.96 \times \sqrt{\left( \frac{0.526(1 - 0.526)}{392} \right) \left( \frac{11,600 - 392}{11,600} \right)} = 0.049 = 4.9 \text{ percentage points}
\]

For council A therefore, the 95 per cent confidence interval is 0.526 ± 0.049

This means that the true proportion (i.e. the equivalent value of \( p \) if the entire population was surveyed) would lie between 0.477 (0.526-0.049) and 0.575 (0.526+0.049) for 95 samples out of 100.

A standard formula for the calculation of a standard error for the estimate of a percentage $p$ from a sample survey is:

$$\sqrt{\left(\frac{p(100 - p)}{n}\right)}$$

where:

- $p$ is the sample percentage
- $n$ is the sample size achieved (number of useable responses)

The standard errors are included in the charts in report so readers can gauge the statistical accuracy of the estimate shown. The example chart below shows the how the standard errors are presented. For carers who have parental responsibility for three children aged 18 or under, 50.4 per cent reported that they had some social contact but not enough. The standard error for this group is ±3.6. Had multiple random samples of the same size been taken and from the same population the standard deviation of those different sample means would be around 3.6%.

**Example chart showing how standard errors are presented**

Weights are used to calculate a national, regional and council type estimate which makes the calculation of confidence intervals for these aggregated results more complicated. The standard formula for variance of estimates in a stratified design has been used taking each council as a stratum.
Taking $H$ to be the total number of councils within the survey; the sampling weight for each council $h$, where $h=1,\ldots,H$, is denoted by

$$W_h = \frac{N_h}{\sum_{h=1}^{H} N_h}$$

where $N_h$ is the number of eligible population elements in each council and

$$\sum_{h=1}^{H} N_h$$

is the overall eligible population for the survey.

The variance is:

$$V(p) = \sum_{h=1}^{H} W_h^2 \left(\frac{1 - \left(\frac{n_h}{N_h}\right)}{n_h}\right) \left(\frac{n_h}{n_h - 1}\right) p_h (1 - p_h)$$

This provides the information needed to calculate the 95 per cent confidence interval, calculated by:

$$\text{estimate} \pm 1.96 \sqrt{V(p)}$$

where:

- $p$ is the sample proportion (statistic of interest) for the aggregated result
- $p_h$ is the sample proportion in council $h$
- $n_h$ is the achieved sample size (number of useable responses) in council $h$
- $N_h$ is the size of the eligible population in council
- $H$ is the number of councils.

In the normal distribution, 95% of the area under a normal curve lies within roughly 1.96 standard deviations of the mean. NHS Digital uses PROC SURVEYMEANS, within the SAS software package, to calculate margins of error. Rather than using 1.96, this uses a calculation\(^{12}\) which gives slightly greater accuracy and makes fewer assumptions about the sample size.

Analysis and Significance testing

Significance testing was carried out to evaluate the key findings from the 2018-19 survey. The term ‘significant’ refers to statistical significance at the 95 per cent level and is not intended to imply substantive importance.

The significance tests are carried out in order to test the relationship between variables in a cross tabulation. The test is for the main effects only, using a Wald test. The Wald test is a statistical test used to calculate the significance of parameters in a statistical model. The Wald test is used in analysis of SACE data in this report to establish whether the association among particular variables is statistically significant. For example the test might help to establish whether there is a statistically significant relationship between question 11 (social contact and isolation) and question 15 (financial difficulties). The test calculates the statistical significance of parameters in a logistic regression model of answers to question 11, in order to establish whether financial difficulties are significantly associated with social contact and isolation.

It is worth noting that the test does not establish whether there is a statistically significant difference between any particular pair of subgroups (e.g. the highest and lowest subgroups). Rather it seeks to establish whether the observed variation in the outcome between groups could have happened by chance or whether it is likely to reflect some 'real' differences in the population.

A p-value is the probability of the observed result occurring due to chance alone. A p-value of less than 5% is conventionally taken to indicate a statistically significant result (p<0.05). It should be noted that the p-value is dependent on the sample size, so that with large sample sizes or associations which are very small may still be statistically significant.

Using this method of statistical testing, differences which are significant at the 5% level indicate that there is sufficient evidence in the data to suggest that the differences in the sample reflect a true difference in the population.

The data quality report includes analysis of whether particular subgroups of carers answer questions in the survey differently. The groups looked at were those who used translated vs English questionnaires, and those who responded online vs other response methods. Chi-squared tests were used to determine whether there is a significant difference between the expected and the observed frequencies in one or more categories. The test evaluates how likely the observations that are made would be seen if there is no difference between the subgroups. Like the Wald test described above, the Chi-squared test provides a p-value. A p-value of less than 5 per cent is conventionally taken to indicate a statistically significant result (p<0.05), i.e. there are differences between the two groups.