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# Representativeness of Adult Social Care Surveys

## Methodology Review

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# Acknowledgements

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# 1 Introduction

## 1.1 Background to the research

The Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE) are complex surveys administered by Councils with Adult Social Services Responsibilities (CASSRs) in England.[1] They are important sources of information about the experiences of people receiving local council social care services in England (ASCS), and carers known to councils (SACE).[2] The information is used by the government and local authorities to understand outcomes experienced by users of social care services and their carers, and to plan for and deliver services.

Although guidance materials for CASSRs carrying out the ASCS and SACE are continuously updated and refined by NHS Digital, the surveys have not taken advantage of recent developments in survey methodology, design and delivery. Some concerns have also been raised about:

- the exclusion of users lacking mental capacity from ASCS, and its overall impact on the representativeness of the survey;
- the exclusion of short-term users of social care from ASCS since the introduction of a new sampling frame in 2014-2015, and the lack of information regarding the experiences of this group;
- declining response rates on both surveys (from 41 per cent in 2010-11 to 31.8 per cent in 2018-19 for ASCS, and from 46 per cent in 2012-13 to 37 per cent in 2018-19 for SACE).[3] An important question is whether this decline is found across all participant groups, or whether certain groups are becoming increasingly under-represented in the surveys' data.

On behalf of the Department of Health and Social Care (DHSC), the National Institute for Health Research (NIHR) has funded Ipsos MORI to carry out a research project to explore these concerns. The research has several components:

- **Secondary analysis of data from the ASCS and SACE** - to explore whether those being sampled and responding to the two surveys are representative of both users of publicly funded social care, and carers known to CASSRs in England;
- **Review of the literature about survey developments and hard to reach groups** – to review practice for collecting the views of people with high needs or who are regarded as 'hard to reach;[4]

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[1] Up to April 2019 there were 152 CASSRs of which 150 took part in the surveys. Isles of Scilly and City of London did not participate because of small populations. In April 2019 Dorset County Council split into two CASSRs so from 2019 there are 153 CASSRs of which 151 would participate in these surveys

[2] The term carers is used here to describe those who look after a family member or friend. It does not include professional care and support workers.

[3] However, it is worth noting that this is in line with declining response rates on many postal surveys- see for instance: Stedman et al (2019) The End of the (Research) World As We Know It? Understanding and Coping With Declining Response Rates to Mail Surveys, Society & Natural Resources, 32:10, 1139-1154.

[4] The term 'hard to reach' is a 'contested and ambiguous term'. It includes those who are 'inaccessible to most traditional and conventional methods for any reason' (Flanagan and Hancock, 2020). The term 'hard to reach' is contested as people in the group may not identify themselves as hard to reach, rather the services may be ineffective in reaching them. In the field of health promotion groups considered to be 'hard to reach' include the oldest old (85 years and over) and ethnic minority groups (Liljas et al, 2019).

- **Methodological review of the ASCS and SACE -** to help assess the representativeness of the surveys, identify opportunities to include under-represented groups and ascertain ways in which the survey could be enhanced through innovations in methodology and more consistent implementation of the current methodology;

- **Consultation with CASSRs -** responsible for running the surveys through an online form and follow-up interviews to explore their experience of running both surveys, and discuss how the experience of short-term users of care could be gathered since they are not part of the main survey methodology;

- **Consultation with stakeholders -** who use the data or have experience in research with these groups;

- **Interviews with service users and carers** - to explore their experiences of the surveys and barriers to participation.

This report contains findings from the methodological review of the ASCS and SACE. Findings from the other elements are included in the main report of the project.

## 1.2 Review of survey methodology

Detailed guidance materials are provided to CASSRs by NHS Digital each year on sampling and recruitment, questionnaire design, administration, data capture and submission. All of these elements may have a bearing on how representative the resulting samples are and the extent to which best practice is employed in the design and conduct of the surveys.

As part of the Adult Social Care Surveys Review, Ipsos MORI has conducted a methodology review of:

- Technical documentation, guidance, materials and questionnaires for how ASCS and SACE should be administered;

- Data outputs from both surveys;

- Previous literature on how both surveys are administered in practice;

- Previous literature on how both surveys could be improved – this includes literature specific to these surveys.[5]

Further details about our approach to reviewing this documentation can be found in Appendix A.

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[5] The literature related to survey methodology in general is covered in the wider literature review.

## 1.3 Objectives

The specific objectives of this methodology review are to:

- Explore the extent to which the ASCS and SACE are being run and managed in accordance with the guidance and challenges involved in doing so;
- Uncover gaps in the evidence from a review of methodology to inform the design of other parts of the project (e.g. the online surveys of CASSRs, and interviews with CASSRs and stakeholders);
- Explore the extent to which the under-representation of certain groups in the surveys is caused by:
    - The design of the surveys (e.g. how eligible populations are defined, the rules for exclusion from the sample);
    - The information available to CASSRS in implementing the surveys (e.g. quality of data about the eligible population);
    - inconsistencies in how the methods are applied across CASSRs (e.g. whether or not translation information sheet is sent to participants).
- Uncover where the surveys work well and where they work less well - to inform sample design and the selection of stakeholders for interview as part of this overall research project.

## 1.4 How to use this document

This document summarises findings from the technical survey documentation and existing literature on survey administration and has three main sections:

- the first covers the findings from the documentation and literature relating to ASCS and outlines the potential implications of the findings for the design, administration, and representativeness of the survey;
- the second covers the findings from the documentation and literature relating to the SACE; and
- the third section highlights some comparisons between the two surveys.

It should be noted that the Adult Social Care Survey has been running since 2010-11 and the Survey of Adult Carers in England since 2012-13.[6] The focus of our review has been on the current methodology and guidance in terms of how both surveys run. However, in the ASCS section, we refer to some key methodological literature (on representativeness and including those lacking mental capacity and other hard to reach groups) written in the early years of the survey between 2010 and 2012.[7]

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[6] At the time when the surveys started NHS Digital was known as the Information Centre for Health and Social Care but we have referred to it as NHS Digital for consistency.

[7] When relevant, findings from this literature are discussed in our review, with reference to the extent to which issues of representativeness have been addressed through subsequent changes in the guidance or methodology and the extent to which there is more that could be learnt and implemented from their findings.

At the time of writing, the guidance for the 2019-20 ASCS survey had been published and the survey was being prepared for by CASSRs. The latest available published data and methodology were from 2018-19. Therefore, the 2018-19 or prior surveys are used when referring to information about completed surveys while, the 2019-20 or prior guidance is used for information on what the guidance says.

# 2 The Adult Social Care Survey (ASCS)

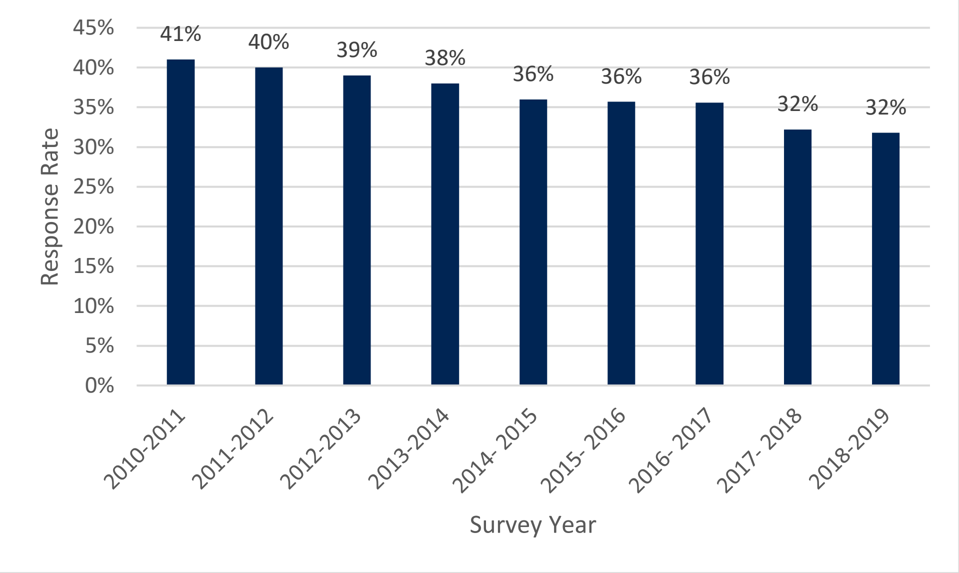
## 2.1 The current survey methodology [8]

### 2.1.1 Overview

The Adult Social Care Survey is a national survey that is run annually by NHS Digital. It collects information about the experiences of social care service users in England. The main mode of data collection is by post. The survey is administered by councils with adult social care responsibilities (CASSRs), but the data is analysed and reported on by NHS Digital both at national and local authority level. The findings from the survey generate estimates about service user outcomes, assess the performance of CASSRs in their delivery of social care services and help to improve services as a result.

As demonstrated in Figure 2.1 below, response rates have declined over the life of the survey; this is in line with many postal surveys.[9]

**Figure 2.1: ASCS responses rates from 2010-2011 to 2018-2019 [10]**



A key question in relation to the representativeness of the surveys is the extent to which response has declined evenly across all groups or whether declines in response have affected some groups more than others. If response declines faster for some groups, this could impact on the representativeness of the achieved sample. The picture is complex and fuller analysis was carried out as part of the secondary analysis element of the project and is reported separately.[11] Our own initial analysis of the public ASCS datasets shows that there is no evidence that ethnic minority groups are becoming less well represented over time because of declining response, while it would appear older people aged 65 and over across all ethnicities (including White British) are becoming less well represented.

It should also be noted that response rates vary considerably between CASSRs. In 2019-2018, the lowest response rate was 17.3 per cent and the highest 52.5 per cent. The majority of CASSRs (109 of

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[8] NHS Digital, ‘Personal Social Services Adult Social Care Survey, England - Methodological and Further Information’, 02 October 2018.
[9] See for instance Stedman et al (2019)
[10] NHS Digital, ‘Personal Social Services Adult Social Care Survey, England - Methodological and Further Information’ from 2010-2011 to 2018-2019
[11] Aznar et al (2020) Main report

the 151 responding that year[12]) had a response rate of between 25 and 40 per cent, and 19 CASSRs had a response rate of less than 25 per cent[13].

**Table 2.1: Summary of overall response rates for CASSRs in England, 2018-19**

| Response rate | Number of CASSRs with each response rate range |
|---|---|
| <20% | 5 |
| 20 to < 25% | 14 |
| 25 to <30% | 26 |
| 30 to <35% | 45 |
| 35 to <40% | 37 |
| 40 to <45% | 21 |
| > 45% | 3 |
| Total | 151 |

*Source: ASCS 2018-19, NHS Digital*

Response rates are lowest in the North West (30 per cent mean across local authorities) and London (31 per cent) and highest in the South West (38 per cent). Within London, response rates are lowest in inner London (29 per cent) and higher in outer London (31 per cent). Within other regions there is variation by type of authority. For example, in Yorkshire and the Humber responses rates are 40 per cent in counties and 36 per cent in unitary authorities and in the South West response rates are 41 per cent in counties and 37 per cent in unitary authorities.[14]

This variation in response rate by CASSR suggests that in looking at issues of representativeness, lessons can be learnt by looking at the activities and approaches of CASSRs with higher response rates and lower disparities in response between different groups. The ASCS response rates for 2018-19 were compared with those for 2017-18 in each CASSR. This showed that response rates went up as well as down from year to year. In 55 per cent of CASSRs response had gone down from 2017-18, with 11 per cent of CASSRs seeing a decline of five percentage points or more. Response had gone up in 43 per cent of CASSRs with increases of five percentage points or more in 14 per cent of CASSRs. An examination by CASSR type showed that in 74 per cent of the 27 shire counties' response rates had declined compared with 46 per cent of inner London and 45 per cent of outer London CASSRs. There was no clear link between representativeness by ethnicity and age and declines in response rates by CASSR.[15]

It would appear that any issues about response and representativeness are related to whether people start completing the questionnaire, rather than issues of dropping out of the questionnaire (for instance because they find it too long). In 2018-2019, more than 90 per cent of those who started the questionnaire answered the final question in all but ten CASSRs.[16] Participants do miss out individual

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[12] The Isles of Scilly and City of London were exempt from the survey in 2018-2019 as the number of service users within their area who met the survey eligibility criteria was too small to guarantee statistically robust results

[13] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Data Quality Report and the Data Quality Annex' 2018-2019

[14] Derived from information in the ASCS Data Quality Annex from 2018-19.

[15] Derived from information in the ASCS Data Quality Annex from 2017-18 and 2018-19.

[16] Derived from information in the ASCS Data Quality Annex 2018-19.

questions and continue with later ones so, item non-response varies between questions (up and down). In 2017-18 and 2018-19 on the ASCS item non-response was 7 per cent or less on all questions. The highest item non-response was on questions about paying for additional care or support, help received from family, how receiving help makes them think about feel about themselves, access to information and whether they feel safe. However, on none of these questions was item non-response greater than 7 per cent.[17]

### 2.1.2 Sampling

Every year, CASSRs choose a date between 30 September and 31 December to extract a list of service users from their systems. This list is the entire eligible population for the survey. To be included, a service user must be in receipt of long-term support services funded or managed by the council, at the point the list is extracted, following a full assessment of need.

A sample of service users are invited to take part in the survey. The findings are then used to make estimates about the whole population. These estimates are subject to a degree of uncertainty, defined as a ‘margin of error’. As the proportion of completed surveys increases, the margin of error decreases. Therefore, CASSRs are required to select a sample large enough so that the survey results have a relatively small margin of error (less than five percentage points).

ASCS uses a sampling method called stratified random sampling. This requires the eligible population to be split into separate groups (or strata), from which a sample is drawn from each group. This helps to make the sample more representative of the eligible population. It also allows CASSRs to oversample in a group of particular interest to ensure there are enough survey responses and that the findings are robust. If it is not possible to assign a service user to a stratum then they are removed. There are four strata, shown in Table 2.2.

**Table 2.2: Survey Stratum in ASCS**

| Stratum | Primary support reason | Age | Service setting |
|---|---|---|---|
| 1 | Learning disability support | Any | Any |
| 2 | Any excluding learning disability support | 18-64 | Any |
| 3 | Any excluding learning disability support | 65+ | Permanent residential or nursing care |
| 4 | Any excluding learning disability support | 65+ | Community based services (including supported living) |

These strata do not account for other characteristics of the population such as gender or ethnicity.

CASSRs must identify service users who should not participate in the survey and should therefore be excluded from the sample frame. This includes people who:

- Have stopped receiving long-term support services;
- Have died;
- Have moved elsewhere;
- Will be in hospital at the time of the survey;

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[17] Own analysis of ASCS public data.

- Are known to not have the mental capacity to consent to take part;
- Are involved in an open safeguarding alert or investigation;
- Are in an active dispute with the CASSR (the 2019-2020 guidance includes a definition of dispute "as a complaint that cannot be resolved by the council and moves on to be handled outside of the council by the ombudsman)".

Some CASSRs will identify and remove non-participants before selecting the sample. In other CASSRs service users may be identified and removed after the sample has been drawn, in which case they are replaced with other service users with similar characteristics. Service users who are removed from the sample are still counted as members of the eligible population but do not form part of the issued sample. The exclusion of eligible cases from the issued sample for the reasons given above is one of the contributors to the under-representation of some groups (particularly those lacking mental capacity), and this is a key focus of this review.

Weighting is used to adjust the survey findings to ensure that the analysis is representative of the eligible population, taking account of CASSR and the four strata described above. From 2014-15 onwards, the survey has used question specific weights which are calculated by dividing the count of the target population by the count of usable responses to that question (the inverse probability of responding to that question) in each CASSR for each stratum. This means that, for example, the proportion of older people (65+) living in residential or nursing homes responding to a specific question is corrected to match the proportion of older people in residential and nursing care in the eligible population. However, the weighting does not correct for the under-representation of subgroups (e.g. specific age groups, ethnicities or gender or combinations of these) within the strata, through variable response. It also does not correct for the systematic and intentional exclusion from the issued sample of certain groups in the eligible population such as those lacking mental capacity or in dispute with the CASSR.

### 2.1.3 Survey design

There are two main versions of the questionnaire: one for service users in residential or nursing care, and one for those who receive community-based services.

NHS Digital also provide a number of accessible versions of the questionnaire including:

- An easy read version (designed for service users with a learning disability);
- A large-print version (designed for people with visual impairments);
- Translated versions (for service users who may not be fluent in English) which are available on request.

The questionnaires are also provided as interview scripts so CASSRs can offer face-to-face or telephone interviews to service users who require this format in order to be able to participate.

#### Content

The survey asks service users about the impact of care and support services on the quality of their life. The survey also collects information on the participants' self-reported health need for support. The main sections of the questionnaire are generic and relevant to all CASSRs. The questionnaire is designed not to have routing so that all questions are relevant to every participant.

There is also the option for CASSRs to include additional questions or open-ended questions for local research purposes, however these amendments are subject to NHS Digital approval. Approval is needed to ensure the number of questions, placement, subject matter, routing and ethical requirements related to any new questions are suitable. A selection of additional questions previously used is available in a question bank available on the NHS digital website.[18] In 2018-19 information was provided on how many local authorities included additional questions without approval (15 of the 150 participating CASSRs) but information was not publicly available on how many included the optional questions.

### 2.1.4 Supporting survey materials

NHS Digital provides all CASSRs with detailed survey guidance, the questionnaires and additional survey materials.

In addition, NHS Digital provide the following documents:

- A cover letter, including easy read and large print versions;
- A reminder letter, including easy read and large print versions;
- A cover letter to care homes and supported living managers to encourage response;
- A letter to care homes to check capacity of their residents;
- A translation request sheet;
- A consent form for face-to-face interviews, including an easy read version.

The guidance and materials are updated every year to introduce improvements and refinements to those documents.

### 2.1.5 Fieldwork and analysis

The recommended fieldwork period is between January to March. During this time, questionnaires are distributed to service users and then collected once completed. In most cases, a questionnaire (the version most appropriate for the individual) is posted to each person in the sample. While CASSRs send standard English questionnaires in most instances, easy read versions are mailed out to all service users in stratum 1 (people with a learning disability). In addition, CASSRs should look at their service user database and identify people who might require:

- An alternative version of the questionnaire (easy read or/and large print);
- Assistance in completing the survey;
- Relevant translated materials should be sent with the initial invitation where the service users first language is known and is not English (as well as the English version of the materials);
- A translation request sheet where the service users' first language is not known by the council.

One reminder letter is sent to each person who does not respond. The completed questionnaires are manually coded onto a data return spreadsheet (provided to CASSRs by NHS Digital) and returned to NHS Digital for validation and analysis. The ASCS Data Quality Annex for 2018-19 shows that in 11 CASSRs the use of reminders was not consistent with NHS Digital guidance. However, there was no clear pattern of these local authorities having exceptionally high or low response rates and these local authorities experienced both increases and decreases in response between 2017-18 and 2018-19.[19]

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[18] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-user-survey-2018-19

[19] Derived from information in the ASCS Data Quality Annex from 2017-18 and 2018-19.

## 2.2 Sources of under-representativeness

Groups are under-represented in the survey data if they form a smaller proportion of the achieved sample size than they form of the eligible population (all service users, at the point data are extracted, who are in receipt of long-term support services funded or managed by the council following a full assessment of need). The causes of under-representation can lie at several stages in the survey process:

1. If the data held by the CASSRs on the eligible population are not up to date or complete at the point the data are extracted, some eligible people may be excluded.

2. The rules for excluding certain groups from the sample frame and initial issued sample will result in eligible service users not being represented in the survey at all (e.g. those lacking mental capacity, those in dispute with the local authority, those in hospital at time of survey fieldwork). If certain types of service user or demographic groups are more prevalent among some of the groups excluded from the survey, this may result in their under-representation in the data.

3. Differential response to the survey as a whole among the final issued sample will also contribute to certain groups being under-represented.

4. Differential response to individual questions within the survey, even among those who complete at least part of the questionnaire and return it.

The full analysis of the survey data to look at the representativeness of the achieved sample compared with the eligible population is a separate strand of this research. However, evidence from information published and made available by NHS Digital and reported on in previous research shows that loss of those lacking mental capacity is a particular issue at the stage of exclusion from the sample frame. At the stage of response, groups such as service users from an ethnic minority background and service users whose primary support need is mental health are under-represented. The following sections look at each of those stages to examine issues of under-representation in more detail.

## 2.3 Completeness of data on the eligible population

The survey design relies on CASSRs having accurate and up to date information about their eligible service user population at the time when the initial sample frame (prior to exclusions) is drawn. Although a three-month timeframe is allowed for extracting this, there can still be issues about the source data being complete at the point of making the extract. NHS Digital monitors when the extracts are taken. It also monitors the extent to which they differ from the Short and Long-term Services (SALT) collection[20], and highlights differences of more than 20 per cent.

In 2018-19, NHS Digital noted that:

- Seven local authorities took the extract outside the designated period: two earlier in September, and five later in January and February.
- There were nine local authorities where the difference from SALT was greater than 20 per cent (with the greatest discrepancy being 95 per cent). Although the mean discrepancy between

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[20] The Short and Long Term Services (SALT) collection relates to the social care activity of CASSRs. It is published annually based on data drawn from council administrative systems. The purpose of the publication is to enable key aspects of the provision of social services across England to be assessed, at both national and local level. Data from the SALT collection are used to create a number of the measures in the Adult Social Care Outcomes Framework (ASCOF).

SALT and the eligible population at CASSR level is -3.6 per cent , this hides considerable variation.[21]

- Some CASSRs reported difficulties in obtaining all the data requested for the SALT sampling process. For example, one council informed NHS Digital that they were unable to include all the eligible service users in their sample at the time of data extraction because some service user information is only available annually.[22]

However, the published evidence suggests that being able to extract the complete and correct eligible population when required is not widely reported by CASSRs.[23]

Another potential issue in the CASSRs' information on the eligible population is the extent to which details about the characteristics of this population are held. Some CASSRs reported that they do not collect certain demographic data such as religion or sexual orientation. Others do not collect ethnicity at the same level of detail as other authorities or have high levels of missing data. This limits the comparability of data across CASSRs and the ability to carry out analysis on the extent to which certain groups may be under-represented in the data.[24] Consideration should be given to whether certain demographic data should be collected as standard across CASSRs in order to monitor service delivery, and target appropriate support or translations when carrying out surveys.

## 2.4 Completeness of the sample frame and issued sample

### 2.4.1 Assessing mental capacity

Official survey guidance from NHS Digital states that CASSRs must identify service users who should not participate in the survey. This includes service users who are known to not have the mental capacity to consent to take part.[25] This is to comply with ethical approval which requires that only those with capacity to consent can participate.

This raises two significant issues for the ASCS. One is how CASSRs can identify who lacks capacity and exclude them from the sample in practice, and consistently. The other relates to the lack of data on the experience of social care services this group: excluding those who lack capacity from the sample frame or from the sample means that an important element of the eligible population is excluded from the research.[26]

### Implementing the guidance around capacity in practice

CASSRs must write to the managers of residential and nursing care homes and supported living establishments to ask whether they care for any service users who lack the mental capacity to take part in this survey. They can do this before the initial sample is selected (thus excluding them from the sampling frame), or afterwards (removing them from the sample and replacing them). The guidance suggests that, despite being more resource-intensive, it is better to contact care homes and supported living establishments before the sample is selected. This is so that service users who lack the mental capacity to consent can be excluded from the sample frame, and do not have to be subsequently

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[21] Derived from information in the ASCS Data Quality Annex from 2018-19.

[22] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England 2017-18 – Data Quality Statement', October 2018.

[23] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England 2017-18 – Data Quality Statement', October 2018.

[24] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England 2017-18 – Data Quality Statement', October 2018.

[25] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England - Information and guidance for the 2019-20 survey year', Updated in January 2020.

[26] The literature review and main report explore how the views of those with cognitive decline could be included in the survey. Aznar et al 2020.

substituted. In cases where the CASSRs receive no response from the care homes and supported living establishments, it is assumed that the service users have the capacity to participate and the surveys are sent out.[27]

The guidance also recommends that CASSRs flag those removed due to lack of capacity on their databases to improve the efficiency of future surveys. This proposal has received mixed support from CASSRs: there is a concern that this method does not account for service users with fluctuating capacity to consent and in this way might exclude individuals unnecessarily which would negatively affect the representativeness of the sample (especially from those receiving care from nursing or residential homes or supported living establishments) and of the survey data. However, the 2019-20 information for care home managers makes it clear that they should report separately on those who have permanent loss of capacity (a new element of the guidance) and explicitly mentions that some residents may have fluctuating capacity.

A 2010 ONS review of the ASCS methodology found that the guidance was unclear about whether determining the capacity of service users required a conversation with the individual or not. It was suggested that this needed to be clarified to help ensure CASSRs were able to confirm the capacity of service users and exclude them where necessary.[28] It was suggested that a consultation with CASSRs should take place to develop a common method for defining eligibility based on capacity to consent.[29] At that time, there were also concerns about the burden involved in implementing the approach to assessing who has capacity. Following discussions with CASSRs who were part of the Social Services User Survey Group [30] and with the Social Care Research Ethics Committee (REC), it was agreed that this should only be applied to people living in residential care homes.

The guidance was amended the following year to improve the consistency across CASSRs of assessing whether service users have the capacity to consent to take. It now puts care home managers in charge of doing so by speaking to the care home resident or by using their own previous knowledge and judgement (previously councils were asked to check capacity for all service users and there were concerns that the process was not being applied consistently).

The standard survey materials include a letter to care home managers explaining how they should assess capacity with the focus being on capacity to consent, rather than capacity to take part. The relevant text is:

*"Before we send the questionnaires to the residents I need your assistance to assess whether each person has the capacity to consent to take part in the survey. To do this, the following issues need to be considered in respect of the individual residents listed:*

- *Will they understand that the survey seeks their views about the quality of their life and their services?*
- *Will they understand that lots of people will be asked these questions and they are not being singled out?*

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[27] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England - Information and guidance for the 2019-20 survey year', January 2020.

[28] Williams and Betts, 'Review of Methodology for the National Adult Social Care User Experience Survey', conducted for the National Health Service Information Centre for Health and Social Care by the ONS Methodology Advisory Service, published December 2010.

[29] Williams and Betts (2010)

[30] The Social Services User Survey Group (SSUSG) oversees a programme of user experience surveys for social services, developing their content and advising on the methodology.

- *Will they understand that these questions are being asked to understand how happy people are with their care and support services and assess their experiences of local care services?*

*If there is no evidence that the person lacks capacity to consent to take part, or if capacity fluctuates and the person may be able to answer at some point then capacity can be assumed.*

*You should not automatically exclude everyone with dementia or a learning disability, as development work which took place for the survey confirmed that many people with these impairments were able to give consent to take part and answer the questions. An easy read version of the questionnaire will be made available for those residents with a learning disability."*

Despite the clear guidance for CASSRs and care home managers in 2018-19, some CASSRs reported difficulties in confirming the capacity of service users in nursing and residential homes or supported living services. This has led, in some cases, to service users being included in the sample without the necessary capacity checks having been completed.[31] While NHS Digital reports on this in their data quality annex, the scale of this is not reported.

## The impact of the exclusion of those who lack capacity for the representativeness of the survey

Within the current survey methodology and ethical approval framework, the main issue in relation to mental capacity is ensuring that the checks are carried out appropriately, and that all participants are able to give informed consent. However, looking at the overall purpose of the survey, as described by the NHS Digital, if those who lack mental capacity to consent are excluded from the sample, this will limit the usefulness of the survey.

In the guidance's methodology and information sections, the following information is given: "*The survey is designed to help the adult social care sector understand more about how services are affecting lives. User experience information is critical for understanding the impact of services, for enabling choice and for informing service development."* [32] User experience information is also relevant for those who lack mental capacity and yet obtaining information on their experience is challenging. Beyond the issue of consent to take part, there is also the practical issue of how to gather views from those who lack capacity.

The question of support in completing the questionnaire is covered in detail in a later part of this review report. In summary, it shows that the majority of participants receive some kind of support in completing the questionnaire, such as having questions read out or answers written. About 10 per cent of participants have the questionnaire completed on their behalf, rather than merely help with completion. Among those receiving care for memory and cognition problems, 26 per cent have the questionnaire completed on their behalf. There is a clear link between satisfaction with care and the type of help received. In the ASCS 2018-19 among those who had no help with the questionnaire, 26.4 per cent reported being extremely satisfied with their care. Among those who had help from a care worker with completing their questionnaire, 40.6 per cent reported being extremely satisfied. The figure for those who had help from someone in their household was 25.2 per cent, and for those receiving help from someone living outside their household it was 23.1 per cent.[33] This demonstrates the risk of bias caused by allowing care workers as proxy respondents and shows that help from family or friends appears to introduce less bias. However, it is also possible that those who are able to get help from a care and

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[31] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.
[32] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.

33 ASCS Annex tables 2018-19.

support worker with tasks such as completing a questionnaire may have a higher satisfaction with their care. It is not possible to distinguish this from potential bias in the data.

A separate research project has also been exploring the potential for developing a proxy version of the questionnaire.[34] It found that there are challenges in assessing outcomes by proxy, such as whose perspective proxy respondents are being asked to provide information from, the potential impact of differing proxy perspectives and motivations, and difficulties around answering questions that were perceived to be 'more abstract', such as dignity. However, those can be mitigated through developing and testing proxy measures in a robust way. In the context of the ASCS, the development of a proxy version offers the possibility of including those who lack mental capacity in the sample. Doing so would require further discussion with the Social Care REC on how to obtain appropriate consent from or on behalf of the service users when proxy respondents are answering on their behalf. However, with the development of a clear and robust proxy questionnaire, consent could potentially be obtained from a consultee tasked with giving advice about a service user's wishes (i.e. to make a judgment on whether they feel the service user would or would not have wished to participate, if they had the capacity to decide).[35] This consultee then has the option of taking part as a proxy. This is the approach taken in the English Longitudinal Study of Ageing when existing panel members lose capacity to take part.[36] Although proxy information gathered from a consultee or someone nominated by the consultee is less reliable than information directly collected from service users, it is still preferable to no information at all, providing the proxy is not involved in the provision of the care being considered in answering the survey questions. If such a proxy option is developed, it will also be important to update and clarify the guidance for carers on providing support when the service user can participate but still requires with some help in complete the survey.

### 2.4.2 Survey fatigue

Given that the service user population is relatively small in each CASSR and people may use services across several years, the same people may be sampled in consecutive years for the survey. The official survey guidance explains that appearing in the sample in consecutive years would not be considered to cause survey fatigue and therefore would not be an acceptable reason for removing service users from the sample. [37]

However, there can be some inconsistency between CASSRs in their approach to addressing survey fatigue. In 2018-19, some CASSRs reported removing service users who had completed the ASCS survey in 2016-17 (three councils removed all services users who had completed the previous survey on this basis). Doing so has the potential to bias the survey as sampling is carried out by strata, and strata with fewer service users are more likely to be affected by the removal of sample for reasons of survey fatigue.

Even where the guidance on survey fatigue is being correctly applied to excluding those involved in other surveys, it highlights that there is potential for bias to be introduced if the previous surveys focussed on

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[34] Caiels et al (2019) Exploring the views of being a proxy from the perspective of unpaid carers and paid carers: developing a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT). BMC Health Services Research, 19 (1).

[35] In England and Wales the Mental Capacity Act 2005 (MCA) has provision for consulting an individual who knows the person with impaired capacity well, such as a family member, to advise about research participation on the person's behalf. The consultee is provided with information about the project and asked what the potential participant's likely wishes and feelings would be about taking part in the project if he or she had capacity. Any indication that the person would not have wished to participate must be respected. Responsibility for deciding whether to include a person lacking capacity lies ultimately with the researcher. Should no appropriate relative or friend be available or willing to act as the person's 'proxy' or 'surrogate', under the MCA there are provisions for a professional to act as a nominated consultee.
Mental Capacity Act. 2005. https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf.

[36] Bridges et al. (2015) The dynamics of ageing: The 2012 English Longitudinal Study of Ageing (Wave 6) Technical Report.

[37] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', published 22 October 2019.

particular groups of service users. NHS Digital advises CASSRs to discuss this with them, and records CASSRs which removed service users who had received another council run survey in the preceding few months (for example one council removed 270 service users on this basis in 2018-19).

### 2.4.3 The exclusion of short-term users

The eligible population of adult social care users was previously determined by a using the Referrals, Assessments and Packages of Care (RAP) system. This has been replaced by Short and Long-term Services (SALT) table in 2014-15. To be included in the SALT table, a service user must (at the point of data extraction) have had a full assessment of need and be in receipt of long-term support services funded or managed by the council. As a result of this change to the sampling criteria, service users who only rely on CASSRs for the provision of equipment, professional support or short-term residential care (up to six weeks) are no longer included in the eligible population. The only exception to this (in which case, the short-term service user *is* included in the eligible population) is when an individual receives professional support for their mental health needs, even where this is the only service they receive.[38] This change to SALT also resulted in 'Full-cost clients' (those who pay for the full costs of their services, but whose care needs are assessed and supported through the LA) being included in the sample through SALT when they were not previously.

This change greatly reduces the number of short-term users included in the sample. However, an announcement from the NHS Digital on the change in ASCS methodology reported that it might enable greater comparability of findings across CASSRs, in that it minimises possible inconsistencies in the inclusion of these service users (which were common, especially for those in receipt of reablement services).[39]

Due to the exclusion of the majority of short-term users in the ASCS, the Department of Health and Social Care has been making a case for a separate survey to capture the views of this group. The number of people receiving short-term care has been increasing in recent years, so the need is becoming increasingly urgent. The proposal is that the survey should gather information on a rolling basis, on a fixed date and after the completion of ASCS. This would require a large enough eligible population within CASSRs for statistically robust data. The current estimate is that between 62 per cent and 97 per cent of CASSRs would be able to take part in a survey of this kind, although available Local Authority resources to run it might be problematic (if the ASCS methodology remains as it currently is with annual surveys).[40]

Although it may be feasible to take an annual extract at one point in time (similarly to the ASCS) of short-term users of care over the last 12 months, there are some obvious issues of recall in carrying out a survey annually when service users may have received six weeks of support up to 11 months before the survey. If only recent or current service users were selected, there would be fewer recall issues, but the sample would be small within a local authority and may not be representative of the population of short-term service users over the whole year. This means that consideration needs to be given to a more rolling approach to extracting the sample for this population, as suggested by DHSC. This could be done by contacting people a fixed time after their short-term care ends. Protocols would be needed for cases where an individual user needs more than one episode of short-term care in a year. A decision needs to be made about whether the case is an individual (who should only be asked about short-term

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[38] Health and Social Care Information Centre, 'Announcement of methodological changes to the Personal Social Services Adult Social Care Survey, England, 2014-15', published in July 2015. (HSCIC is the previous name of NHS Digital)

[39] Health and Social Care Information Centre, 'Announcement of methodological changes to the Personal Social Services Adult Social Care Survey, England, 2014-15', published in July 2015. (HSCIC is the previous name of NHS Digital)

[40] Department of Health, 'Business case for a survey of short-term support to maximise independence (reablement) clients', published in 2010.

care once) or whether a case is an episode of care meaning the same user could take part more than once (providing the burden is not considered to be excessive). If the survey took place after an episode was complete, it should be borne in mind that the user may still be receiving care which may be another episode of short-term care or may be a transition into long-term care. Rolling sample design would need to take account of seasonality, with weighting used to correct for this (if sample sizes in the stratum used in the design are sufficient).

## 2.5 Response

### 2.5.1 Under-represented groups

The guidance does not currently provide any recommendations on how to encourage the participation of specific under-represented groups. These under-represented groups include people with mental health problems, working-age people, nursing home residents, people with severe disabilities, people from an ethnic minority background, and those from more deprived areas.[41] Their under-representation in the survey makes it difficult to gain a good understanding of their perspectives on the outcomes from the care they receive.[42]

The guidance emphasises the importance of maximising response generally, particularly to ensure that the survey does not suffer from the bias associated with those who are less satisfied being more likely to respond to the survey. It also highlights the availability of support to ensure people, such as those not fluent in English, with sensory impairments and with limited literacy, are not excluded from the survey. However, there is no discussion that certain groups are known to be under-represented in the survey and how to encourage their participation. A single response rate is published for each CASSR but response rates for subgroups in England or individual CASSRs are not published, meaning awareness in CASSRs about under-represented groups is likely to be limited.

Beyond this, it is difficult even to determine the extent to which some groups are under-represented due to the broad categories used by CASSRs to record information. For example, according to Malley (2017), "*most CASSRs report ethnicity according to six categories (White, Mixed, Asian, Black, Chinese and other), which are clearly too broadly specified to pick up on under-representation of the growing and relatively new immigrant communities, such as people from Eastern Europe*."[43] Additionally, ethnicity is a very poor indicator of English literacy and therefore cannot be used to assess the extent to which people illiterate in English are under-represented. The published raw data includes information on the issued and responding sample, offering scope for analysis but this only includes very broad information about age, ethnicity and other demographic groups (16-64/65+, white/ non-white). Access to more detailed data is controlled, making it challenging to carry out more detailed analysis of response for relevant subgroups and across groups.

The explanation for the under-representation of these groups could be complex and is currently poorly understood. For example, it may be that the survey is not accessible enough to certain groups.[44] It may also be that some groups invited to take part see the survey as less relevant or may lack understanding about the value of the survey, and thus the importance of taking part. These specific issues are addressed in the following sections.

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[41] Malley, 'Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators- An Application to Adult Social Care in England', a thesis submitted to the Department of Social Policy at the London School of Economics by in January 2017.

[42] A detailed analysis of which groups are under-represented in response is the focus of the secondary analysis part of this project but previous research provides some evidence on this.

[43] Malley (2017)

[44] Accessibility relates to whether participants are able to access information, and participate in the research in the format it is provided in.

### 2.5.2 Weighting for non-response

Survey weighting is a process whereby weights are applied to the survey data to make the sample more accurately reflect the characteristics of the population from which it was drawn and to which an inference will be made. The correction technique assigns an adjustment weight to each survey respondent. People in under-represented groups get a weight larger than 1, and those in the over-represented groups get a weight smaller than 1.

At present, the weighting scheme for the survey adjusts for the under-representation by stratum and CASSR but not for other characteristics which may be under-represented. The ONS review of the ASCS methodology, suggested that a weighting scheme could be developed and applied to ‘correct’ the non-response and under-representation of certain groups. However, when the survey was established, it was judged to be too complicated for CASSRs to carry out, especially in addition to population weighting.[45] The official survey guidance at present does not suggest CASSRs apply any additional weighting. This could be to address the exclusion of groups from the sample (such as those lacking mental capacity) or to address lower response among certain groups. Any new weighting scheme would need to include detailed guidance for CASSRs on how to apply it or would need to be prepared by NHS Digital based on data provided by CASSRs.

### 2.5.3 Survey fatigue

CASSRs may exclude service users from the sample if they have taken part in other surveys, but not in previous years of the ASCS. The impacts on the issued sample are covered in section 2.4. However, survey fatigue may also impact on response to the survey:

- Firstly, the ASCS is carried out annually and is based on a random sample. This means that an individual may be asked to take part in two or more consecutive years.

- Secondly, the sampling is carried out by strata and this means that service users may vary in the extent to which they are likely to be sampled in two consecutive years. This may also vary by CASSR, with service users in small strata CASSRs potentially being sampled every year.

This could lead to lower response rates among groups which are more affected by fatigue. Over the whole survey in 2018-19, 34 per cent of the eligible population were sent a questionnaire but this varied from less than 20 per cent in 23 local authorities, to more than 75 per cent in 18 local authorities. In these local authorities most service users would be sampled every year.

The percentages of eligible service users sent a questionnaire by stratum shows that stratum 2 (18-64, excluding learning disability) is most likely to be affected by repeated sampling.

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[45] Williams and Betts (2010)

**Table 2.3: Percentage of eligible population issued to ASCS by stratum (2018-19)**

| Stratum | Percentage issued overall | Number of local authorities with <75 per cent of the stratum issued |
|---|---|---|
| 1. Learning Disability support | 31 per cent | 18 |
| 2. 18-64, excluding Learning Disability | 36 per cent | 26 |
| 3. 65+ in Residential Care, excl Learning Disability | 31 per cent | 10 |
| 4. 65+ in Community, excl Learning Disability | 34 per cent | 20 |

A greater focus on the impacts of survey fatigue on response, and the uneven impacts of this in individual local authorities, could assist local authorities in encouraging response among these groups. The survey invitation letter explains how participants were selected and that it is voluntary, but does not offer any acknowledgement that they may have received the same questionnaire in the past and that taking part each year is valuable to enable local authorities to monitor the care being received. An explicit mention of the value of participating each year may be helpful in boosting response, and might assist in boosting response among the ‘18-64 excluding Learning Disability’ stratum, where most mental health service users would be included (one of the under-represented groups).

### 2.5.4 Use of incentives

The current 2019-2020 official guidance advises all CASSRs *not* to offer financial incentives to try and ensure the data is as comparable as possible across local authorities.[46] The wording does not forbid their use but discourages this.

Yet some CASSRs choose to use incentives to encourage participation and this information is recorded by NHS Digital in the data quality annex. In 2018-19, four local authorities were recorded as having used incentives, but the nature of the incentives offered is unknown.

Analysis was carried out by NHS Digital on question responses from councils that used incentives, compared to those that did not. Analysis of the ASCS 2017-18 data showed that the response rates for the six CASSRs which used incentives that year were lower than those for the remaining 144 CASSRs (though the differences are not statistically significant).[47]

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[46] NHS Digital, ‘Personal Social Services: Adult Social Care Survey, England - Information and guidance for the 2019-20 survey year’, January 2020.

[47] NHS Digital (2018) Personal Social Services Adult Social Care Survey, England 2017-18, Data Quality Statement https://files.digital.nhs.uk/E5/0D875E/pss-asc-eng-1718-data-quality-statement.pdf

**Table 2.4: Average response rate and Margin of Error achieved by CASSRs that did and did not offer incentives**

| | Used Incentives | Did not use incentives |
|---|---|---|
| Average response rate | 30.0% | 33.6% |
| Average Margin of Error[48] | 4.0% | 4.5% |

*Source: ASCS 2017-18, NHS Digital*

There were some differences in the individual question responses. Overall, it appeared that CASSRs which offered incentives had lower levels (60.6 per cent) of respondents who answered they were extremely or very satisfied with the care and support they received, compared to CASSRs that did not offer incentives (65.1 per cent).[49] This may reflect differences in satisfaction levels in the CASSRs which chose to use incentives rather than any impact of the incentives.

In assessing whether incentives have an impact, more complex analysis than this is needed, since incentives may have been offered in CASSRs where response is low, and so it is not possible to judge from the analysis conducted what impact the incentives had on response. An experiment where CASSRs are randomly assigned to incentive or no incentive (or comparison of response in an individual CASSR when incentives are not offered and when they are), repeated over time, would be more useful. Further analysis on the type of incentive offered and its impact on the response rate of different groups, including harder to reach ones, would also be useful.

Whilst existing research suggests that incentives significantly increase response rates in some other surveys (specifically among some of the key groups who typically do not respond to surveys e.g. young people and those with lower incomes), there is currently insufficient evidence from the ASCS on the impact of incentives. This could be because CASSRs tend to offer conditional incentives (e.g. prize draws), which are less effective than unconditional pre-paid incentives (e.g. cash or shop vouchers).[50]

Given the lack of evidence of the effectiveness of incentives as part of ASCS, and more general concerns about creating a sense of obligation among participants to complete the survey, Malley and Smith (2012) conclude that further research (including a randomised control trial) is required before incentives are officially recommended.[51] A review of the ASCS methodology conducted by ONS in 2010 also suggested that analysis into the effectiveness of incentives should be done to inform future strategy, and that if included in the official guidance, it should be noted that unconditional incentives have a greater effectiveness on response rate than conditional incentives.[52] However, current financial pressures on local authorities mean that it is unlikely that incentives could be required across all CASSRs and could only ever be optional, unless funded by NHS Digital.

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[48] Margin of error is a statistic expressing the amount of random sampling error in a survey's results.
[49] NHS Digital (2018) Personal Social Services Adult Social Care Survey, England 2017-18, Data Quality Statement
[50] Malley and Smith (2012) ‘Understanding and addressing under-representation in a postal survey of social care users’, for the Policy Research Programme at the Department of Health under the Quality and Outcomes of Person-Centred Care Research Unit.
[51] Malley and Smith (2012)
[52] Williams and Betts (2010)

## 2.6 Supporting materials

### 2.6.1 Guidance on seeking help to complete the survey

If service users require help to complete the survey, the official survey guidance suggests that they seek assistance from family members or friends. NHS Digital permits service users to be assisted in completing the survey if needed, because it recognises this is essential to ensuring the survey is representative of as many service users as possible. This has the potential to reduce response bias. However, in cases where service users are assisted in completing the survey, it is important that their views and experiences (and not the views and experiences of the person assisting the service user) are recorded.[53] This is stressed in the survey guidance and the cover letter for participants.

A research project carried out by the Personal Social Services Research Unit (PSSRU), which aimed to review specific areas of concern around how the ASCS would operate, suggested several measures which could help to avoid the data being influenced by people providing assistance to service users in the completion of the survey.[54] Most of these are included in the current survey design, including:

- Provision of explicit instructions to the front cover for people providing assistance (this is covered but is addressed to the service user rather than the carer);
- Inclusion of additional questions in the survey about the person providing assistance (their relation to the participant and how they helped them);
- Signposting to the survey for carers, to highlight opportunities for carers' views and experiences to be heard (this is not included in the letter because the carer's survey does not happen every year).

Avoiding bias may be particularly difficult in cases where the person providing assistance in the completion of the survey is closely involved in the service users' care, e.g. in care homes. Given that service users in care homes may be more likely to need and seek help from care home staff, a number of specific measures, suggested by the ONS review [55], are used to minimise the data being influenced by care home staff. They include:

- A letter from CASSRs to care home managers is used to gain support for the survey in advance and explains their role in providing assistance to participants. This is intended to ensure care home staff are engaged with the survey process and are able to offer assistance to residents in the appropriate way if needed;
- The letter to the care home manager suggests care home staff should encourage residents to seek assistance from visitors, advocates or the council helpline, before asking staff, as they are less likely to bias the participants' responses;
- The letter to the care home manager explains the way in which the data will be used, to ensure care home staff understand that the findings will not be used to judge the care home. This might encourage care home staff to remain impartial when providing assistance to residents.

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53 NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.
54 NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.
55 NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.

The nature of help received, as well as the source of support, is recorded in the questionnaire and published by NHS Digital.[56] As discussed in 2.4.1, the survey results do differ according to whether help is received in completing the questionnaire and whom the help is received from.

The majority of participants do receive help of some kind in completing the questionnaire (79 per cent reported receiving help overall, with 87 per cent of those in residential care homes receiving help in 2018-19).[57] Although the guidance advises against help from care workers in completing the survey, and suggests that councils should encourage friends and relatives to help, rather than those involved in providing services, it does recognise that this can be hard to achieve. Indeed, overall a quarter (25 per cent) received support from a care worker and this was highest for those with a learning disability (47 per cent) and those living in residential care (32 per cent). Therefore, support from care workers as well as friends and family is well-established on the survey, even if it is cautioned against and the guidance suggests this is an exception. In practice most participants, including those using easy read and translated questionnaires, still need support to use them.

Among those receiving assistance, the most common form of help was someone reading out the questions (48 per cent of the whole sample received this help in 2018-19), and the majority had some input into the responses given. However, despite the guidance provided to care homes, and in the cover letter, ten per cent of the sample overall reported that someone else responded on their behalf, and this figure was 26 per cent of those requiring help with memory and cognition. This also varied by who was providing support, with only 2 per cent of those who received help from a care worker having the questions answered for them compared with 18 per cent of those receiving help from a non-care worker. However, the data also show that 32 per cent of those who had help from a care worker reported talking through the questions with someone else, suggesting that care workers are offering more than just reading and writing help in completing the questionnaire.

### 2.6.2 The potential for a proxy version of the questionnaire

Researchers have been exploring the possibility of developing a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT) scale.[58] This poses challenges given that evidence suggests that carers tend to under-report care recipients' quality of life compared with care recipients' self-reported quality of life. There is also potential confusion over whose views are being sought and the risk that once a proxy version is available, those who would have been able to take part themselves may be excluded from a self-report option. Discussions were held with unpaid carers individually and care and support workers in focus groups. Unpaid carers were more comfortable with the idea of being a proxy participant than paid care workers were. This was because paid care workers' training emphasised the importance of service user involvement and the answers they would record reflected the care they were providing themselves. The researchers recommend that where a proxy approach is being used, the views of the proxy and their perceived views of the service users should also be captured. It also suggested that a comment box should be offered to allow explanations to be given (though the feasibility of handling this open data in the context of the ASCS needs further consideration). Finally, the role of the proxy respondent in the completion of the questionnaire and their relationship to the service user should be captured in the questionnaire. They should also be given clear guidance around what they should and should not do.

Cognitive testing of the ASCS questionnaire in the context of a research project about satisfaction with social care among Pakistani, Bangladeshi and white British service users highlighted the difficulty which

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[56] ASCS 2018-19 Annex tables
[57] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', 22 October 2019.
[58] Caiels et al. (2019)

unpaid and paid care workers had in answering satisfaction questions from the perspective of the service user, as well as confusion over who was referred to as 'you' in the question wording.[59] Although, the cover letter explains that 'it is only your views and experiences that are important here so they must complete the form by recording your exact responses to the questions', within the main questionnaire there is no reminder to respond only from the service user perspective. Thus, when using the current questionnaire, once completion is underway, and questions repeatedly refer to 'you', it could be that those answering on behalf of the service user slip into answering from their own perspective.

Given that proxy responses are already being received from the ASCS, and there is evidence that it is challenging and carers vary in the way they respond, the development of a proxy version with clearer guidance to carers about their role and whose perspective is being captured would be valuable. This would ensure that the quality of proxy data already being captured is improved and may also mean that some service users in the sample who are currently unable to take part could do so through a proxy survey.

The high response to the easy read version of the ASCS, and the role of care workers in supporting service users to take part using this option, suggests an alternative easy read questionnaire aimed at those who have age-related cognitive decline could be developed to enable them to give their views even if the standard questionnaire is not feasible for them. Furthermore, if a more explicit proxy approach is taken for those who could not access any type of questionnaire, consideration should be given to whether there is a group who could give consent to take part and provide views on their quality of life and service use experience using a more flexible and open-ended tool.

### 2.6.3 Survey letters and reminders

The official survey guidance states that CASSRs are not required to send the second reminders if a "sufficiently high response rate" has already been achieved. A review of the ASCS methodology by ONS suggests that CASSRs should contact all non-responders with two reminders to minimise non-response bias. Additionally, recording information about the responses collected after each reminder could be used in future surveys to inform communication strategies and optimise response rates.[60]

A review of the ASCS methodology conducted by ONS suggested that CASSRs should consider using a mixed-mode follow-up approach, as research shows this to be optimal for maximising response rates. This involves using different stimuli each time participants are contacted (e.g. a thank you card for the first contact, followed by a letter and attached questionnaire for the second contact).[61] However, NHS Digital decided at that time that a single reminder letter was all that was feasible for local authorities.

The review recommends several other specific changes to the survey letters, which could help to optimise response rates.[62] These include:

- Using more expressive phrases to demonstrate gratitude for participation;
- Reference the availability of other versions of the questionnaire;

- Placing the information about confidentiality higher up so it is more prominent;

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[59] Gray et al (2014) Exploring Satisfaction with social care services among Pakistani, Bangladeshi and white British populations: Findings from cognitive interviews.
[60] Williams and Betts (2010)
[61] Williams and Betts (2010)
[62] Williams and Betts (2010)

- Reducing the length of the letter.

Additionally, there is evidence to suggest that personalised survey letters (i.e. addressing the individual by name) and handwritten or personalised signatures (i.e. from the research team) can positively impact the response rate of postal surveys.[63]

Malley (2017)'s exploratory analysis suggests further research (including a randomised control trial) should be done to explore the potential of 'chasing' non-responders by email.[64]

Since participants may be invited to take part in consecutive years, and CASSRs should have this information, including a thank you for previous participation in the letter for the following year could be valuable by acknowledging that they have previously taken part. This would be straightforward to implement, though would add some cost given the need for differential processing of letters.

## 2.7 Survey design

### 2.7.1 Survey mode

The primary mode of the ASCS is postal, though scripts for face-to-face and telephone interviews are made available to CASSRs, and an online survey was piloted in two CASSRs in 2018-19. NHS Digital could consider extending the use of alternative modes to help improve response rates.

A review of the ASCS methodology conducted by ONS in 2010 suggested that CASSRs should be encouraged by NHS Digital to conduct interviews with care home residents in cases where the resident had no one other than the care home staff to assist them.[65] The ONS review also recommended that NHS Digital should consider encouraging CASSRs to facilitate face-to-face or telephone interviews in order to obtain information from service users who are unable to self-complete the survey e.g. people with learning disabilities. The review suggested that as well as providing this information on the survey documentation, this should be proactive: CASSRs should actively contact users with learning disabilities to check whether someone can help them to complete the survey, or to offer them the opportunity to complete an interview, to avoid possibly biasing results should service users rely on care workers for assistance.[66] [67]

The review also suggested that, if available, translators could facilitate the face-to-face interviews to help improve the response rates among ethnic minority groups.[68] Face-to-face interviews might also help improve response rates if offered in follow up communications with non-responders.[69] Of course, offering this support to participants is dependent on the resources available within the CASSR, which could lead to inconsistencies.[70] There may also be issues of safeguarding related to the provision of face-to-face interviews by CASSR staff. In order to conduct in person interviews, staff might need appropriate disclosure and barring clearance or training- which may not be available for research and analytical staff in local authorities. This meant that NHS Digital decided in 2011 (recorded in a response to ONS) to

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[63] Malley and Smith (2012)
[64] Malley (2017)
[65] Williams and Betts (2010)
[66] Williams and Betts (2010)
[67] NHS Digital, 'Personal Social Services: Adult Social Care Survey, England - Information and guidance for the 2019-20 survey year', Updated in January 2020.
[68] Malley and Smith (2012)
[69] Malley (2017)
[70] Williams and Betts (2010)

make these options permissible in the survey guidance but did not require CASSRs to encourage these activities.[71]

The 2019-20 guidance suggests that face-to-face or telephone interviews may be suitable for those with sensory impairments and/or limited literacy skills and should only be offered to service users who request them in response to the initial mailing or reminder letter, and where it is not possible to find appropriate support to enable them to complete a postal questionnaire. NHS Digital provides three face-to-face and two telephone scripts for this purpose in order to ensure a consistent approach. The cover letter for the survey does contain the clear information: "*You may also request to complete the survey by telephone or in person. If you would like to make a request or if you have any questions, then please get in touch using the details in the 'contact us' section below*". However, this is on the second page and may be difficult to find for those who would struggle with a paper questionnaire.

The guidance suggests that the number completed in this way should be small.[72] In line with this guidance, in 2018-19, 99.8 per cent of questionnaires were completed by post, with 67 questionnaires completed face-to-face and 43 questionnaires completed by telephone. Four local authorities completed one questionnaire face-to-face and one local authority completed 63 questionnaires this way. Fifteen local authorities completed one or two questionnaires by phone with one local authority completing 24 questionnaires by phone. All interviews were carried out using the English version of the questionnaire. Although mixed mode approaches to data collection present challenges, there is certainly scope to extend the use of other modes on the ASCS in order to improve response, particularly among hard to reach groups, as the survey already has materials prepared in three modes. However, doing this would have resource implications for local authorities.

The review of the survey methodology conducted by ONS states that whilst an online methodology could reduce fieldwork costs, speed up data collection and improve the data processing, it relies on intended participants having access to the internet and for them to have a certain level of computer literacy. The ONS review in 2010 concluded that an online methodology was unlikely to be suitable for the ASCS at that time, given the low online coverage among the target population. The review recommended against an online mode even as part of a mixed-mode design. [73] However, digital access has changed considerably in the last decade and the 2018-19 survey included a pilot of an online questionnaire. This was completed by 19 participants across two local authorities, representing one per cent of respondents in those local authorities. The initial letter sent to service users contained both a postal version of the survey and the option to complete the survey online via a link in the letter. Both CASSRs offered an online version for community and residential services and only one offered an easy read version. No responses were received using the online easy read version. The percentage of responders using the online version was the same in both local authorities (1.4 per cent).

In its review of the methodology, ONS called for a reassessment of the interview materials to ensure that they are comprehensive and also easy to understand. This is particularly important for interviews with people with learning disabilities, given the first introduction to the interview is the cover letter included in the postal questionnaires. The review advised that the interview materials must contain the necessary instructions for the interviewer to obtain informed and explicit consent. Whilst this enables consistency

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[71] Information Centre "SSUSG Response to ONS Review into the Methodology for the Adult Social Care Survey" https://webarchive.nationalarchives.gov.uk/20120802165131/http://www.ic.nhs.uk/services/social-care/review-approval-and-development/ssusg/ssusg-papers--19-april-2011

[72] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Information and guidance for the 2019-20 survey year', published June 2019.

[73] Williams and Betts (2010)

across interviewers, it is important that some flexibility is allowed so that content can be explained in a way that is appropriate to the individual participant.[74] The questionnaire for use in interviews includes clear information for the interviewer about how to approach the interview, explain consent, make it clear that participation is optional and to give the opportunity for the participant to ask questions. This is thus all in line with the recommendations made by ONS.

Therefore, it seems that the appropriate tools are available for offering interviews on the ASCS. The issues in relation to offering further modes relate more to the extent to which these are encouraged, whether those who would benefit are aware of the option, and the extent to which CASSRs have the necessary resources and time.

### 2.7.2 Questionnaire design

Item non-response[75] to the survey is low and most people return fully completed questionnaires. It could be argued that a high number of fully completed questionnaires is a sign that the questionnaire is well designed. However, this is difficult to judge given the survey population and the range of issues with the response (e.g. others completing it on behalf of the service user). A detailed focus on the questionnaire is beyond the scope of this review. However, it is relevant to consider whether questionnaire design issues contribute to this issue of under-representativeness.

Existing literature on the survey provides several recommendations as to how the questionnaire design could be improved to help make completion easier and increase response rates. These include:

- Removing all routing – in general, the public find paper questionnaires with routing difficult to navigate, and when this is complex can result in errors where CASSRs include additional questions.[76] Routing is automatic in online surveys so this would reduce this issue;

- Review some of the questions that are currently less relevant for some participants – for example, not all questions may be relevant to self-funders;[77]

- Ensure consistency in the presentation of response categories so that none are given visual prominence over others.[78]

Consideration could also be given to the relevance of the questionnaire to all service users. Feedback during the advisory group for this project highlighted that not all the questions are felt to be relevant, and some may be considered intrusive, for example those relating to personal care (using the toilet, dressing etc). However, the requirement to measure all aspects of ASCOT and the need to avoid complex routing means that it is difficult to avoid this. An introduction to the questions most likely to be considered irrelevant or intrusive which acknowledges that the questions may appear less relevant to certain people and explains why they are still important for everyone to answer could be useful in increasing the acceptability of the survey and facilitating response in future years. This is relevant for the issue of representativeness as certain groups may be more likely to consider the questions irrelevant. For example, questions which focus on physical needs may appear to be less applicable to some of those with mental health support needs than for some other groups. However, to compile the ASCOF

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[74] Williams and Betts (2010)

[75] Item non-response refers to individual questions which are not answered by those who do complete at least part of the questionnaire and return it.

[76] NHS Digital, ‘Personal Social Services: Adult Social Care Survey, England 2017-18 – Data Quality Statement’, published in October 2018.

[77] NHS Digital (2015) Adult Social Care User Experience Surveys: Summary Findings from Consultation Feedback on the Implications of the Care Act https://webarchive.nationalarchives.gov.uk/20180328130852tf_/http://content.digital.nhs.uk/media/16553/Adult-Social-Care-User-Experience-Surveys/pdf/CareActConsultation-Surveys.pdf/

[78] Williams and Betts (2010)

measures, full data is needed from all participants, regardless of their circumstances and the questionnaire is designed for everyone to answer the same question. Although an online mode could assist with appropriate routing or wording, the need to maintain paper self-completion modes in parallel and the standard ASCOT measurements limit the variation which would be possible. The potential to have different wording for the cover letter for the different survey stratum could also assist with this issue, by explaining why questions are relevant. An online survey could facilitate the inclusion of additional questions which are relevant to participants with different circumstances and which address issues they are keen to feed back on.

Findings from cognitive testing of some new questions suitable for short-term users highlighted small changes to those questions, which could help make completion easier, some of which would also be relevant to the main questionnaire, such as:[79]

- Including additional answer codes on some questions to ensure they are appropriate for all participants, specifically those who have transitioned from short-term to long-term care packages (mainly relevant to short-term care users);

- Shortening the questionnaire (either by removing questions or laying it out differently), as it was deemed too long by some participants in the cognitive testing because with a paper questionnaire the observed length may discourage people from even starting to complete the survey;

- Including a definition of ‘care workers’ so that participants are clear who they should consider when answering questions about care workers (this is only relevant to one question in the standard questionnaire but since it is an important question about who helps them, offering a clearer definition could be helpful);

- Adding “as a result of your care” at the end of relevant question stems to encourage participants to think about outcomes instead of improvements.

### 2.7.3 Alternative versions of the questionnaire

Offering the questionnaire in a variety of formats is an important way in which CASSRs can maximise the accessibility of the survey and ensure that people in the selected sample are able to take part.

The NHS Digital guidance for CASSRs instructs them to use their records to identify the communication needs of their service users.[80] They are told to consider the following questions which can be used to guide their use of the alternative questionnaire formats:

- *“Is there someone who is already known to the participant who could help them complete the questionnaire?*

- *Is it necessary to arrange assistance for this service user?*

- *Does the participant require an easy read version of the questionnaire?*

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[79] Pilley etal ‘Question testing for the Adult Short-term Care Users Survey - Report on findings from cognitive interviews on questions about experiences of short-term social care’, published in June 2017.

[80] NHS Digital, ‘Personal Social Services: Adult Social Care Survey, England - Information and guidance for the 2019-20 survey year’, Updated in January 2020.

- *Does the participant require a large-print questionnaire?*
- *Does the service user require the questionnaire translated into a language other than English or the provision of an interpreter? "*

## Translations and need for languages other than English

NHS Digital provides translated versions of the questionnaire for CASSRs to offer to participants for whom English is not their main language. Three additional languages were offered in 2016-17 (French, Italian and Tamil), to supplement the 14 languages offered in previous years. These were selected as the languages missing from the survey as well as being reported most frequently as first languages within the 2011 census. The languages offered in the 2019-20 survey are Arabic, Bengali, French, Greek, Gujarati, Hindi, Italian, Mandarin, Polish, Portuguese, Punjabi, Somali, Spanish, Tamil, Turkish, Urdu, Vietnamese. In 2018-19, the translated materials were made available to CASSRs earlier, so that they could be included in the initial survey invitation (in cases where it was known that the service users' main language was not English).

An ONS review of the ASCS methodology in 2010 suggested that response rates among ethnic minority groups could be improved by better signposting the availability of translated versions of the questionnaire, as well as information on how to access them. For example, by including a one-page insert with all the mailings to provide the necessary information. A translation request sheet is now made available for CASSRs to use, but they are also advised to use prior information on the language needs of service users. CASSRS can send out the separate translation request sheet which provides information on how to obtain a translated version of the letter in all the relevant languages. It instructs the reader to write their name and address directly beneath the relevant language, and return the form in the envelope provided, meaning that the CASSRs know which language questionnaire to send.

The ONS report also suggested that as well as being able to request translated materials in the post, if possible, CASSRs should consider providing a weblink to a site where translated materials can be downloaded and printed. Aside from not being accessible to those users with limited or no access to the internet, this might be problematic in cases where councils have included specific additional questions, in which case they might need to make alternative arrangements or omit this option.[81] There is no information on the extent to which CASSRs offer this and it is not suggested as an option in the guidance.

Analysis of the survey data by NHS Digital shows that less than 1 per cent of service users completed a translated version of the questionnaire, however this has increased slightly in the last two surveys. In 2018-19, 0.3 per cent completed a translated questionnaire, which is the equivalent of 186 survey participants, compared with 0.2 per cent in 2017-18 and 0.1 per cent in 2016-17.[82] In the survey, participants are asked about the help offered to them in completing the survey and one of the options is "Someone else translated the questions for me". Overall 20.5 per cent of participants selected this item, highlighting the potential for greater use of translated materials to ensure consistency in translation, rather than people relying on translating the English version themselves. It is possible that this code is being interpreted more broadly than translation into another language since the item appears between "Someone else read the questions to me" and "Someone else wrote down the answers for me" so some may have interpreted it to mean "someone helped me to understand the question". Of the nearly 15,000

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[81] Williams and Betts (2010)

[82] NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', published 02 October 2018. NHS Digital, 'Personal Social Services Adult Social Care Survey, England - Methodological and Further Information', published 22 October 2019. Also analysis of data published by NHS Digital from 2019 survey.

who reported someone having translated the questions for them, 60 responded in a non-English questionnaire and the rest using the English version. It may be helpful in the future to understand the extent to which questionnaires are being translated into another language versus the extent to which people are receiving help with understanding and if so, splitting this code into two could be helpful.

NHS Digital analyses the data from those who use translated questionnaires to assess whether the responses given by those using translations are consistent with responses given by those who completed in English.[83] In 2018-19 this showed differences in all five of the questions analysed (including satisfaction with services, feeling safe, social isolation). It should be noted that those who complete in translation may have different characteristics from the overall sample who complete in English in terms of ethnic origin, age, stratum etc. This analysis could be improved by comparing the translated data with participants with a matched demographic profile, as well as comparing the translated data with participants who reported that someone helped them by translating. In addition, it would be valuable to explore not only the quality of data produced by translated questionnaire, but also the extent to which the need for translation has been met.

In her 2012 review, Juliette Malley suggested that better data about service users is needed in order to improve the targeting of accessible or translated materials to the participants who could benefit from them, to improve response rates.[84] The data quality annex includes information on what percentage of the sample within each CASSR has no information on ethnicity. In 2017-18 there were only six local authorities where more than five per cent of the sample were missing information on ethnicity. This included Bradford where 25 per cent and Halton where 23 per cent were missing this information. This suggests that in most local authorities, information on ethnicity is available where needed but there are individual local authorities where this may still be an issue. The sample information includes information on whether a translation was used and in only one local authority was this missing for any of the sample. However, there is no sample information provided to NHS Digital on their main language so local authorities would either have to use other records which are not submitted to NHS Digital, or assume a potential need for translation based on ethnicity.

## Easy read questionnaire

The easy read questionnaires are available in standard and large print. They are designed for people with a learning disability. CASSRs are instructed to offer them to all the sample in stratum 1 (learning disability all ages), and to anyone else who requests it or has requested it in the past. There is one version of the easy read questionnaire, regardless of whether the setting is community or residential care.

Alongside better signposting and information on how to access alternative versions of the questionnaire, CASSRs were involved in a consultation with ONS when the survey first started suggested several changes to the easy read version of the questionnaire, which is provided to people with learning disabilities. Below we describe the suggestions made and the extent to which they have been incorporated.[85]

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[83] NHS Digital, ‘Personal Social Services: Adult Social Care Survey, England 2018-19 – Data Quality Statement’, published in October 2019.
[84] Malley (2017)
[85] Williams and Betts (2010)

**Table 2.5: Recommendations and current procedures in relation to the easy read versions**

| Recommendation for the easy read version of the questionnaire made by ONS consultation | Current procedure on the ASCS |
|---|---|
| The **use of images –** although the use of smiley faces, different size ticks and crosses, and thumbs up and down is generally successful in conveying answer scales, the use of a thumbs down symbol alongside a cross for the middle/neutral points is confusing | The questionnaire only includes ticks and thumbs up for positive responses and crosses and thumbs down for negative responses, with neutral responses indicated only by a neutral face. However, for four-part questions the slight negative option also uses the neutral face in combination with a 'thumbs down' and a cross which may potentially be confusing. Also, the final questions in the questionnaire contain no smiley faces, ticks or thumbs |
| The **length of the questionnaire**, which may be too long for participants with learning disabilities. | The questionnaire contains some optional questions to reduce the length but there are 26 core questions which is long for this group, according to the general questionnaire design literature. Because the questions are designed to inform the ASCOT measurement, there may be limited scope to reduce questions further however it would be useful to explore the questions that are used less often with a view to possibly reducing the overall length; |
| The **matrix-format** questions, which may not be clear enough for participants with learning disabilities | There are two grid questions on the questionnaire |
| The **positioning of the question text**, which is currently separated from the response categories and therefore risks not being read | Although there is a gap between the question and the answer categories, each page contains only one question and local authorities are instructed not to change this and so this is unlikely to be an issue (though this layout makes the questionnaire long). |

The response rate among those in stratum 1 with a learning disability is higher than for some other stratum (40 per cent compared with 32 per cent overall), which suggests that the accessibility of the survey to those with a learning disability is not adversely affected by issues with access to the easy read questionnaire. In fact, the response rate among those offered the easy read questionnaire was 40 per cent compared with 31 per cent for the standard questionnaire. The easy read version was used by 91 per cent of participants in stratum 1 (learning disability all ages). Questions about improvements to the questionnaire design and quality of data from the questionnaire are beyond the scope of this review.

Despite the good response among those with learning disabilities and widespread use of the easy read version, there are concerns about the current version used on the ASCS, especially for groups such as those with autism. Development work has been carried out by the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU) at the PSSRU to develop an improved easy read version of ASCOT.[86] [87] The aim was to improve acceptability and make the questionnaire more widely accessible, and the instrument was developed with the intended target population. Changes included revisions to layout, revisions to question stems and response options and new images. The psychometric properties have been examined, and the instrument was found to perform well. Subsequent work was carried out to develop an online version of the instrument. So far, these easy read developments have not been incorporated in the ASCS.

## 2.8 Key findings and recommendations

The findings and recommendations below are based on evidence from the methods review. Final findings based on evidence from across the research are included in the main report.

### 2.8.1 Eligible population extract and representativeness

- Not all demographic information is collected by all councils, nor is it collected in a consistent way across councils, which results in some data not being comparable across CASSRs. This makes it difficult to determine if some groups are under-represented in the survey. Requiring all local authorities to collect all relevant data in a consistent manner using standard variables would assist with this. Greater use of data on the demographic characteristics of the eligible population and responding sample in England and by CASSR, would help raise awareness of which groups are most under-represented and could assist CASSRs in addressing this in the way they approach the survey and in particular certain groups.

- The inclusion of short-term users in a sample extract may require a different cycle from the annual approach used for long-term users to avoid issues of recall bias and changes in circumstances in the months after short-term care ended. For example, the survey may need to be run more frequently. NHS Digital should undertake analysis of the number of short-term users annually and by period throughout the year, overall, and by CASSR to assess an appropriate frequency which minimises burden on local authorities but would generate an appropriate representative sample of short-term users over the year.

### 2.8.2 Sample frame and selected sample and representativeness

- The official survey guidance, which states that CASSRs should flag service users known to lack the capacity to consent to participate in research on their systems, may be excluding individuals who experience fluctuating capacity. CASSRs also report finding it difficult to determine the capacity of some users. The clear guidance in 2019-20 which distinguishes between permanent and fluctuating capacity, and provides information to care homes on determining capacity, should assist with this. However, this should be reviewed and consideration should be given to providing further guidance for CASSRs and care homes. This could include example scenarios and explaining how questionnaire completion can be handled when someone with fluctuating capacity

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[86] Razik et al. (2019) ASCOT Easy Read: usability evaluation of an electronic adaptation. QORO Discussion Paper Number 2953.
[87] Turnpenny, et al (2018). Developing an easy read version of the adult social care outcomes toolkit (ASCOT). Journal of Applied Research in Intellectual Disabilities, 31(1), e36-e48.

has been included in the sample (emphasising that there is a window for completion which means that someone who could give consent any time during the fieldwork window should be included in the sample).

- At present around a quarter of service users with memory and cognition issues have their survey completed by someone else. Since proxy interviews are effectively happening (and below we suggest a more formal development of this), the question of capacity to consent should be revisited and consideration should be given to providing the option of consent via a consultee. This would need discussion with the Social Care REC. For this group who lack the mental capacity to take part at all, information should be collected by a proxy questionnaire completed by the consultee or another appropriate person. This would collect the views of both the carer and the service user (as perceived by the carer). The previous work on proxy versions by PSSRU should form the basis of any development of a proxy version. [88]

- Even where the questionnaire is not completed by someone else and service users have capacity to take part, most participants have help in completing the survey, and this includes questions being read out, answers being written down and questions being discussed. The guidance to CASSRs and the covering letters could more clearly acknowledge this and provide clearer guidance on who could assist (family and friends preferable to care workers) and how they can help (not answering on behalf of someone). Clear guidance to care homes could also be provided on the acceptable limit of support from a care worker (which may be different from that for an unpaid carer) and providing clear information on who would not be a suitable assistant.

- Although the guidance is clear on the rules for excluding service users who may experience survey fatigue, further work with individual CASSRs or targeted discussions is needed to ensure this is implemented consistently and those who have taken part in the previous ASCS are not excluded. However, taking into consideration the declining response rates, the high percentage of users in some CASSRs and stratum who are invited to take part in consecutive years, and the pressures on local authorities, consideration could be given to reducing the frequency of the survey from annual to every other year. This could be arranged to alternate with the SACE or to occur in the same year so data are aligned. This could also free up local authorities to carry out a rolling survey of short-term users in the intervening year, or to carry out additional analysis of the survey results and follow up the previous year’s survey findings with qualitative research to explore some of the emerging issues and understand the implications in more depth.

### 2.8.3 Response and representativeness

- There are a number of under-represented groups in the survey, making it difficult to gain a good understanding of their perspectives or to establish whether they have unmet social care needs. These groups include people with mental health problems, people who live in more deprived areas and those from ethnic minority groups. More could be done to share the nature of their under-representativeness with CASSRs to highlight where the challenges lie and to help CASSRs target efforts effectively, as well as to identify and learn from good practice. On the basis of the secondary analysis element of this project, some key indicators could be published at a CASSR level showing response rates (among issued sample or even percentage of eligible population responding) for some key groups known to be under-represented. This could be done at a national level but also an individual CASSR level to raise CASSR awareness of the issue.

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[88] Caiels et al (2019)

- Although the guidance focusses on maximising response, and on ensuring the survey is accessible to particular groups, there is little guidance on the causes of under-representativeness for different groups and how these could be addressed in practice. This could assist CASSRs in using the tools available to them, such as targeted reminders and suitable wording for different service users in their letters, and engagement with community organisations to improve this.

- The differential impacts of survey fatigue on response by CASSR, the proportion of the stratum sampled each year and the willingness of different groups to take part repeatedly should be discussed with CASSRs. Reducing the frequency of the survey (from annually to biannually for example), or providing clearer wording about the value of the survey taking place annually on the cover letter could assist in gaining the cooperation of those most affected by fatigue. Sending a thank you letter or acknowledging and thanking them for their previous help in the survey in the cover letter could also assist. Where local authorities have taken action as a result of the survey findings this could potentially be included in the cover letters at a local level to show participants that taking part does make a difference.

- Only one reminder with a questionnaire is required in the survey guidance. Ensuring that a questionnaire is always sent with the reminder, and greater encouragement of a second reminder, not only when response is low but when the response from particular subgroups is low, could assist in boosting response. While this would add to the survey costs, it could be particularly useful among hard to reach groups. As CASSRs hold information on the sample, there is also the potential to target reminders to groups where response is lower – this could be stratum or certain demographic groups. The reminders should be adapted to help improve response rate e.g. include clearer signposting to alternative versions of the questionnaire.

- The evidence on the benefit of incentives on the ASCS is limited and there are clear budget constraints. However, there is wider evidence that incentives can improve response on other surveys. If this is something considered as a way of boosting response, particularly among certain groups, then further methodological research is needed. For example, split sample experiments could be carried out where some people receive an incentive and others don't, to look at the impact of offering incentives on the response rate.

- A more detailed look at trajectories in response for individual CASSRs may be a helpful first step in exploring how some CASSRs have managed to maintain response rates.

- Even after the recommendations in this report have been implemented, some under-representation may remain. Through the use of information about the characteristics of the eligible population and the responding population, the weighting scheme could be developed to take account not just of stratum but also of demographic characteristics associated with differentials in representation (whether caused by exclusion from the sample frame or differing levels of response). The weights could be calculated centrally by NHS Digital based on information supplied by CASSRs about the eligible and responding populations, or could be calculated locally by each CASSR.

### 2.8.4 Survey mode and alternative formats

- At present face-to-face and telephone interview materials are provided for all CASSRs and the cover letters make service users aware of this. However, the guidance to CASSRs emphasises that only a small number should be carried out this way and suggests this should be for particular groups. Furthermore, the information about their availability is positioned low down on the second page of the cover letter for service users, meaning that those who have trouble accessing a paper questionnaire may never read that far. The very small numbers using these options suggest there is scope to extend their use by encouraging CASSRs to use them and making the information about the options more accessible to service users. Official guidance should encourage CASSRs to actively offer the option to complete the survey via a face-to-face or telephone interview, while offering guidance on how to avoid biasing results (e.g. making it clear the person asking the questions is independent of the service provider). Specific measures could be implemented to make it clearer how participants can seek appropriate support to complete the survey e.g. including clearer instructions on the survey and supporting materials. However, this would require additional resources which might not be possible. CASSRs could decide to target specific groups with low response rates to offer the alternative modes.

- Although the early review of the methodology in 2010 warned against the use of an online mode, digital penetration is far wider now, and this should be reconsidered (particularly in the light of increased online use since COVID-19 restrictions were introduced in March 2020). Moving to a fully online methodology at this moment in time would not be appropriate given access to the internet in this country [89], particularly among the specific audience for this survey, but there may be scope to introduce it as an option. The pilot of the online mode in 2018-19 should be repeated in future and the findings used to inform future developments[90]. If a proxy version is developed, and the role of supporting unpaid carers in assisting with completion is clarified, there may also be scope for offering this information and the proxy version online. In the Your Care Rating Survey, the resident questionnaire is offered on paper only but the family and friend questionnaire is available on paper and online.[91] It is also possible that an online option may improve response among young adult service users, including those with mental health needs. However, negative impacts on response overall and among some groups is possible.[92] Any experiment should identify whether the groups with better response using a mixed mode approach are those which are under-represented (meaning it could reduce bias) or are over represented (meaning it could exacerbate response bias). Although offering an online version may provide longer term cost savings, the initial cost of introducing it and combining it with paper may be greater than continuing with a paper only methodology.[93]

- Given that a low percentage of participants complete a translated version of the questionnaire, better data about service users is needed in order to improve the targeting of accessible or translated materials to the participants who could benefit from them.

- The questions asking about help given during the questionnaire completion should be refined to make it clearer who is receiving the help and what categories such as ‘help with translation’ mean. The content and order of these categories could assist with this. A better understanding of the nature of help received could be used in developing improved guidance.

- Several changes to the easy read version of the questionnaire could be made to help make completion easier e.g. reduce the length and remove the matrix style questions, which may be

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[89] Burton and Jackle (2020) Mode Effects Understanding Society Working Paper Series No. 2020 – 05

[90] NHS Digital are currently working on a pilot for 2020-21. There is no online option in 2019-20

[91] https://www.yourcarerating.org/creo_files/upload/default/18-043331-01_YCR per cent20Technical per cent20Note per cent20website-2019_V1_iuo.pdf

[92] Burton and Jackle (2020)

[93] Burton and Jackle (2020)

difficult to interpret. The previous work done by the PSSRU on developing an improved version of the easy read questionnaire for ASCOT should inform any changes to ensure they are consistent.[94]

- Consideration should also be given to developing an easy read type questionnaire targeted at those with age-related cognitive decline, as well as other more flexible data collection methods to allow those with some capacity to take part, even if they could not complete a standard questionnaire. This could help improve response among these groups, as well as enabling people to take part more independently.

### 2.8.5 The role of care homes

- The survey materials include two communications to care homes to explain the value of the survey and how residents can take part, and how to determine capacity to consent. However, given the challenges of determining capacity, the potential need for a new approach and the level of support needed for care home residents to take part, there may be scope for CASSRs to use other methods to engage with care homes in facilitating the completion of the survey. For example, obtaining help from family and friends and enabling residents to take part themselves with appropriate support. This could be through the encouragement of follow up phone calls and visits to care homes, as well as through the preparation of guidance for the relatives and friends of care home residents on the importance of the survey and how they can help. Although this is included in the cover letter to service users, communications targeted at those helping could encourage appropriate support to be given. The cost implications of this should be considered and appropriate resource allocated if this becomes part of the standard guidance.

- CASSRs should be asked to provide details to NHS Digital about the number of service users excluded from the sample because of mental capacity issues. In order to assess the extent to which the checks are being carried out consistently across CASSRs, these should also report on the number of homes contacted and the number of homes which approach them with details of who to exclude.

### 2.8.6 General

- NHS Digital effectively updates the ASCS and SACE guidance every year with clear signposting of what has changed from the previous year and this approach should be continued.

- The bank of additional questions is useful, and NHS Digital should do a regular review of questions and whether to include them in the survey. This should address the extent to which the questions are used with a view to shorten the questionnaire overall as much as is possible. The frequency of the review would involve a balance between keeping the questionnaire up to date with policy developments while maintaining consistency for time series.

- Response rates have been declining generally on the ASCS and while addressing the issue of lack of representativeness of certain groups may help with this, where the under-represented groups are small this will have limited impacts on overall response rates. Offering a proxy option, making the role of unpaid carers in supporting completion more explicit and offering alternative modes may assist in halting the decline in response.

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94 Turnpenny,et al (2018)

- Existing literature on the survey provides several recommendations as to how the questionnaire design could be improved to help make completion easier and to increase response rates e.g. removing all routing (this is already the situation on ASCS), including additional answer codes and providing a definition of ‘care workers’. The repeated participation of the same service users means that the ease of completing the questionnaire could impact on future response.

- All of these recommendations should be considered in the light of other developments on the survey and in social care statistics more generally. For example, the implications of the ASCOF Refresh work [95] should feed into final recommendations, as should discussions within NHS Digital and DHSC about the costs and organisations of these surveys.

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[95] https://ipc.brookes.ac.uk/about-ipc/news/ASCOF.html

# 3 Survey of Adult Carers in England (SACE)

## 3.1 The current survey methodology [96]

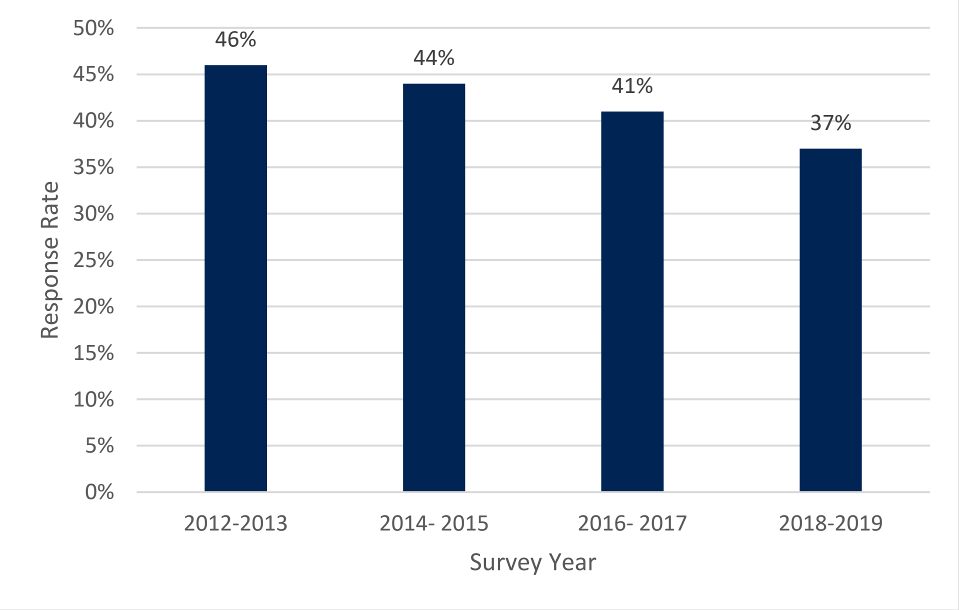
### 3.1.1 Overview

The Survey of Adult Carers in England (SACE) is a biennial national survey that is run by NHS Digital. It collects information about the experiences of carers in England by collecting their views on a number of topics that are considered to be indicative of a balanced life alongside their unpaid caring role.

The main mode of data collection is by post. The survey is administered by councils with adult social care responsibilities (CASSRs) but the data is analysed and reported on by NHS Digital, both at the national and local level. The findings from the survey help to improve services and assess the performance of CASSRs in the services and support they provide to carers.

The survey started in 2012-13 after an optional pilot in 2009-10 in which 59 CASSRs participated. Response rates have declined over the life of the survey, in line with the Adult Social Care Survey (ASCS) and other postal surveys.[97]

**Figure 3.1: SACE responses rates from 2012-2013 to 2018-2019[98]**



It should also be noted that response rates vary considerably between CASSRs with the lowest response rate being 11.8 per cent and the highest 64.2 per cent in 2018-19. However, more than a third of participating CASSRs have a response rate of between 31 and 40 per cent, with only 14 per cent having a response rate of 30 per cent or less.

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[96] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Methodological and Further Information’, 25 June 2019.
[97] See for instance Stedman, R., C. et al (2019)
[98] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England - Methodological and Further Information’ from 2012-2013 to 2018-2019

As on the ASCS, issues with response seem to relate to whether carers take part at all, rather than break-offs and incomplete questionnaires. In 2018-19, responses to the final question were received from 97 per cent of respondents. Levels of missing data are higher for some specific questions, suggesting that participants persist to the end even if individual questions are missed. An example is question 5 which asks about the services which the person they care for has used in the last 12 months, which requires a 'yes', 'no' or 'don't know' answer on all categories and where up to 19 per cent are missing on some categories (lunch club and meals services).[99]

### 3.1.2 Sampling

During survey years, CASSRs choose a date between 1 June and 30 September to extract a list of carers from their systems. This list is the entire eligible population for the survey. Before 2016-17, the eligible population was carers aged 18+ who had a carer's assessment or review from the local authority in previous 12 months. In 2016-17, the eligible population was extended to include carers who have not been assessed or reviewed in the previous 12 months. The reason for the change was that under the Care Act, local authorities have a duty to provide information and advice. This means carers may be receiving support as a result of this signposting even if they have not been assessed or reviewed during the year.

It should be noted that carers are recorded in their own right in SALT (Short and Long-term Support) and so could include those who care for someone who is not receiving any social care from the local authority. In 2014-15 a new data item was added to indicate whether the cared-for person is known to the local authority and whether they are included in SALT. The sample is restricted to those carers who have had some contact with the local authority at some point. As such, it does not cover all carers.

The eligible population is all carers who would be contained within the last four rows of the Long-term SALT return[100], that it is to say those:

- aged 18 or over;
- caring for someone aged 18 or over;
- who either received "support direct to carer" or "no direct support to carer" in the 12 months prior to the extract date, irrespective of whether their cared-for person received respite care.

The findings from the survey are used to make estimates about the whole population. These estimates are subject to a degree of uncertainty, defined as a 'margin of error'. As the proportion of completed surveys increases, the margin of error decreases. Therefore, CASSRs are required to select a sample large enough so that the survey results have a relatively small margin of error (less than five percentage points).

Councils are asked to send questionnaires to a random sample of carers. Unlike the ASCS, there is no stratification during sampling, perhaps because information about the characteristics of carers and those they care for is limited. CASSRs must identify carers who should not participate in the survey. This includes people who:

- Have stopped being a carer;
- Have died, or the person in receipt of their care has died;
- Have been hospitalised at the time of the survey;

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[99] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 Data Quality Annex
[100] The first row of this table is excluded because it contains carers who are aged under 18.

- Are involved in an open safeguarding alert or investigation;
- Are in an active dispute with the CASSR at the time the survey is being sent out;
- People who were carers for only a short spell that ends before the survey is carried out.
- Carers removed from the sample for any of these reasons are replaced with other randomly selected eligible carers.

### 3.1.3 Survey design

The questionnaires contain generic sections, which are relevant to all CASSRs, and some sections which are customisable by CASSRs. They can include additional questions or open-ended questions for local research purposes, however these amendments are subject to NHS Digital approval. A selection of additional questions previously used is available in a question bank available on the NHS Digital website.[101]

The core questions feed into five measures on the Adult Social Care Outcomes Framework (ASCOF), including provision of measures for carer quality of life and satisfaction. The carer quality of life or outcome measure has three categories in contrast to the four categories in the social care service user measure. A four-category version has been developed but not yet implemented on the survey.

Alongside the main version of the questionnaire, there are a number of accessible versions:

- A large-print version (designed for people with visual impairments);
- Translated versions (for service users who may not be fluent in English).

The questionnaires are also provided as interview scripts so CASSRs can offer face-to-face or telephone interviews to service users. There are no easy read versions for SACE produced as standard by NHS Digital. However, the guidance states that local authorities have to make the following formats available if requested by carers:

- Easy read
- Braille
- Audio for visually impaired people
- An electronic version of the questionnaire to be sent and returned via email (for those with sensory impairments).[102]

### 3.1.4 Supporting survey materials

NHS Digital provides all CASSRs with detailed survey guidance, the questionnaires and additional survey materials, such as invitation letters and interview scripts. The guidance is updated every two years to introduce improvements and refinements.

### 3.1.5 Fieldwork and analysis

The recommended fieldwork period is between October and November. During this time, questionnaires are distributed to carers, and then posted back once completed. In most cases, a questionnaire (the

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[101] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-carers-survey-2018-19

[102] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Information and guidance for the 2018-19 survey year’, published June 2019.

version most appropriate for the individual) is posted to each person in the sample, with one reminder letter sent to each person who does not respond. The guidance says that "*A second copy of the questionnaire should be included with the reminder letter* ". [103]

In order to maintain consistency in design across CASSRs and avoid putting pressure on carers to participate, NHS Digital's guidance advises against sending out a second reminder or making telephone calls even when response is low, in order to maintain consistency in design across local authorities and avoid putting pressure on carers to participate.[104] The completed questionnaires are manually coded onto a data return spreadsheet (provided to CASSRs by NHS Digital) and returned to NHS Digital for validation and analysis.

### 3.1.6 Data analysis and weighting

Weights are used to calculate a national, regional and council type estimate. The standard formula for variance of estimates in a stratified design is used, taking each CASSR as a stratum.[105] Weights are calculated for each question by dividing the count of the population of concern by the count of usable responses to that question (the inverse probability of responding to that question) in each local authority. This improves the accuracy of the aggregate level results, because variability in sampling and response rates between local authorities is accounted for. However, the weighting does not correct for the under-representation of subgroups within the strata, through variable response. For example, it does not correct for the under-representation of specific age groups, ethnicities (or combinations of these) within a CASSR. It also does not correct for the systematic and intentional exclusion from the issued sample of certain groups in the eligible population.[106]

## 3.2 Sources of under-representativeness

Groups are under-represented in the survey data if they form a smaller proportion of the achieved sample size than they form of the eligible population (all carers aged 18+ for which the local authority has a record of support). The causes of under-representation can lie at several stages in the survey process:

1. If the data held by the CASSR on the eligible population is not up to date or complete at the point the data are extracted, some eligible people may be excluded.

2. The rules for excluding certain groups from the sample frame and initial issued sample will result in the eligible carer not being represented in the survey at all (e.g. those in dispute with the local authority). If certain types of carer or demographic groups are more prevalent among some of the groups excluded from the survey, then this may result in their under-representation in the data.

3. Differential response to the survey among the final issued sample will also contribute to certain groups being under-represented.

The full analysis of the survey data to look at the representativeness of the achieved sample compared with the eligible population is a separate strand of this research. The key issue in terms of eligible population for the SACE seems to be in relation to obtaining the relevant information from third parties. At the stage of response, groups such as ethnic minority groups and working age carers may be under-

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[103] Personal Social Services Survey of Adult Carers in England. Information and guidance for the 2018-19 survey year
[104] Personal Social Services Survey of Adult Carers in England, 2018-19. Data Quality Statement
[105] Personal Social Services Survey of Adult Carers in England, 2018-19. Methodological and Further Information
[106] It should be noted that in this report where figures about numbers related to methodology are quoted these are unweighted. It is relevant to look at actual numbers using certain questionnaire modes, tools etc, not the adjusted numbers.

represented. There also appears to be an issue in relation to response among carers who do not believe they or the person they care for are receiving support from the council or who do not recognise themselves as carers. The guidance to CASSRs also raises the hypothetical example that if those who are more likely to respond to the survey are more likely to be dissatisfied with the services they receive, there is a risk of dissatisfaction being over-reported. The question of whether those who are satisfied are under-represented is something which can be addressed in the secondary analysis by looking at results according to response rates between groups, local authorities and over time.

## 3.3 Data on the eligible population

### 3.3.1 Defining the eligible population

Defining the eligible population for SACE is complex because of the wide definition of carers and because providing support to carers is contracted to third parties in many cases. NHS Digital provided an additional document in 2018 to assist CASSRs in making decisions about who is and is not eligible.[107] This complexity about who should and should not be included in SALT LTS003 can lead to inconsistency in application between local authorities.

A data quality statement on SACE from NHS Digital highlighted a number of issues that were reported by CASSRs in 2018-19.[108] These issues may have impacted on the completeness and quality of their data, and the ability to draw comparisons across CASSRs. One issue is whether the extract is complete in terms of the inclusion of eligible cases. Where individual level data is held by the third party providing the support service, CASSRs may have numbers on their SALT record for reporting purposes, but not have individual case level data and details which would enable them to send out surveys. This particularly affected carers from Mental Health trusts.[109]

In reporting on findings, it is important to be clear that the survey does not represent all carers, but rather the subgroup of carers who have been in contact with their local authority. Given the available sampling frame, it would not be possible for CASSRs to survey those who they or organisations they commission are not in contact with using this survey design. It is likely that some groups in the wider carer population are less likely to be in touch with the local authority (e.g. some ethnic minority groups where there may be a stigma attached to seeking help[110], or those with less need for support). However, an approach which advertises the survey among a wide group of carers would not be a random sample and is not recommended for this survey.

Another result of the complexity of defining the carer eligible population and the role of third parties is that the population can be very broadly defined and may include some who would not consider themselves to be eligible. This reflects the change to the way of defining the eligible population in 2016-17 in line with the Care Act where a wider group of carers have their needs assessed.[111] Some carers who are invited to take part are unaware that the services they use are commissioned by the council, and therefore respond to the survey invitation to say that they are not eligible to participate. A related issue is that some of those in the eligible population and included in the sample do not self-identify as carers, and therefore do not complete the survey. Both of these issues impact on response but are included here as they relate to the definition of the eligible population.

The technical report of the pilot version of the survey in 2009-10 commented that there are ‘hidden carers’ who are not in contact with social services and do not realise they are using services commissioned by the council, or who do not view themselves as carers. This shows there has been an awareness of this issue from the start of the survey.[112] While the cover letter does use the term ‘carer’ with a definition, it also says the survey aims to get carers’ views on the services they receive. This could lead to those who do not label themselves as carers or do not receive any council-funded services

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107 NHS Digital (2018) Sace_additional_info_scenarios on eligibility
108 NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, published 25 June 2019.
109 NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, published 25 June 2019.
110 Gray et al (2014)
111 HSCIC (2015) Adult Social Care User Experience Surveys: Summary Findings from Consultation Feedback on the Implications of the Care Act
112 Fox,et al (2010) Personal Social Services Survey of Adult Carers in England – 2009-10: Survey Development Project. PSSRU Discussion Paper 2643

feeling that the survey is not relevant to them. Although the cover letter uses the term ‘carer’ which can be interpreted in its narrow sense, the questionnaire does not, suggesting that the language in the cover letter could become broader in line with the questionnaire content. More precisely:

- the questionnaire introduction refers to ‘*Caring for others*’ and ‘*If you look after a family member, partner or friend in need of support*’ instead of using the term ‘carer’ - so that it is more straightforward for someone who does not label themselves as a ‘carer’ to take part;

- question 4 of the survey ( *“Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?)* gives participants the option to tick ‘*We haven’t received any support or services from Social Services in the last 12 months’* - so that it is straightforward for someone who cares for someone not receiving commissioned services and who does not label themselves as a ‘carer’ to take part.

Among those who did complete the questionnaire, there was an increase in the percentage of respondents reporting that they did not use any services between 2014-15 and 2016-17 when the eligible population for the survey changed. In Question 4 of the survey, 16.8 per cent of respondents reported they did not receive any support or services from Social Services in last 12 months in 2014-15 compared with 22.4 per cent in 2016-17. This suggests that it is possible that the issue of people not recognising the relevance of the survey for them may have increased with the change in eligible population. If even those who take part report less use of council services than before, there may also be a growing number of people who do not even get beyond the cover letter because they do not receive any services.

### 3.3.2 Quality and availability of data

Among those included in the eligible population there are also issues about the information available to explore the representativeness of the issued sample. This is caused by three main issues:

- Not all relevant fields being collected by all CASSRs. In particular, data on sexual orientation, ethnicity and religion is not available for all CASSRs, which will limit any analysis exploring under-representativeness in those groups;

- Information being collected and held by third parties which means the consistency of this information and access to CASSRs may be limited;

- Potential errors in the transfer of this information to NHS Digital. For example, in 2018-19, a design error meant that the data return spreadsheets did not include space for CASSRs to record the details of participants whose age and gender were unknown.[113]

To address the issue of missing information about demographic characteristics, consideration should be given to whether certain demographic data should be collected as standard across all CASSRs in order to monitor service delivery and target appropriate support or translations when carrying out surveys.

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[113] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, published 25 June 2019.

### 3.3.3 Exempt CASSRs

The official survey guidance states that CASSRs are required to select a sample large enough so that the survey results have a relatively small margin of error (less than five percentage points). This is to ensure estimates about the whole population can be made from the survey data.[114] This can be an issue in CASSRs with a small population of carers.

In 2018-19, several CASSRs informed NHS Digital that they were unable to meet the margin of error requirement. NHS Digital advised them not to implement any additional measures to increase response rates (e.g. sending a second reminder letter), to ensure a consistent methodology and reduce burden or stress on carers.

Two CASSRs were exempt from the survey because the number of carers within their locality who were eligible to be included in the survey population was too small to guarantee statistically robust results.[115] One of these CASSRs participated anyway, but their results are not included in the overall results.

## 3.4 Issued sample

The following groups in the eligible population are excluded from the issued sample:

- Carers who have died,
- Carers who have moved away from the area,
- Carers who will be in hospital at the time of the survey,
- Carers who have moved into residential or nursing accommodation,
- Carers who are in active dispute with the council at the time the survey is being sent out,
- Carers who are involved in an open safeguarding alert or investigation,
- Carers who have contacted the council in the past expressing a preference to opt out of surveys or complain about receiving a survey,
- Carers whose cared for person has died,
- People who were carers for only a short spell that ends before the survey is carried out.

The guidance to CASSRs makes it clear that they should not exclude carers on the basis that they have ’a reputation for complaining about services’ because of the bias this would cause.[116]

Although there is potential to include people who have cared for someone who has died over the last 12 months, there are issues of sensitivity which means this would be inappropriate. The cover letter does acknowledge that some people may receive the questionnaire after the person they care for has died, and asks them to complete it if they feel able or to return it blank.

Unlike the ASCS, exclusion for reasons of lacking mental capacity is not a particular issue. There is no system for excluding those who lack mental capacity, and carers would generally not be found among care home residents but are excluded if they are in a care home. It is possible that there are carers who would lack mental capacity to take part once invited, but this would impact on the survey response rate rather than the issued sample.

Unlike the ASCS, where short-term users are not included in the eligible population, the sample for SACE may include short-term carers (i.e. people who are caring for someone who has had short-term

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114 NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, published 25 June 2019.

[115] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, published 25 June 2019.

116 NHS Digital (2018) Personal Social Services: Survey of Adult Carers in England. Information and guidance for the 2018-19 survey year

support) if they are still on the CASSR records. All of those who have been assessed and had advice or information (regardless of when) would be eligible, unless the local authority is aware that they have stopped being a carer. It would be possible to remove the exclusion of short-term carers, however this could have further negative impacts on response rates. If this exclusion criteria were removed, the wording of the questionnaire and cover letter would need to change to reflect the fact that caring could be in the past.

## 3.5 Response

### 3.5.1 Calculating sample sizes

The official survey guidance states that CASSRs are required to choose a sufficiently large sample size so that population estimates from individual questions are sufficiently robust (i.e. at 95 per cent they have a confidence interval of not more than +/- 5 per cent). To do this, CASSRs should use the sample size calculator, into which they enter the number of eligible carers and the expected response rate[117]. The guidance specifies that the predicted response rate could be estimated from local surveys of carers CASSRs may have conducted, or their response rate to the last SACE. It is extremely important that CASSRs make sensible estimates of response rates when calculating their sample size. In 41 CASSRs in 2018-19, the achieved sample size was not sufficiently large to meet the minimum requirement.[118]

### 3.5.2 Underrepresented groups

Information published by NHS Digital about the profile of the issued and responding sample shows that:

- those aged 18-64 are under-represented in the responding sample (47.3 per cent compared with 57.0 per cent of the issued sample);
- non-white groups are also under-represented in the responding sample (11.5 per cent compared with 16.1 per cent of the issued sample);
- there is no difference in the gender profile of the responding (31.7 per cent are men) and issued samples (31.3 per cent are men).[119]

A detailed analysis of which groups are under-represented in response is the focus of the secondary analysis part of this project and there is limited previous research on this. As well as looking at demographic or carer type groups which may be under-represented, the analysis explores whether there is any evidence that those who are satisfied are under-represented by comparing satisfaction for different subgroups and at different times, though noting that there may be genuine differences in satisfaction for different groups.

### 3.5.3 Survey fatigue

Unlike the ASCS, there is no guidance on excluding carers from the sample because they have been invited to take part in other surveys. The only mention is to exclude those who have opted out of surveys or complained about receiving surveys. The size of the eligible population in some areas combined with the need to achieve minimum sample sizes means that questionnaires are issued to the whole eligible population in smaller CASSRs. There were 38 CASSRs where this was the case in 2018-19, and a further 29 where 80 per cent or more of the eligible population was issued. This suggests that survey fatigue may well be an issue among carers in those smaller CASSRs - which could negatively impact on response rate and affect some groups more than others (leading to overall lower response rates or

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[117] SACE Sample Size Calculator, 2018-19.
[118] SACE Data Quality Annex, 2018-19
[119] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Understanding Surveys', published 25 June 2019. https://files.digital.nhs.uk/6A/E32A5F/PSS_SACE_Understanding_Surveys_2018-19.pdf

differentially lower response rates among particular groups in a CASSR). However, it is worth noting that CASSRs where 80 per cent or more of the eligible population are issued include several with well above average response rates (the average response rate across England in 2018-19 was 37 per cent). The fact that the survey is carried out every two years rather than annually may mitigate the impact of sampling such a high proportion of the eligible carer population each time the survey is done. Also, not all the carers will be the same each time the extract is run, so even where 100 per cent are sampled, some of this population will have changed.

### 3.5.4 Incentives

There is no mention of incentives in the SACE guidance or in the methodology and technical information. Use of incentives is not reported on in the data quality annex.

## 3.6 Survey design

### 3.6.1 Survey mode

#### Online

In 2018-19, the vast majority (99.4 per cent) of returned questionnaires were completed by post, with a very small proportion (0.1 per cent) of participants having completed an interview (either face-to-face or by telephone). For the first time, two CASSRs (which we will refer to as CASSR one and CASSR two) were permitted to pilot an online version of the survey. In CASSR two, a 'push to web' methodology was used whereby a letter was sent without a questionnaire and the paper questionnaire was only sent with the reminder letter. [120] Online responses from these two CASSRs accounted for 0.4 per cent of all responses. Therefore, at national level there is minimal bias estimates caused by the different methods of data collection because of the small numbers.[121] Within both of these councils, online surveys represented 29 per cent of responses. It is notable that the response rate in both councils was lower in 2018-19 than in 2016-17 when two modes were offered. For the survey as a whole, response rates dropped from 41 per cent in 2016-17 to 37 per cent in 2018-19, and the drop in these two CASSRs was greater, despite offering the online mode. CASSR one had a response rate of 47.5 per cent in 2016-17 and 33.6 per cent in 2018-19, and CASSR two had a response rate of 43.3 per cent in 2016-17 and 27.9 per cent in 2018-19). The drop-in response rates for ASCS in these two CASSRs when the online mode was offered was less, perhaps because on the ASCS the paper questionnaire was sent with the initial letter, rather than just with the reminder.

While there was some variation between the 2016-17 survey and the 2018-19 survey results, as well as between the data collected by different methods, analysis of the data by NHS Digital shows that there was also variation across many of the councils and therefore it is unlikely to be a result of the change in methodology.

The results from CASSR one shows that there were significant differences between the age distribution of the eligible population and the responding participants for both online and other modes (mainly paper), but the direction of these differences differed between the two modes. The online participants had a higher proportion of carers aged 18-64 than the eligible population, whereas participants using other modes (mainly paper) had a higher proportion of carers aged 65+ (though these differences were not statistically significant).

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[120] It is unknown whether this was also used in CASSR one.

[121] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement', published 25 June 2019.

For CASSR two, there was a significant difference between the age breakdown of the eligible population and those responding by post, telephone and face-to-face. However, there was no difference between the age distribution of the eligible population and participants who responded online. This suggests that the participants who responded online better reflect the age profile of eligible population compared to the other methods.[122] Again, those responding online had a younger age profile than those responding by other methods.

If more CASSRS include an online method in the future, it is likely that the use of an online mode will yield a higher proportion of responses from those aged under 65, compared to using the postal method.[123] Since overall those aged 18-64 are under-represented in the responding sample[124], introducing an online mode may have the effect of improving the representativeness of the survey, even if overall response rates are not improved. Previous literature suggests that a web only approach can lead to lower response rates.[125] Although paper was offered in the pilot, it was only offered at the reminder stage in CASSR two. The implication of the lower response rates in CASSRs where the online mode was offered needs to be considered before this mode is rolled out more widely. Further experimentation is also needed on the impact on response and response bias of different approaches to offering online options ('push to web' where online is offered initially and an option where both paper and online are offered together). A control group of paper only also needs to be offered in the same CASSR at the same time so that conclusions can be drawn even if external events impact on response rates.

#### Interviewer administered

Although scripts for face-to-face and telephone interviews are made available to CASSRs, they are encouraged to use these in only a small number of cases where it is requested and where there is reason such as sensory impairment, which means the paper questionnaire is unsuitable. It is not advocated as a method of boosting response generally. In 2018-19, there were two CASSRs where five or more carers completed the survey face-to-face and six where five or more competed it by telephone.[126] Most CASSRs had no completes by either of those modes suggesting that most councils are following the guidance to make these alternative modes an exception.

### 3.6.2 Questionnaire design

During the development work for the survey, it was highlighted that the circumstances of carers can vary considerably according to their own characteristics and the circumstances of the person they care for. The technical report of the pilot version of the survey carried out in 2009-10 recommended that "*The heterogeneity of the eligible sample population of carers requires that very specific questions should be avoided. Questions focusing on a narrow area risk disenfranchising those respondents to whom the questions are not relevant*".[127] The SACE questionnaire reflects this recommendation in that the outcomes questions are not service-specific, but instead ask about general outcomes such as being able to spend time as they wish or control over daily life. They do not ask about experience of specific services.

In contrast to the four categories used in the ASCS, they follow a three-category approach[128] to reflect different levels of need as follows:

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[122] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement', published 25 June 2019.
[123] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement', published 25 June 2019.
[124] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Understanding surveys', published 25 June 2019.
[125] Dillman et al (2014) Internet, Phone, Mail and Mixed-Mode Surveys: The Tailored Design Methods.
[126] Analysis of 2018-19 SACE data.
[127] Fox,et al (2010)
[128] Fox,et al (2010)

- Preferred situation – where needs are met to the desired level,
- Low level needs – where there are needs but these do not have an immediate or longer-term health implication,
- High level needs – where there are needs and these have an immediate or longer-term health implication.

The Care Act has come in since the questionnaire was designed. It has particular provision for the needs of carers and their role in providing care and support. Although it does not directly relate to representativeness, consideration should be given as to whether the questions as they stand capture the information needed to assess the experience of carers and the role of the local authority in supporting them since the Care Act came in. A consultation was carried out in 2015 to explore the implications of the Care Act for the ASCS and SACE.[129] It made a number of recommendations, including the need for the questions to be amended to reflect the shift in emphasis to wellbeing, the need to assess quality of information and advice, and more information needed on the quality and experience of assessments.

### 3.6.3 Alternative versions of the questionnaire

Official survey guidance states that CASSRs should use information about participants to ensure that they use appropriate communication methods. For example, in the case of participants with sensory impairments, CASSRs can contact them by telephone to invite them to participate in the survey. For participants who might require the assistance of a sign-language interpreter, CASSRs should consider organising for the first contact to be made by someone known to the participant, such a social worker.[130]

At present, an electronic version of the questionnaire can be sent to participants with sensory impairments who otherwise would not be able to participate in the survey. For these participants, the questionnaire can be returned by email. Whilst this helps to ensure representativeness among this group, it is important to consider that this requires Internet access and a certain level of computer literacy, which may not be present in low-income areas or among older participants. For this reason, scripts for face-to-face or telephone interviews are also provided.[131]

Translated versions of the questionnaire are available in 17 languages. These can be requested using a special translation request sheet which is intended to be sent out with the initial invitation letter, although the guidance does not provide any instructions on when and how to post this sheet. The guidance does say that CASSRs should send out questionnaires in the first language, when they know a carer's first language is not English, in addition to sending the English questionnaire. In 2018-19, less than 0.2 per cent of returned questionnaires were translated versions.[132] It is notable that while 10 per cent of carers overall reported they had help to complete the questionnaire in 2018-19, 48 per cent of those using a translated questionnaire had help. This suggests that among those requiring a translation, language is not the only barrier to completing the questionnaire. Other barriers may include lack of literacy skills, the fact that some people speaking minority languages use dialects which do not have a written form (for

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[129] HSCIC (2015) Adult Social Care User Experience Surveys: Summary Findings from Consultation Feedback on the Implications of the Care Act

[130] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Information and guidance for the 2018-19 survey year', published June 2019.

[131] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-carers-survey-2018-19#materials

[132] NHS Digital, 'Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement', published 25 June 2019.

example, most people of Bangladeshi origin who do not have English as a first language speak Sylheti which is not written), cultural barriers or lack of confidence in completing questionnaires.[133]

In 2018-19, due to an administrative error, translated reminder letters were not made available to CASSRs. Instead, CASSRs were advised to send the original cover letter in place of the reminder letters where appropriate.[134] This may have had an impact on the rate of translated questionnaires used that year.

In a data quality statement from NHS Digital, analysis shows that in 2018-19 there were some significant differences between the data collected from translated questionnaires and questionnaires in English. However, the scope for detailed analysis and identifying significant differences was limited by the small number of questionnaires completed and no further detail was given.[135] Since so few questionnaires are completed in translation, the impact on overall estimates is likely to be negligible. However, if the percentage of surveys completed in translation increased, the potential impact of translations on answers given and associated bias introduced would become of greater concern. The differences found suggest that there may be differences in the experiences of people using the two types of questionnaires. Further research into this is necessary to determine whether other factors, such as age and gender, influenced these results.[136] This analysis could be carried out by comparing the translated data with participants with a matched demographic profile, as well as comparing the translated data with participants who reported that someone helped them by translating. In addition, it would be valuable to explore the extent to which the need for translation has been met.

There is no easy read version of the questionnaire for SACE from NHS Digital, although CASSRs are told they should supply an easy read version if it is requested. Easy read is intended for adults with learning disability. Among those who completed the survey (using the standard questionnaire) in 2018-19, 2.8 per cent of carers reported a learning disability, and among this group 37 per cent reported help with completing the questionnaire. [137] It may be that there are other carers with a learning disability who are not able to participate. It is unknown what percentage of the issued sample have a learning disability and whether response would be better among this group with an easy read version. Because of a lack of sample information for this group in the carer sample, it would not be possible to target an easy read version to learning disabled people as is done for the ASCS.

### 3.6.4 Help with completing the survey

The cover letter explains to carers that if they feel unable to complete the questionnaire by themselves, they can ask a friend or relative to help them. The letter also explains how they could get help from an independent helper (advocate). As with the ASCS, it explains that even if they get help, it is their own views which should be recorded.

In 2018-19, 10 per cent of carers overall had help with completing the survey. There is no further information available on who provided the help or the nature of the help.

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133 Gray et al. (2014)

[134] NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, 25 June 2019.

135 NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, 25 June 2019.

136 NHS Digital, ‘Personal Social Services Survey of Adult Carers in England, 2018-19 – Data Quality Statement’, 25 June 2019.

137 Analysis of publicly available data from SACE 2018-19.

## 3.7 Key findings and recommendations

The findings and recommendations below are based on the review of the methodology and are to be brought together with evidence from the secondary analysis and primary research in the main report.

### 3.7.1 Eligible population extract and representativeness

- In 2018-19, CASSRs reported several issues that resulted in incomplete datasets across CASSRs. This was related to not having information from third parties or not having all the information about the eligible population. Where basic contact and identify information is missing, it means they cannot be included in the sample frame. Where some demographic information is missing, the person can be included in the sample frame but with less knowledge about their characteristics.

- Improving the available data about the characteristics of the eligible population would assist in assessing the representativeness of the responding sample. Improving basic contact details would ensure the sample frame better reflects the intended eligible population. Some local authorities are moving to new systems for handling data about their user and carer populations and if these are successful, their use could be encouraged more widely.

- Small populations of carers in touch with the local authority create challenges in some areas, as it often means limited access to a sufficiently large eligible population to produce reliable estimates. Consideration could be given to asking two geographically close CASSRs with similar characteristics to work together to produce cross local authority data which is sufficiently large for analysis. This would rely on there being suitable similar CASSRs willing and able to work together.

- The survey represents only carers who have been in touch with the council. The method for extracting the sample from SALT means this is inevitable, but CASSRs should use other evidence to understand more about 'hidden carers'. CASSRs sometimes carry out other surveys in their wider population of residents and questions about help and support provided to others could be included in these. They could also work with third sector organisations who support carers to gather information from this group. The change in 2016-17 to include carers who have not had an assessment in the last 12 months means the inclusion criteria are as wide as they can be with this survey design based on contact with the CASSR.

- Young carers under 18 are not represented by the survey, but given issues over consent and the nature of the questionnaire this is a reasonable exclusion. Feedback on the experiences of young carers should be sought using a different approach, such as working with organisations which support young carers, or including questions about caring in other local authority research about young people, followed up by small scale qualitative methods (though the cost implications of this should be considered).

### 3.7.2 Sample frame and selected sample and representativeness

- The exclusion criteria used to remove cases from the eligible population before issuing the sample seem reasonable and there are no obvious changes which could be made to improve representativeness at this step.

### 3.7.3 Response and representativeness

- Carers aged 18-64 years and those who are non-white are under-represented among respondents to the survey. More work is needed to understand which particular subgroups within these broad categories are under-represented, as well as whether carers supporting people with particular types of need (such as mental health needs) are under-represented. Under-representation matters because it may affect population estimates. If certain groups which are less satisfied are under-represented in the results, then the extent of dissatisfaction may be under-estimated. On the other hand, if those who are dissatisfied are more likely to respond to the survey in order to have a say, dissatisfaction may be overestimated. More analysis is needed on which groups are under-represented and how changes in their response rate and representation over time relates to the survey estimates.

- There is evidence from local authority feedback that some of those invited to take part do not feel the survey is relevant, as they do not receive services or do not identify as a 'carer'. The question about satisfaction with services allows for a 'do not receive services' response. The use of this option has increased from when eligibility criteria were widened in 2016-17. If the responding sample includes an increasing number who have not received services, then the overall sample is likely to have done, potentially increasing the number who feel the survey is not relevant and so do not take part. Consideration should be given to making the covering letter more general in its wording (e.g. using the phrase 'help and support') so that the wide group invited to the survey recognise that it is relevant for them.

- Survey fatigue may be an issue in response because of the high proportion of eligible carers sampled each time, however this survey is only run every two years, which means people are only asked to take part infrequently which may reduce fatigue in those asked to take in two consecutive surveys, and reducing the chance that the same people are sampled each time as there will be turnover in the carer population. The survey invitation does not allow for feedback to be given on how the findings have been used and what value the survey has for the local authority. Doing so could assist with maintaining response among those asked to complete the survey every time it is run.

### 3.7.4 Survey mode and alternative formats

- The use of telephone and face-to-face as an alternative to postal completion is limited, in line with NHS Digital guidance. An online mode has been trialled which indicated that it might help address the under-representation of adults aged 18-64 if the use of online is extended to other CASSRs. However, evidence from two CASSRs which took part in the trial suggests it may not have a positive impact on response rates and could potentially have a negative impact. Further experimentation about the use of online modes is needed.

- As suggested for the ASCS, consideration could be given to providing greater encouragement and support for CASSRs to offer face-to-face or telephone interviews when self-completion approaches are not accessible to carers.

- Translations are used by a small proportion of participants and those using them need greater help from others in completing the survey than carers as a whole do, suggesting more could be done to support completion among those who face language, cultural or literacy barriers to taking part. More research is also needed on the extent to which differences in the results for those who use a translation compared with the rest of the sample relate to use of the translation (methodological) or other characteristics which affect their experiences (genuine differences in satisfaction).

- There is no easy read version in the SACE, although the survey data show that some carers do have a learning disability (and could potentially benefit from having an easy read version). More evidence would be needed before recommending whether the addition of an easy read version would help improve response among this group. It would be advisable for consistency and efficiency for NHS Digital to organise their own easy read version rather than asking CASSRs to arrange it individually.

### 3.7.5 Short-term carers and users

- Carers may be short-term carers themselves or may care long-term for someone who is a short-term user of local authority services. The eligible population of carers includes those who may have been a carer for a short time and includes carers regardless of whether the person they care for is a long-term user of social service support. However, councils can exclude carers who cared for a short time and no longer do so from the sample frame even if they appear in the eligible population extract. Although there is no blanket exclusion of short-term carers from the eligible population, there is some inconsistency across CASSRs, with some including short-term carers and some excluding them from the survey. Consideration could be given to removing the short-term care grounds for exclusion.

### 3.7.6 General

- The core questions were set in the questionnaire before the Care Act was implemented. The bank of additional questions is useful, and NHS Digital should do a regular review of questions and whether to include them in the survey and whether changes are needed to reflect the evolved relationship between CASSRs and carers under the Care Act. The eligibility criteria have evolved in response to the Care Act but the questionnaire itself has not and this should be reviewed following the ASCOF refresh.

- Response rates have been declining generally on SACE (in line with response rates on surveys generally) and while addressing the issue of lack of representativeness of certain groups may help with this, where the under-represented groups are small this will have limited impacts on overall response rates. Consideration should also be given to halting the general decline in response, for example through making it clear how the survey results make a difference in the local authority and nationally.

# 4 Comparisons and Implications

## 4.1 Comparisons between ASCS and SACE

By exploring the official survey approaches for both ASCS and SACE, it has been possible to identify a number of issues that affect representativeness and response rates. Unsurprisingly, given the similarities in subject matter and administration, there are several areas for comparison between ASCS and SACE. The section below outlines some key parallels between the surveys, which could be helpful for the commissioner of both surveys – NHS Digital – and the administrators of both surveys – CASSRs, to inform their future design.

### 4.1.1 Completeness of data

In both surveys, there are some disparities in the demographic information collected by different CASSRs. For example, sexual orientation and ethnicity is not collected by all CASSRs.[138] Incomplete datasets make it very difficult to make inferences about the views of certain groups, or to determine whether certain groups are being underrepresented. It also reduces the ability to make comparisons across different CASSRs. Ethnicity is not available for the eligible population in NHS Digital's records making it difficult to assess the impact of exclusion criteria on the ethnic representativeness of the surveys and this affects both surveys. Limited information on ethnicity and first language also makes targeting translated versions of the questionnaire challenging.

### 4.1.2 Underrepresented groups

Aside from the issue of lacking demographic information, a number of groups of people are underrepresented in each survey. An issue relevant to ASCS and not SACE is the exclusion of those who lack mental capacity from the sample frame. However, for both surveys lack of capacity to complete a paper questionnaire may reduce response rates among those who are invited to take part, over and above any exclusion from the sample frame.

In ASCS, the groups under-represented in response tend to be those with mental health problems, those who live in more deprived areas, working-age people, nursing home residents, people with severe disabilities, and people from ethnic minority groups. However, the main research on this used data from the 2010-11 ASCS[139]**.** Since then, response has declined on this survey and little is known about the impact of the decline of response rates as a whole on representativeness. In SACE, the groups most underrepresented are working age carers and carers from ethnic minority groups, but there has been limited research on this issue using SACE data.

### 4.1.3 Guidance on seeking help to complete the survey

Given the target population for ASCS, there is a lot of information in the official survey guidance and existing literature on how participants can seek help to complete the survey if needed (e.g. if they have a learning disability or are too frail to write). There are several suggestions (detailed in the relevant section above) as to how the guidance can be made clearer to make it easier for participants to seek appropriate help. One recommendation is that SACE should be signposted on the ASCS materials to highlight the opportunity for carers' views and experiences to be heard separately. This could reduce the likelihood of

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[138] As an example, in 2018-19 12 per cent of the issued sample had blank ethnicity data and a further 10 per cent had a code for ethnicity not stated.

[139] Malley (2017)

bias being introduced by those helping service users to complete the ASCS survey. It could also have the effect of encouraging response to SACE. However, because SACE is only run every two years and takes place earlier in the year than the ASCS, carers may have to wait 18 months before they have an opportunity to have their say which may limit the effectiveness of this approach.

### 4.1.4 Survey mode

In 2018-19, two councils piloted online versions of both surveys. Across both CASSRs, one per cent of respondents completed the ASCS online, while 29 per cent of carers completed SACE online. However, it is notable that response in both councils was lower in the year when the online option was available, suggesting that offering two modes does not improve response and could potentially have a negative impact on the response rate. However, there are indications that there is potential for an online methodology to improve representation of working age adults on the SACE. More research using split sample experiments on a larger number of CASSRs is needed before definitive conclusions can be drawn.

On both surveys, a handful of local authorities carry out more face-to-face or telephone interviews than would be required by people with sensory impairments. Although these modes offer the potential to allow those who would otherwise not respond to take part, there are costs and comparability issues with extending the use of these methods, even if using the standard scripts provided by NHS Digital.

### 4.1.5 Questionnaire design and survey content

The technical report of the pilot version of SACE (2009-10) and the ONS review of the ASCS in 2010 suggested several ways that the questionnaires could be improved to help make it easier for participants to complete and therefore to potentially increase the response rate. Those initial recommendations were implemented in the questionnaires as they are now.

However, the social care context has changed since the surveys were designed following the implementation of the Care Act, with an emphasis on prevention and strength-based approaches, the recognition of the role of carers and the continued pressure on budgets. Therefore, consideration could be given to the content of the questionnaires. A research project and consultation are currently taking place to review and refresh ASCOF (which includes measures from both ASCS and SACE).[140] While the focus of this project is on representativeness rather than the survey content, any recommendations will need to be put into the context of this wider review of ASCOF. Furthermore, the ASCS and SACE questionnaires need to reflect how they can be more relevant to service users and carers as the role of carers and nature of support offered by CASSRs has changed. This might improve both surveys' response overall or among particular groups.

### 4.1.6 Reminders to take part

One reminder is sent to participants on both surveys. Even where response is low, NHS Digital does not permit CASSRs to send a second reminder because of the potential bias this could introduce, as those who respond to second reminders may be different from those who respond earlier. There are also concerns about service users or carers feeling coerced into taking part. The standard approach of survey organisations for general population survey often involves two or even three reminders (e.g. Active Lives

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[140] ADASS has commissioned the Institute of Public Care (IPC) at Oxford Brookes to carry out this research. https://ipc.brookes.ac.uk/what-we-do/consultancy/ipc-ascof.html

Survey). An experiment to explore the impacts on second reminders on overall response and on response bias could be considered (if CASSRs would have the resources to send second reminders).

### 4.1.7 Alternative versions of the questionnaire

For both surveys, the representativeness and response rates could be improved by conducting additional research into the groups that might benefit from accessible or translated materials.

In the case of the ASCS, research is needed to inform the targeting of alternative versions of the questionnaire to participants that could benefit from them, for example, by ensuring the necessary demographic information is collected and flagged on council systems. This seems to work well for the easy read questionnaire because it is designed for use in one of the sample stratum (learning disability), and so the information to target it is readily available to councils. This is less true for translated questionnaires since information on first language is not standard and ethnicity is not always collected by councils. If CASSRs were requested to collect this information from service users and carers as standard, this would be beneficial in targeting survey materials and understanding their service user population more generally.

In the case of SACE, there were some significant differences between the data collected from translated materials and questionnaires in English. This suggests that there may be differences in the experiences of people using the two types of questionnaires. Therefore, further research is necessary to determine whether other factors (such as age and gender) also influenced these results.

Both surveys could benefit from improving the signposting to alternative versions of the questionnaires, early in the covering letter.

The issues of proxy responses for service users who cannot complete a survey themselves because they lack mental capacity is specific to the ASCS. This can lead to potential confusion over whose views are being sought and the impact could be that carers report their own perceptions, which tend to under-report care recipients' quality of life. However, the idea of introducing a proxy version of the questionnaire on the ASCS needs to be considered alongside its impact on SACE as this could increase burden on carers, particularly in years when both surveys are run.

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# Appendix A: Methodology

For this desk-based review, Ipsos MORI utilised a structured approach to recording and evaluating information which focused on the survey methodology (i.e. sampling, eligibility, invitation materials, guidance on administration). Information from the data quality annexes about individual local authorities and summary data from NHS Digital on response among particular groups has also been considered. When reviewing the methodological documents and evidence the following issues were considered:

Likely impact on sample **representativeness**;

**Participation** of high need and hard to reach groups;

Ease of **implementation of the survey** in practice.

## Points to consider in reviewing documentation and evidence to inform the methodology review

- Quality and consistency of information about population;
- Approach to determining eligibility for the survey (not all in overall population are eligible);
- Approach to identifying sample and information provided to NHS Digital (e.g. not all LAs collect religion or sexual orientation);
- Use of sample size calculator;
- Evidence of difference between guidance and practice in identifying population, eligible population, sample;
- Evidence of fieldwork practices which may impact on representativeness of responding population;
- Information about which groups are under-represented and at which stage (eligibility or response);
- Issues such as need to do a census/ repeated burden on same users year on year;
- Involvement of care homes as gate keepers, completers of questionnaires (should not), facilitators;
- Approaches to facilitating inclusion of hard to reach groups (offer and use of easy read, translations, alternative modes);
- Quality and clarity of guidance given to LAs;
- Quality and clarity of guidance given to participants (which may impact upon representativeness or ability of hard to reach groups to participate);

- Features of the questionnaire design which may impact upon representativeness or ability of hard to reach groups to participate);
- Relevance of questionnaire to different users;
- Anything which relates to short-term users - e.g. any design features which are suitable for short-term users/ unsuitable/ impact of previous changes on this group;
- Any other issues which could shed light on representativeness and inclusion of hard to reach groups.

# Appendix B

## Response and changes to the design or guidance by survey year for ASCS

| Year | Methodological changes, and changes to the guidance | Response rate |
|---|---|---|
| 2010-2011 | guidance not available online | 41 per cent |
| 2011-2012 | 1) incorporation of stratification with service users being placed into one of four strata in the sampling design - previously a simple random sample was used.<br>The reasons for this are twofold:<br>• To increase precision of the results as the stratification design ensures the sample is more representative of eligible users than might be achieved via a simple random sample.<br>• To allow local authorities to over-sample for groups of service users which are of interest to them, and therefore achieve more robust results for these subgroups.<br>2) putting the care home manager in charge of assessing whether service users in residential care, nursing care or supported living have the capacity to consent to take part (previously councils were asked to check capacity for all service users and there were concerns that the process was not being applied consistently). | 40 per cent |
| 2012-2013 | guidance not available online | 39 per cent |
| 2013-2014 | guidance not available online | 38 per cent |
| 2014- 2015 | There have been a number of changes introduced:<br>1/the replacement of the Referrals, Assessments and Packages of Care (RAP) return with the Short and Long-term services (SALT) collection, which has resulted in a change to the target population for the survey.<br>2/the introduction of the Equalities and Classifications Framework (EQ-CL), which has resulted in changes to some of the auxiliary data collected as part of the ASCS process.<br>3/there have been changes to the sample substitution criteria for the survey, and a change to the way in which sample weights are calculated when analysing the data. | 36 per cent |
| 2015- 2016 | guidance not available online | 35.7 per cent |

| | | |
|---|---|---|
| 2016- 2017 | Changes to the guidance:<br>1/ Aligned content with the recent development in the Survey of Adult Carers in England<br>Changes to the questionnaire: a new question was included in the standard version of the community questionnaire; question 2c 'Which of the following statements best describes how much choice you have over the care and support services you receive?'<br>2/ The potential use of specialist survey software to present the questionnaires has also been included.<br>Changes to covering and reminder letters- The covering and reminder letters have been streamlined to make these more focused and engaging<br><br>Changes to questionnaires<br>1/ An additional question has been included in the standard versions of the community questionnaire: "Which of the following statements best describes how much choice you have over the care and support services you receive? By 'choice' we mean being able to choose from a range of care providers and services and make changes as and when required."<br>2/ Response options are: 1) I do have enough choice over care and support services; 2) I don't have enough choice over care and support services; and 3) I don't want or need choice about care and support services. The emphasis was on a simple question that was easy to interpret.<br><br>Changes to translated materials - In addition to the fourteen languages provided in previous years, three additional languages have been procured for use in 2016-17 (French, Italian and Tamil). These were selected as the languages missing from the survey as well as being reported most frequently as first languages within the 2011 census. | 35.6 per cent |
| 2017- 2018 | Changes to the guidance:<br>1 The content has been amended with minor rewrites and edits to improve clarity.<br>2 Figure 1 has been revised to better accommodate and reflect the process followed by CASSRs in running the survey<br><br>Changes to covering and reminder letters<br>1. The covering and reminder letters have been streamlined to be clearer, more engaging and to ensure respondents are able to access questionnaire content more quickly.<br>2. Minor updates and formatting changes<br>3. Extra optional text has been added, which informs users that they may contact the council directly, without returning the blank questionnaire, if they do not wish to participate in the survey. | 32.2 per cent |

| | | |
|---|---|---|
| 2018-2019 | Changes to guidance:<br>1/ inclusion of a paragraph on not including additional questions in data return and how to code data returns sent in on the original version of the questionnaire but after the reminder letter has been sent out.<br>2/ additional clarity added on independent complaint contact numbers.<br>3/Appendix E amended to clarify there is only one version of the easy read questionnaire that can be used for service users both in the community and in residential and nursing care | 31.8 per cent |
| 2019-2020 | Changes to the guidance:<br>1. Clarity on what formats of the survey are produced by NHS Digital.<br>2. Paragraph on emailing letters to care homes amended to ensure only secure emails are used.<br>3. Removed reference to carers<br>4. Additional clarity on the submitting of materials is for review only and not approval.<br>5. Additional clarity on only removing service users who have a Court Appointed Deputy<br>6. Appendix E amended to confirm that the easy read materials do not need to be printed in colour<br>7. Definition of a dispute added<br>8. Confirmation that CASSRs can choose how long to accept surveys once the fieldwork period has ended.<br>9. Change to the guidance on the letter to care home and service users can be logged as having permanent loss of capacity.<br>10. Service users who are known to lack capacity should be excluded from the sample, regardless of support setting.<br>11. Service users under a DoLs authorisation should be excluded from the sample.<br>12. Additional guidance on the coding of unknown Ethnicity Group.<br>13. Clarity on including out of area service users in the sampling frame if they are funded by the council.<br>14. Clarity on not needing to send out the translation request sheet for service users who are known to have English as their first language.<br>15. Requirement to following safeguarding rules for face-to-face interviews.<br>16. Clarity of what report to send to respondents who request to receive one.<br>17. NHS Digital advise no more than six additional questions are added to the survey.<br>18. Clarity on when to send out translation request sheet<br>19 Amendment to date for sending in materials.<br>20. Further clarity on which questionnaire to use, including when a support setting changes. | N/A |

# Ipsos MORI's standards and accreditations

Ipsos MORI's standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a 'right first time' approach throughout our organisation.

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## ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos MORI was the first company in the world to gain this accreditation.

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## ISO 27001

This is the international standard for information security designed to ensure the selection of adequate and proportionate security controls. Ipsos MORI was the first research company in the UK to be awarded this in August 2008.

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## ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.

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## Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos MORI endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation.

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## Data Protection Act 2018

Ipsos MORI is required to comply with the Data Protection Act 2018. It covers the processing of personal data and the protection of privacy.

# For more information

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## About Ipsos MORI Public Affairs

Ipsos MORI Public Affairs works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. Combined with our methods and communications expertise, this helps ensure that our research makes a difference for decision makers and communities.

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