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Representativeness of Adult Social Care Surveys: Main Report

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Executive Summary

Background and aims

The Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE) are surveys administered by local authorities in England, using guidance from NHS Digital. The ASCS covers long-term adult service users with services funded or arranged by their local authority and SACE covers the carers of adults with social care needs, who are in touch with their local authority. The surveys cover topics such as satisfaction with care, quality of life, and outcomes from receiving care and support. The results feed into the Adult Social Care Outcomes Framework (ASCOF).

This research was funded by the National Institute for Health Research, on behalf of the Department of Health and Social Care (DHSC).

The research aims were to explore which groups are under-represented in those surveys and why, and how this can be addressed.

Methodology

The research was carried out between May 2019 and October 2020 and involved several elements:

- **Analysis of data from the ASCS and SACE** to explore whether those being sampled and responding to the two surveys are representative of long-term users of publicly funded adult social care (ASCS), and adult carers known to local authorities (SACE) in England.
- **Review of the literature about survey developments and hard to reach groups** to understand best practice for collecting the views of people with high needs or who are regarded as hard to reach.
- **Methodological review of the ASCS and SACE guidance and methodology published by NHS Digital.**
- **Consultation with local authorities** responsible for running the ASCS and SACE to explore their experience of running both surveys. An online census survey and in-depth telephone interviews were carried out.
- **Consultation with stakeholders** who use the data or have experience in research with service users and carers. This involved 15 in-depth telephone interviews.
- **In depth telephone interviews with service users and carers** to explore their experiences of the surveys and barriers to participation (six with service users and four with carers).

Under-representation in the surveys

There are two main causes of people being under-represented in the survey:

- People who are in the eligible population for the survey not being issued to the sample (because of deliberate exclusions from the sample frame or inadequate sample data)
- People who are sampled for the survey not responding to the invitation to take part (because of non-contact, refusal or inability to take part).

Summary data about the eligible population for each survey, together with individual level data about those who were invited to take part in the survey, were obtained from NHS Digital through a DARS (Data Access Request Service) application. The proportion of the eligible population issued to the sample was compared for different groups. The response rates were compared by group for both surveys in different years.

The secondary analysis showed that for the ASCS there were some groups under-represented at both the point of issuing the sample and responding to the survey, including people with memory and cognition support needs, and those living in nursing settings. Those with learning disability support needs living in residential settings were under-represented in the issued sample but not in the percentage responding. The groups who were under-represented in survey responses but not in the issued sample were those with mental health as their primary support reason, the youngest and the oldest service users and all ethnic minority groups.

In the SACE, women in the oldest age group were under-represented in the issued sample compared with men but not in response. The groups which were under-represented in the issued sample and in response rates were the youngest and oldest carers. While those from ethnic minority backgrounds were under-represented among older carers, they had higher response rates than white carers among younger carers.

Issues related to sampling from the eligible population

The research showed that as well as the issues around under-representation of certain groups in the sample, there are key groups of service users and carers who are not part of the eligible population. Although these groups may be of interest to local authorities they are not included in the surveys for a variety of reasons. The excluded groups include service users who have received a short-term package of care, those who receive equipment only, those who have received advice or signposting or who self-fund their care. Carers are excluded if they have not contacted their local authority (or any third party commissioned by local authorities for supporting carers). The introduction of the Care Act gives local authorities responsibility to provide support for well-being and prevention of further care needs among those who need care and their carers. There has also been a growth in the use of strength-based approaches to providing support, which means there is concern that the eligible populations for the surveys should be reconsidered. The inclusion of short-term care users is a high priority for DHSC.

NHS Digital guidance instructs or permits the exclusion of certain groups for ethical reasons. The process for excluding those lacking mental capacity, which involves local authorities working with care homes, is challenging. There is also a challenge of maintaining up to date and accurate records on both surveys. This results in the exclusion of some people who would be eligible for the survey, especially on SACE.

Barriers and facilitators to responding to the survey

Our research shows general barriers to taking part in these surveys as well as barriers specific to certain groups.

There was a lack of clarity about the purpose of the surveys. Service users and carers do not always understand that taking part will not impact on the services they receive as an individual. Local authorities value the surveys for benchmarking between authorities and comparison over time. There is also interest in the surveys as an opportunity to receive feedback and hear the voices of service users and carers. However, the information from the surveys is often insufficient to assess the impact of service changes or to plan improvements, owing to a lack of detail. The idea that taking part might result in further help from the local authority could be a motivator to take part but it also acts as a barrier when there is a concern that their response could result in services being taken away from them. Although the invitation materials are comprehensive, they are not successful in conveying the aims of the surveys and how they are used and what difference they make. Incentives are not generally offered and so this motivator for taking part is not available. In some local authorities and sample stratum the same people may be invited to take part in the ASCS every year and this can lead to survey fatigue, especially when other surveys are carried out on similar topics by other organisations.

Older people with cognitive decline face particular participation barriers. They often rely on support to participate but this is not always available and when it is, may bias results. Concerns among care home staff that the ASCS is used to assess the care they provide can prevent them facilitating support for residents to take part. The easy read questionnaire could be adapted to be used to assist older people with cognitive decline in taking part. Those with learning disabilities are well-represented in the ASCS by response rates. Everyone in this group is sent an easy read questionnaire. But the current easy read questionnaire has limitations with dated images and is unsuitable for certain groups within the learning disability sample. However, together with support from carers or advocates it does generate a good response rate among this population. The research has suggested that there would be scope for an adapted easy read questionnaire to be used to assist older people with cognitive decline in taking part.

Uptake of translated questionnaires is low and ethnic minority groups, especially those where language could be a barrier, have lower response rates. Barriers to taking part are not just related to language issues. Within many local authorities the number of service users and carers from ethnic minority groups is too small for useful analysis of ethnic differences, which means understanding and improving their representativeness is a lesser priority for local authorities.

Among mental health service users there can be a lack of understanding that their services are provided by the local authority. There are also issues with the quality of contact details because they may be held by a third party.

In the SACE the definition of the eligible population is broad and inclusive. However, eligible carers do not always recognise themselves as carers and face care responsibilities, including form filling.

Innovations in methodology

The surveys are carried out by post using a paper questionnaire. Alternative modes such as face-to-face and telephone interviews are rarely used. An online pilot was carried out in two local authorities in 2018-19 which resulted in small numbers completing the survey online. There is an appetite for online methods among local authorities, as well as among service users and carers. However, it is recognised by local authorities and potential survey participants that an online survey would not be suitable for all groups and would need to be combined with other modes.

At present about 10 per cent of participants in the ASCS receive help with completing the questionnaire but there is no formal proxy version. A formally designed and tested proxy version would allow those who cannot complete the survey by themselves the opportunity to be included within the survey.

In 2021-22 a client level return will be introduced for adult social care statistics. If the sample requirements of the ASCS and SACE are built into the design of this, it could offer the potential for innovation in the way the surveys are run. There would be potential for some centralisation to make processes more efficient, freeing up local authorities to spend more time analysing and interpreting results.

Key recommendations

The recommendations from this research are grouped under several themes.

Defining the eligible population and managing the sample

Consideration needs to be given to which groups currently excluded from the eligible population or issued sample are of sufficient importance to develop innovative ways of including them. Short-term users of care are one priority group which could be approached using a rolling or census approach.

The organisation, consistency and content of records should be improved to include standard information on characteristics such as language needs or ethnicity. The information submitted by local authorities about the eligible, issued and responding population should facilitate easy analysis of under-representation and make sharing of this a standard part of the survey process. Analysis of this should be provided to local authorities to enable them to address under-representation at a local level.

NHS Digital could devise standard data sharing agreements for local authorities to use with third parties to ensure that data about users and carers can be shared in a way which is compliant with GDPR.

Research tools

There are a range of research tools based on the Adult Social Care Outcomes Toolkit - compatible with both surveys - which have been developed but not integrated. Tools that could improve response rates among under-represented groups include a proxy version of the questionnaire, and an updated easy read questionnaire. There is also scope for further developments such as an adapted easy read questionnaire for those with cognitive decline.

An online option (letter invites people to take part online before offering a paper questionnaire) for some groups should be considered and developed using systematic experiments.

The addition of a comments box would be of value but would need to be carefully managed so the information can be effectively used.

Support to take part

Even with a range of tools, some service users and carers will still need further assistance to take part. The survey guidance allows for support from advocates but only where there is an existing relationship. However, there could be scope to suggest advocacy organisations are involved (if the funding arrangements could be agreed) if this would facilitate the inclusion of those who lack support. Whenever assistance is being given there is potential for bias, so clear guidance in the invitation and suitable wording about whose views are being sought would assist.

Engagement

The literature shows that engaging with under-represented and seldom heard groups is essential for improving their participation in research or service use. Engagement with under-represented and seldom heard groups could be improved at a national and local level through third sector organisations and care providers.

Local authorities could engage with community organisations locally to offer reassurance about the survey and explore how they could build trust in the community and assist with taking part. Local authorities could work with care homes to understand the best way of communicating, how to carry out mental capacity checks, how to facilitate participation and to reassure them they are not being audited. There are also national level bodies such as the National Care Forum (NCF) which could potentially be involved in the steering group for the study.

A participant focussed redesign of the survey materials (cover letter, translation sheet, information materials and questionnaires) could reduce burden in understanding the information and show how taking part could make a difference.

Survey organisation

Any changes to the ASCS and SACE need to be considered in the light of other reviews and developments (such as the ASCOF review), client level SALT returns and debates about improvements to adult social care statistics. Issues such as changing the frequency or level of centralisation should consider how this could improve efficiency and quality impact on response rates and burden, the impact on funding for local authorities, the scope for the data which are collected to be used more fully, or explored using follow-up research. Incentives have the potential to improve response rates, but any introduction needs to be fully tested to understand impact on representativeness, bias and the most effective way of administering them.

Crucially, analysing and sharing easily accessible data about under-representation of key groups needs to become a standard part of information provided to local authorities to enable them to address under-representation at a local level in their context.

Glossary

Abbreviations

ASCOF	Adult Social Care Outcomes Framework
ASCOT	Adult Social Care Outcomes Toolkit
ASCS	Adult Social Care Survey
CASSR	Council with Adult Social Services Responsibilities
CQC	Care Quality Commission
DHSC	Department of Health and Social Care
LD	Learning disability
LA	Local Authority
MH	Mental health
NIHR	National Institute for Health Research
PSD	Physically and sensorially disabled
PSSRU	Personal Social Services Research Unit
QoL	Quality of life
SACE	Survey of Adult Carers in England
SALT	Short and Long-term Support
SCRQoL	Social care-related quality of life
REC	Research Ethics Committee
SSUSG	Social Services User Survey Group

Technical terms

Acquiescence bias: is when survey participants tend to select positive response options more often than negative options even if that is not their 'true' answer.

Response rate: This is a measure of what percentage of the people invited to take part in a survey actually take part.

Stratum: This describes a group into which members of a population are divided during sampling. The plural is strata. The process of creating strata is called stratification. The ASCS sample is stratified. The SACE sample is not stratified.

Under-representativeness/under-representation: In this report, this refers to when certain groups of people form a smaller percentage of those responding to the survey, than they do of the population eligible for the survey or than of the sample issued to the survey. If a group is not properly represented in the survey responses then the published results will not fully reflect their views and experiences, unless this is corrected through weighting.

Weighting: This is a statistical technique used to ensure that groups who are under-represented in survey results have greater weight given to their responses so that overall published figures are representative of the population as a whole. For example, if older people are under-represented then each older person may be given a weight of greater than one so that each response from older people overall reflects their proportion in the population rather than the survey data.

1 Background and approach

1.1 Context and need for research

The Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE) are surveys administered by Councils with Adult Social Services Responsibilities (CASSRs) in England.¹ In this report we will refer to these as local authorities. The survey materials and protocols are provided by NHS Digital who also collate and publish the results. The surveys are important sources of information about the experiences of people receiving local authority-funded social care services in England, and their carers. Both surveys provide outcome measures for the Adult Social Care Outcomes Framework (ASCOF).²

Although guidance materials for local authorities 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. Concerns have also been raised about:

- The exclusion of users lacking mental capacity from the ASCS, and its overall impact on the representativeness of the survey.
- The exclusion of short-term users of social care from the 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 the ASCS, and for the SACE response rates dropped from 46 per cent in 2012-13 to 37 per cent in 2018-19).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.
- Whether the surveys are effective in capturing the views of people with high needs and hard to reach⁴ groups.

1.2 Key research questions and aims

The specific objectives of this research project are as follows:

- Review the representativeness of the ASCS and SACE, and the reasons for certain groups being under-represented in the survey data.

¹ Up to April 2019 there were 152 local authorities 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 local authorities so from 2019 there are 153 local authorities of which 151 would participate in these surveys

² <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/upcoming> [accessed 21/4/20]

³ However, it is worth noting that this is in line with declining response rates on many postal surveys- see for instance Stedman, R. (2019)

⁴ 'Hard to reach' is a term used in the literature but it 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). Another term used is 'seldom heard'. In this report we use the term 'hard to reach' but acknowledge its limitations.

- Identify ways in which the views of under-represented groups could be better captured by local authorities by:
 - reviewing the current methodology; and
 - exploring other examples of best practice.
- Identify ways in which the surveys could be enhanced by using recent developments and innovations in survey methodology.
- Provide recommendations which will outline options to improve the representativeness of the surveys.

1.3 Overview of methodology of this project

This research has been carried out by Ipsos MORI to explore the concerns highlighted. It has been funded by the National Institute for Health Research (NIHR) on behalf of the Department of Health and Social Care (DHSC). The research has several components which are described in more detail in the methodological annex.⁵

- **Secondary analysis of data from the ASCS and SACE** to explore whether those being sampled and responding to the two surveys are representative of long-term users of publicly funded social care (ASCS), and adult carers known to local authorities (SACE) in England.
- **Review of the literature about survey developments and hard to reach groups** to understand best practice for collecting the views of people with high needs or who are regarded as hard to reach.
- **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. The main sources for this were the guidance and methodological publications published by NHS Digital as well as previous independent methodological reviews or literature about the surveys.
- **Consultation with local authorities** responsible for running the ASCS and SACE to explore their experience of running both surveys and discuss how the experience of short-term users of care could be gathered. An online survey was carried out and responses received from 94 participants from at least 73 different local authorities between December 2019 and January 2020. This was followed up in February and March 2020 with 14 in-depth telephone interviews with participants who agreed to an interview and who together represented a range of local authorities and experiences of running the surveys. These interviews explored some of the issues raised in the survey in more depth.
- **Consultation with stakeholders** who use the data or have experience in research with service users and carers. This involved 15 in-depth telephone interviews with third sector organisations, academics and government bodies or regulators to explore their experiences of using the data and alternative approaches to be seeking

⁵ Details about the research methodology can be found in Annex A, and research materials including the online consultation's script and the discussion guides for stakeholders, service users and carers can be found in Annex D.

feedback from service users and carers, particularly those known to be under-represented.

- **Interviews with service users and carers** to explore their experiences of the surveys and barriers to participation. This involved ten in-depth telephone interviews with six service users and four carers to explore the experiences of taking part in research about satisfaction with social care. We originally planned to do 20 interviews with users and carers, with the view to get a range of experiences and different profiles of participants. However, due to the timing of the research coinciding to the beginning of the COVID-19 pandemic and the first lockdown, all the fieldwork was carried out remotely rather than face-to-face. The number of interviews was also reduced. This is a limitation of the research.

1.4 Structure of report and how to use

This report brings together findings from the research as a whole and concludes with implications and recommendations. More detailed literature⁶ and methodological⁷ reviews are also available as separate documents, but the key points from these reviews are included in this main report. The report is arranged thematically to bring together findings from the various aspects of the project, to explore the implications and develop recommendations. For instance, this means the different strands of the primary research are presented together, with their findings were triangulated and synthesized by themes.

The findings relating to ASCS and SACE are usually presented separately, except where the same finding is relevant to both surveys. This report covers contains the following chapters, each with a summary at the end:

2. **Methodology of both the ASCS and SACE** which provides background context for the rest of the report.
3. **Representativeness of the surveys** to show which groups are most under-represented in each survey through secondary analysis. The chapter gives an overview of how limitations in the sample frames, deliberate exclusions during sampling and differences in response rates between groups contribute.
4. **Eligible population and the sample** which focusses on the causes of under-representativeness related to the quality of data on the eligible population and the protocols for selecting the sample for the surveys. This chapter includes sections on the exclusion of those lacking mental capacity and short-term users of care.
5. **Barriers and facilitators to participation in the research** which focusses on issues related to response and how differences in non-response contribute to certain groups being under-represented.
6. **Innovations in research methods** which may assist in addressing the issues raised in the previous two chapters.
7. **The surveys in practice** which discusses issues which may indirectly impact on the representativeness on the surveys and which are important in deciding on appropriate recommendations.

⁶ Aznar,C. et al (2020) Ipsos MORI (Literature Review)

⁷ Aznar,C. et al (2020) Ipsos MORI (Methodology Review)

8. **Other developments in social care statistics**, which need to be considered when making recommendations to ensure that the issue of representativeness is addressed in the broader context of how social care outcomes are measured and for what purpose.
9. **Implications and recommendations** drawn together based on the findings in the previous chapters.

At the time of writing, the latest available published data and methodology were from 2018-19 for both the ASCS and SACE. Therefore, the 2018-19 or prior surveys are used when referring to published findings; the 2019-20 or prior guidance is used for information on how the surveys are run. Since the data and main evidence used for this review were from before March 2020 (the exception being interviews with service users and carers) this report does not explore the impact of the COVID-19 pandemic on representativeness. The focus is on general issues unrelated to the pandemic.

2 Methodology of the ASCS and SACE

This chapter gives a brief overview of the approaches and methods for the Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE). A more detailed methodology review for each survey is provided in a separate report.⁸ This section does not cover the methodology of this research project which is described in the methods annex.

2.1 Adult Social Care Survey (ASCS)

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 paper questionnaire sent by post. The survey is administered by councils with adult social care responsibilities (CASSRs),⁹ but the data is analysed and reported on by NHS Digital both at national and CASSR level.

Eligible population

The population for the ASCS is service users in receipt of long-term support services funded or managed by the council following a full assessment of need, at the point the list is extracted.¹⁰

Prior to sampling, certain groups in the eligible population are excluded from the sampling frame, including those who have died, are in hospital, are in dispute with the local authority, or lack mental capacity to take part.¹¹

Sampling

The ASCS uses a stratified random sampling method. Each local authority in England splits the sampling frame into groups or strata and selects a random sample of adult social care users from each stratum.¹² NHS Digital provides a Sample Size Calculator to local authorities to enable them to select an appropriate size of sample, based on their service user population and previous response rates.

Having drawn the sample, each local authority conducts the survey for its locality. The sample of service users are invited to take part in the survey. The findings are then used to

⁸ Aznar, C. et al (2020) Ipsos MORI

⁹ Please note we will be using the term local authority rather than CASSR in the rest of the report.

¹⁰ The eligible population is that recorded in table LTS001b of the Short and Long Term (SALT) return. 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).

¹¹ These exclusions are described in more detail in Chapter 3.

¹² There are four strata: 1. Learning disability support (any age). The remaining three strata cover all support reasons except learning disability. 2. Age 16-64, 3. Age 65 and over in residential or nursing care, 4. Age 65 and over using community based services.

make estimates about the whole population after weighting to take account of the local authority and the four strata. The current ASCS weighting¹³ does not take account of other characteristics.

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 several accessible versions of the questionnaire including:

- An easy read version (designed for service users with a learning disability), sent to all service users in the learning disability stratum and available to others on request,
- A large print version (designed for people with visual impairments and available on request),
- Translated versions (for service users who may not be fluent in English) which are sent to those known to need them and are also available on request.

The questionnaires are also provided as interview scripts so local authorities can offer face-to-face or telephone interviews to service users who require this format to be able to participate, but this is intended for a minority of service users where there is a specific reason why they cannot complete the paper questionnaire.

In addition to the questionnaires, NHS Digital provides all local authorities with detailed survey guidance, and additional survey materials:

- 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 with brief information about the survey written in multiple languages inviting participants to contact the local authority for a translated version of the questionnaire,
- 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.

Content

The survey asks service users about the impact of care and support services on the quality of their life.¹⁴ It also collects information on the participants' self-reported health and wellbeing. While the main sections of the questionnaire are generic and relevant to all local authorities, there is also the option for local authorities to include additional questions or open-ended questions for local research purposes. Such amendments are subject to NHS Digital approval.

¹³ Data are weighted to make the analysis representative with the same proportion in each stratum as in the issued sample (see glossary for more information about weighting).

¹⁴ The core questions are drawn from the Adult Social Care Outcomes Toolkit (ASCOT) developed by the Personal Social Services Research Unit (PSSRU). <https://www.pssru.ac.uk/ascot/> [accessed 22/4/20]

Fieldwork and analysis

The recommended fieldwork period is between January to March. During this time, questionnaires are distributed to service users and then returned by post once completed. In most cases, a questionnaire (the version most appropriate for the individual) is posted to each person in the sample. While local authorities send standard English questionnaires in most instances, easy read versions are mailed out to all service users with a learning disability. In addition, local authorities 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 where the service user's first language is known and is not English (as well as the English version of the materials),
- A translation request sheet where the service user's first language is not known by the council.

One reminder letter is sent to each person who does not respond and should be sent with a questionnaire. The completed questionnaires are manually coded onto a data return spreadsheet (provided to local authorities by NHS Digital) and returned to NHS Digital for validation and analysis.

2.2 SACE

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 topics considered to be indicative of a balanced life alongside their unpaid caring role.

The main mode of data collection is by paper questionnaire sent by post. The survey is administered by local authorities, but the data is analysed and reported by NHS Digital, both at the national and local level. The findings from the survey help to improve services and assess the performance of local authorities in the services and support they provide to carers.

Sampling

During survey years, local authorities 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 the previous 12 months. In 2016-17, the eligible population was extended to include carers who had not been assessed or reviewed in the previous 12 months.¹⁵ The eligible population is all carers who would be contained within the last four rows of the Short and Long-term Support (SALT) return,¹⁶ that is to say those:

¹⁵ The reason for the change was that under the Care Act local authorities have a duty to provide information and advice which means carers may be receiving support as a result of this signposting even if they have not been assessed or reviewed during the year.

¹⁶ The first row of this table is excluded because it contains carers who are aged under 18.

- 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.

Carers are recorded in their own right in the Short and Long-term Services (SALT) collection and so could include those who care for someone who is not receiving any social care from the local authority. The sample is restricted to those carers who have had some contact with the local authority at some point so does not cover all carers.

Local authorities send questionnaires to a random sample of carers with the size determined by a Sample Size Calculator provided by NHS Digital. There is no stratification in the carer survey sample.

Content and survey design

The questionnaires contain generic sections, which are relevant to all local authorities, and some sections which local authorities can adapt. They can include additional questions or open-ended questions for local research purposes; however, these amendments are subject to NHS Digital approval. 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.

Alongside the main version of the questionnaire, there are 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 local authorities can offer face-to-face or telephone interviews to service users. NHS Digital also provides all local authorities with detailed survey guidance, and additional survey materials, such as invitation letters and interview scripts. The guidance is updated every two years to introduce improvements and refinements.

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 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”.¹⁷ The completed questionnaires are manually coded onto a data return spreadsheet (provided to local authorities by NHS Digital) and returned to NHS Digital for validation and analysis.

¹⁷ Personal Social Services Survey of Adult Carers in England. Information and guidance for the 2018-19 survey year

3 Representativeness of the surveys

This chapter looks at which groups are most under-represented in each survey and whether this relates to limitations in data about the eligible population, the creation of the sample frame, deliberate exclusions during sampling or differences in response between groups invited to take part in the survey.

The chapter includes the analysis of the ASCS and SACE datasets since 2015 and explores the representativeness of the achieved sample, including the extent to which:

- The issued sample is representative of the eligible population, and
- The responding sample is representative of the issued sample.

Before presenting the findings, we look at what is meant by representativeness and how service user and carer groups can become under-represented at different stages of the surveys.

3.1 Definitions and approach

Definition 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 which is:

- ASCS: 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, or
- SACE: all carers aged 18+, caring for an adult 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 local authorities on the eligible population is not up-to-date or complete at the point the data are extracted, some eligible people may be excluded from the eligible sample frame or there may be insufficient information to send them a survey invitation.
2. The rules for excluding certain groups from the sample frame and initial issued sample will result in eligible service users not being included in the survey at all (e.g. those lacking mental capacity, those in dispute with the local authority, those in hospital at the 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. Differences in response rates to the survey as a whole by different groups in the final issued sample will also contribute to certain groups being under-represented. It should be noted when exploring representativeness that there have been 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).¹⁸ 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.

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

Sources of under-representation in the ASCS

Limitations in the definition of the eligible population

Strictly, the survey should only be considered under-representative if it does not correctly represent the eligible population. However, it should be acknowledged that the eligible population defined for the ASCS (long-term users of local authority funded services) excludes several significant groups of people with care needs which local authorities support in other ways, namely:

- Short-term users, who receive short-term professional support or residential care episodes for up to six weeks have been excluded since 2014-16, meaning there is no information from the ASCS on this group¹⁹ (this is covered in more detail in Chapter 4),
- Service users whose services are not paid for directly by the local authority (self-funders) but where the local authority may have some involvement in the provision of the service (e.g. grant for a third sector organisation) or where the local authority provides support through a social worker but long-term care is not arranged,
- Those who rely on local authorities only for the provision of equipment,
- Those who receive advice and signposting from the local authority; the introduction of the Care Act 2014 with an emphasis on prevention and the parallel development of strength-based approaches means that in some cases support is provided through signposting, advice and equipment.

Limitations in the sample frame

Feedback from the online survey of local authorities and in-depth interviews suggested that local authorities spend a considerable amount of time and effort in ensuring the completeness and quality of the data on the eligible population from which the sample is drawn. Overall, this process was felt by local authorities to be effective for the ASCS and the quality of the sample frame adequate for the distribution of a postal survey, though with some concerns about mental health service users (discussed in Chapter 4).

¹⁸ However, it is worth noting that this is in line with declining response rates on many postal surveys- see for instance: Stedman, R. et al (2019)

¹⁹ An individual user may in practice receive multiple episodes of short-term care. Even though they may receive care for a long time they are not classed as a long-term user and would not be eligible for the survey.

NHS Digital publishes information on disparities between the SALT data²⁰ and the eligible population information provided by the local authority. This shows that there were nine local authorities where there was a difference of greater than 20% between the SALT data and the eligible population figures provided by the local authority. This suggests that in a minority of local authorities there are issues with defining the eligible population.²¹

Deliberate exclusions during sampling

- Local authorities must identify service users who should not participate in the ASCS and should therefore be excluded from the sample frame or should be replaced if included in the sample and later found to be in one of these categories. The full list of exclusions is given in section 4.3 but important exclusions include those who:
 - Have died or moved elsewhere,
 - Are known not to have the mental capacity to consent to take part,
 - Are involved in an open safeguarding alert or investigation or are in,
 - in an active dispute with the local authority²²

Evidence from information published and made available by NHS Digital shows that loss of those lacking mental capacity is a particular issue at the stage of exclusion from the sample frame.²³ There is an established process through which local authorities should liaise with care homes to identify those who are living in residential care and lack mental capacity. This is a one of the key focusses of Chapter 4.

Local authorities are also permitted to implement their own discretionary additional exclusions, for example, by removing those who they deem to be survey fatigued after inclusion in other surveys. This is also discussed further in Chapter 4.

Differences in response rates from groups in the issued sample

Some groups tend to be under-represented among participants, even if they are included in the sample, which may relate to challenges they face in taking part in the survey. Previous research on the ASCS shows there are lower response rates from groups such as:²⁴

- People with mental health problems;
- Adults who have cognitive or memory impairments, such as dementia or learning disabilities;
- People who live in more deprived areas and those from ethnic minority groups;
- Physical disabilities can also create challenges for responding to postal surveys.

Our own analysis of ASCS data is described in section 3.3.²⁵

²⁰ The Short and Long Term Services (SALT) collection relates to the social care activity of Councils with Adult Social Services Responsibilities in England. It is published annually based on data drawn from council administrative systems.

²¹ ASCS Data Quality Annex from 2018-19.

²² 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”.

²³ NHS Digital (2019).

²⁴ Malley, J. (2017)

²⁵ Analysis of NHS Digital data provided through the Data Access Request Service (DARS).

The explanations for under-representation of these groups could be complex and are currently poorly understood. For example, it may be that the survey is not accessible enough to certain groups.²⁶ 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 Chapter 5.

Sources of under-representation in the SACE

Limitations in the definition of the eligible population

The definition of an eligible carer in SACE is less clear-cut. Local authorities hold data on their carers in a variety of ways, sometimes in their own right and sometimes just as part of the information held about service users. Different local authorities use different definitions of carers in their recording process, for example, a carer can include people with a carers card, those who used a service or those who are just linked through a service user.

The survey does not consistently represent all carers, but rather the subgroup of carers who have been in contact with their local authority in their own right or through the person they care for, thus limiting the eligible population to a subsample of all unpaid carers. At the same time, some carers who are invited to take part are unaware that the services they use are commissioned by the council, and some of those in the eligible population do not self-identify as carers.

Limitations in the sample frame

There are several key issues in terms of the data on the eligible population which forms the sample frame for the SACE. These may impact on the completeness and quality of its data and the ability to run the SACE. Those are linked to:

- Difficulty in obtaining the relevant information from third parties: where individual level data is held by the third party providing the support service, local authorities 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.
- Carer information being held within the records for service users, with limited information about them such as lacking their address or other contact details.

Deliberate exclusions during sampling

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,

²⁶ Accessibility relates to whether participants are able to access information, and participate in the research in the format it is provided in.

- 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.

Unlike the ASCS, where short-term users are not included in the eligible population, the sample for SACE may include short-term carers if they are still on the local authority records. There is also no guidance on excluding short-term 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.

Differential response rate

Information published by NHS Digital²⁷ 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).

A detailed analysis of which groups are under-represented in response is the focus of the following section.

3.2 Previous evidence on the under-representativeness in surveys

Although there is little evidence in the literature specifically about the overall representativeness of the ASCS and SACE responding populations and why certain groups tend to respond better than others, there is a wealth of literature on non-response to surveys in general, and especially among harder to reach groups which looks at reasons for non-response and methods for encouraging participation. This is the subject of a separate review we have conducted and is published separately.²⁸ Crucially, it is not only the characteristics of users and carers but the behaviour of the organisations delivering the surveys that can affect response rates; non-participation is not a constant attribute of a person and different sets of influences act on the sample members to determine their likelihood of participation.²⁹

Whilst it is rarely possible to determine which category a non-respondent falls into; non-response can be divided into four categories for the ASCS and SACE:

²⁷ NHS Digital (2019)

²⁸ Aznar, C. et al (2020) Ipsos MORI (Literature Review)

²⁹ Smith, N. & Malley, J. (2012)

1. Being excluded from the sampling frame (e.g. because living in a care home and lacking mental capacity),³⁰
2. Failure to receive the survey request (e.g. non-delivery or interception),
3. Refusal to participate,
4. Inability to respond (e.g. illiteracy in English, physical or cognitive impairments).³¹

Approaches which can improve representation of harder to reach groups include involving those groups in the design of the research and materials, working with gatekeepers, community and other groups to build trust and understanding of the value of the research, and flexibility in approach so that people with different needs are able to respond. Capturing the experiences of those with cognitive decline is particularly challenging and consideration is needed of how those with mild or moderate decline could give informed consent and use easy read or supported interviews. For those with more advanced cognitive decline, the use of proxies may be necessary. An overall point which applies to all hard to reach groups is that there is a diversity of experience and any approach needs to be responsive to the needs of individuals.

3.3 Secondary analysis of ASCS and SACE data

Data was obtained from NHS Digital³² to explore the representativeness of the surveys from two main angles:

- The extent to which the issued sample for each survey is representative of the eligible population for that survey,
- The extent to which the responding sample is representative of those who were invited to take part in the survey.

For the first analysis we used data on the issued sample for each survey and detailed summary population data for the eligible population. For the second analysis we used case level data about the issued sample and whether or not they had responded.

In this section we provide a summary of findings from the analysis. The purpose is to identify which groups are under-represented and this forms a basis for the rest of the report. The detailed findings from the secondary analysis are provided in the Secondary Analysis Annex B. This provides details of findings including percentages, bases and approach.

Data from ASCS: 2015-16, 2016-17, 2017-18, 2018-19 and SACE: 2016-17, 2018-19 were used in the analysis.

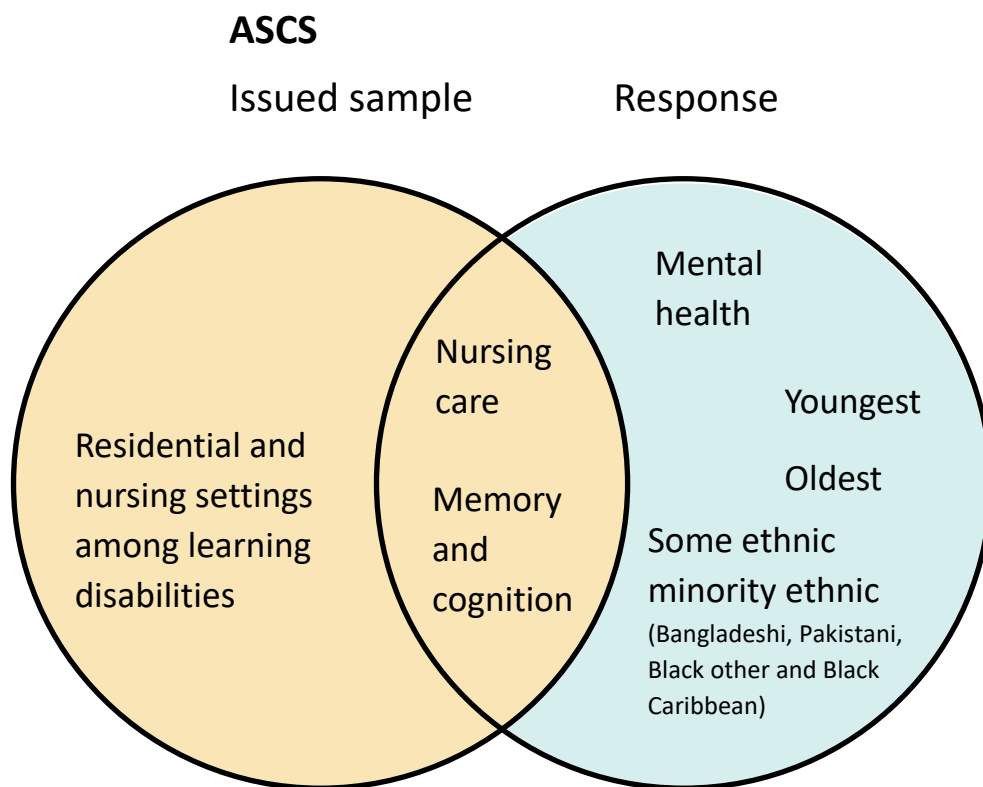
³⁰ Smith, N. & Malley, J. (2012)

³¹ Malley J & Fernandez J-L (2012)

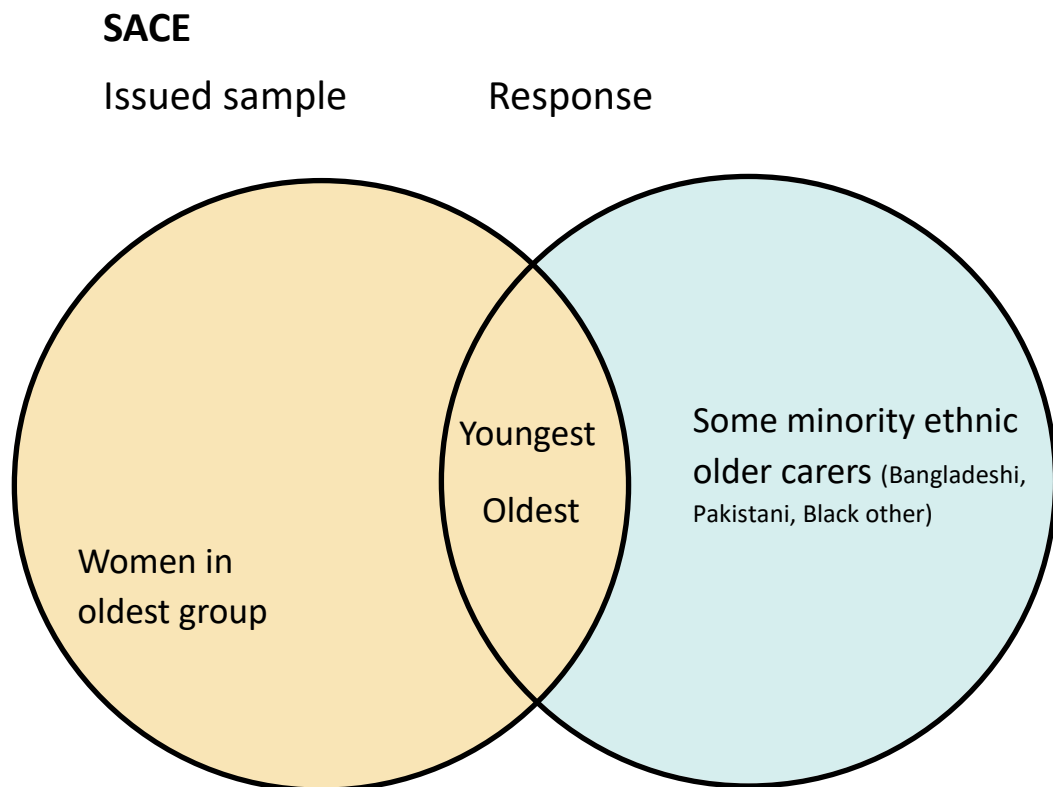
³² Data Access Request Service (DARS) was used to obtain data which is not publicly available (e.g. numbers in detailed age or ethnic groups)

The diagram below shows which groups are most under-represented for the ASCS and SACE. Those on the left are under-represented in the issued sample but not among the responding sample, those in the middle are under-represented in both the issued and responding sample. Those on the right (blue) are under-represented among the responding sample but not among the issued (or in the case differences by ethnicity it is unknown whether they are under-represented among the issued sample owing to lack of data). The response analysis shows that the youngest and oldest are under-represented in the responding sample. Because the age split in the eligible population data which was used for the issued sample analysis is 18-64 and 64+ (combining the younger and middle age groups) it is possible that there are also age patterns in under-representativeness by issued sample which are hidden.

This shows that those living in nursing care settings and those with memory and cognition needs are under-represented in both the issued and responding samples. Those with mental health needs are under-represented in response but not in the issued sample. Although those with a learning disability are well-represented in the issued and responding samples generally, those with a learning disability in residential and nursing settings are under-represented in the issued sampled compared with those in community settings.



The diagram below shows a summary of under-representation for SACE. Women in the oldest age group are under-represented in the issued sample, although overall women are better represented than men. Overall the youngest and oldest carers are under-represented in both the issued sample and the responding sample. Older carers from ethnic minority backgrounds are under-represented in the responding sample but it is unknown whether they are under-represented in the issued sample because there is no information on ethnicity in the eligible population.



Chapter Summary

- Under-representation in the surveys occurs for two overarching reasons:
 - Exclusion from the sample frame which may result from deliberate guidance to exclude or lack of information about the eligible population,
 - Non-response to the survey once a service user or carer has been invited to take part which may result from non-contact, refusal or an inability to take part.
- The secondary analysis shows that in the ASCS those who need support with memory and cognition and those who are living in nursing settings are under-represented in both the issued sample and the responding sample. Local authorities were aware of and concerned about the under-representation of these groups.
- Although those with learning disabilities are well-represented by response in ASCS, within the learning disability stratum those in residential and nursing care settings are under-represented in the issued sample compared to those living in the community.
- In the ASCS those with mental health support needs, the youngest and the oldest service users are most under-represented through response but there is no evidence of under-representation in the issued sample for these groups.
- Information is available about under-representativeness by ethnicity in terms of response. This shows that in the ASCS those from non-White groups are under-represented with the greatest under-representation among those from Pakistani, Bangladeshi, Black other and Black Caribbean backgrounds). It is unknown whether they are under-represented in the issued sample.
- In SACE, the youngest and oldest carers are under-represented in both the issued sample and though lower response rates. There is no evidence of under-representation by the primary support reason of the person they care for.
- In SACE, the issue of under-representation by ethnicity is mainly found in the oldest age group and to some extent among those aged 45-64. Among the youngest group response rates among some ethnic minority groups are higher than among white carers.
- The age categories in two bands on the public data hide differences in response by age since response is highest in the middle age groups and lowest in the youngest age groups which are combined in the 18-64 age group.
- In the ASCS, some groups are under-represented in almost all local authorities (e.g. those with memory or cognition support needs) while for others the extent of under-representation varies by authority (e.g. under-representation of those in residential and nursing settings) which means there is scope for learning across local authorities.

4 Eligible population and the sample

The causes of under-representation of some groups in the ASCS and SACE data lie at several stages in their processes. This chapter looks at challenges around achieving representative samples compared with the eligible population of service users and carers.

In doing so, it discusses:

- The issues faced by local authorities before the surveys are issued when collating data on the eligible population of services users and carers, and drawing the sample, and
- The rules for excluding certain groups from the sample frame and initial issued sample, and how this can result in some of the eligible service user and carer populations not being represented in the surveys at all.

4.1 Challenges with the eligible population records

The designs of the ASCS and SACE rely on local authorities having accurate and up-to-date information about their eligible service user and carer populations when the initial sample frames (prior to exclusions) are drawn.³³

Although a three-month timeframe is allowed for local authorities to extract the eligible population data in each survey, there can still be issues about the source data being complete enough at the point of extraction. This can lead to some eligible people being excluded from the surveys altogether.

Local authorities tend to be confident in the data quality for service users

Being able to extract the complete and correct eligible population for the ASCS does not seem to be a widespread issue in relation to the representativeness of the survey. The interviews with local authorities highlighted how much time and resource they had to spend to ensure the accuracy and usability of the data they held with some performing weekly data checks. In addition to contact details, getting a good coverage of personal information such as age, gender, and ethnicity was perceived to be critical.

Overall, the local authorities we talked to were satisfied with the quality of the information available for service users on the SALT return with a couple of caveats:

- Data quality and completeness vary across local authorities, with some not collecting ethnicity at the same level of detail as other local authorities or having high levels of missing other demographic data such as religion or sexual orientation.

³³ See Chapter 2 for details of the eligible population for each survey. A discussion of the limitations of the eligible population definition for each survey is covered in Chapter 3.

- There are some concerns, shared by local authorities and some other stakeholders we talked to, that service users with mental health support needs are under-represented in the ASCS because of the poor level of contact details for this group. It is common for third party organisations, particularly health organisations, to provide support services on behalf of local authorities, so local authorities do not hold contact details or might struggle to access those service users' records.

However, carers' records are not as complete and accurate as the ones of service users

Local authorities reported several issues around the data quality for carers, even for basic contact details, and how those could result in incomplete datasets. Several reasons for this were discussed:

- Carers' details are not always recorded in their own right: they are often collected as part of the contact details local authorities gather about service users. Practically, this means that if a service user dies and their records are deleted, the contact details of their carers are also deleted and lost. In addition, social workers do not always record carers' name and contact details if they consider the amount of care those carers provide is small.
- The definition of eligible carer is not clear-cut. Overall, defining the eligible population for SACE is complex because of the wide definition of carers. Some local authorities we talked to highlighted the ambiguity over who is a carer and who isn't, despite the provision of an additional document by NHS Digital giving further information on the definition.³⁴
- In many cases, the provision of support to carers is contracted to third parties who can be reluctant to share carers' contact details with local authorities who do not have direct contact with carers themselves. Local authorities believed this issue has been exacerbated since the introduction of GDPR in 2018. One local authority explained how they have 5,000 carers included in their SALT return but knows of 20,000 carers registered with a carer support organisation.

Acknowledging these issues might impact on the completeness and quality of carers' data, and the ability to draw comparisons across local authorities. The local authorities we talked to felt it was critical to improve their basic contact details and ensure the sample frame better reflects the intended eligible population. It is worth noting that among local authorities we interviewed some are moving to new systems for handling data about their user and carer populations which they believed could lead to data quality improvements for carers. The new systems varied between local authorities. However, it was also mentioned that there will be a central change for SALT returns to be provided as client level data rather than summaries collated by each local authority.³⁵

³⁴ NHS Digital (2018)

³⁵ <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collection-materials-2020> - September 2019 letter has details of moving to client level data for 100% of local authorities in 2020-21 with client level data flows being mandatory from 2021-22. This is discussed in more detail in Chapter 8.

Local authorities also find they hold details for people who are eligible but do not see themselves as carers

Local authorities reported that not all carers in their eligible population identify as 'carers' or accept that label, preferring to see themselves as family members and friends. Those 'hidden carers' may not be in direct contact with social services and do not realise they are using services commissioned by the council or supporting someone who receives services.

There's a lot of people who receive the carers' survey and associate caring with a paid role of carers and I have to explain that it's an informal caring role and that yes you may be the wife or the husband or the son or the daughter but you are caring for that person, which is, you know, we're also trying to commission services to help carers who are in this position and that their responses help us for commissioning purposes. (Local authority)

In addition, many carers are reluctant to ask for help or resist help because they prefer to see themselves as independent and managing.

4.2 Assessing mental capacity and the role of care homes

Official survey guidance from NHS Digital states that local authorities must identify service users who should not participate in the ASCS. This includes service users who are known to not have the mental capacity to consent to take part.³⁶ This could be service users who are in residential or nursing care or supported accommodation and are known to lack the mental capacity to consent to participate in the survey or service users who are known to have a Court-appointed Deputy, indicating that they lack the mental capacity to consent to take part.

This is to comply with ethical approval which stipulates that the survey should only be completed by those who have capacity to consent under the Mental Capacity Act 2005.

This raises two important issues for the ASCS: first, how local authorities identify service users who lack capacity and exclude them from the sample frame; second, how doing so results in a lack of data on the experience of this group.

³⁶ NHS Digital (2019)

Local authorities have difficulty engaging care homes in the task of assessing mental capacity

Local authorities delegate the task of checking mental capacity of those in residential care to the managers of residential and nursing care homes and supported living establishments. They are expected to check capacity to give consent to the survey by speaking to their care home residents or by using their own previous knowledge and judgement.³⁷ Local authorities can choose whether to request these checks before or after the sample is drawn. Local authorities write to care homes to ask whether any of the service users in the sample frame or sample lack the mental capacity to give consent to take part in this survey. A standard letter is provided which sets out the issues to be considered in making this decision.³⁸

In cases where the local authorities receive no response, it is assumed that the service users have the capacity to participate.³⁹ This means that despite the procedure to exclude this group from the sample frame or sample, if care homes do not respond, surveys are sent out to those who potentially lack mental capacity.

In our online survey of local authorities, half of participants who responded to this question (38) agreed that care homes in their area are successful in excluding those lacking mental capacity, with 5 per cent strongly agreeing and 44 per cent tending to agree. Among the local authorities we spoke to in the in-depth interviews, it was clear that only a minority of care homes responded to their request to send details of residents in the sample lacking mental capacity. This varied between the local authorities which only heard back from around ten per cent of care homes and those which reported that they managed to engage more than a third.

The local authorities interviewed for this research deployed a range of methods to contact care homes about the ASCS. For instance, one explained how they did not use the template letter provided by NHS Digital, but instead phoned all the care homes in the area to inform them about the survey taking place. Their responses are given over the phone by over 90 per cent of homes. Where email is used, fewer responses are received from care homes.

One of the local authorities we talked to went a step further and asked a local organisation to go to care homes and offer their support to residents who had the capacity to consent and were willing to take part in the survey. In 2019-20, they managed to assist with the completion of 397 questionnaires from care home residents completed in this way. We talked to this local organisation as part our research. They emphasised how face-to-face contact has been key to their success in engaging care home staff (as well as participants) and believed care homes tend to respond less well to emails and letters.

³⁷ Previously councils were asked to check capacity for all service users and there were concerns that the process was not being applied consistently

³⁸ The issues are as follows:

- 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?
- 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.

³⁹ NHS Digital (2018)

One of the reasons suggested for lack of engagement from care homes was that the quick turn-around between the receipt of the 'ASCS letter to care home and supported living managers to check capacity' and the mailing out of questionnaires meant that some care homes simply did not have enough time to respond. The time allowed for this seemed to vary between local authorities, however the success in obtaining feedback from care homes seemed to relate more to the approach taken to contacting them than the time allowed for this.

There is little or no awareness of how care homes assess mental capacity

Our interviews with local authorities indicate that little is known about how care homes, and who in care homes, assess the mental capacity of residents. Overall, it was felt that:

- The care homes, which do respond and engage with local authorities, can sometimes be too strict and hasty in asking local authorities to exclude certain residents from the survey sample. Likewise, one of the non-LA stakeholders we spoke to believed care home staff tend to be unfamiliar with the principle of assumed capacity which makes it clear that a person must not be treated as unable to make a decision unless all possible efforts have been taken without success.

We've noticed over the years that the surveys would go to the care homes, they hit the reception, and the default would almost be, 'Well, sorry, these people in these homes haven't got the capacity to answer the survey.' So, we weren't allowed to survey them, in principle.

(Local authority)

- There can be a lack of consistency in assessing capacity not only between different care homes, but also within care homes. For instance, one local authority participant explained how he contacted a care home several times this year and was given different answers about who had capacity and who didn't (though it should be noted that this is consistent with an approach which understands that capacity can vary and should not be assumed).
- Local authorities suspected that care homes tend to exclude service users with fluctuating capacity to consent and in this way might exclude individuals unnecessarily which would negatively affect the representativeness of the sample. This belief was corroborated by one care manager we talked to:

Capacity care plans are reviewed monthly, and when it's noticed their capacity going down, they're deemed as not having capacity. No in-between, whether you have it or not.

(Care Home Manager)

It is unclear whether limitations in the effectiveness of care homes in excluding those with mental capacity is due to lack of understanding over who should be included in the survey and how capacity should be assessed or whether it relates to engagement with the process.

The issues raised exist despite the fact that the NHS Digital guidance sets out that: *“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”*.⁴⁰

The letter to care home managers provides three questions to be considered in assessing mental capacity but they are not worded in a form which could be used directly with service users. Each care home manager would need to adapt the questions into their own words.

Local authorities feel that the survey is not a priority for care homes

In our interviews with local authorities, participants expressed the view that the ASCS is not really seen as a priority for care homes. They also raised concerns that care homes' engagement in facilitating response has been decreasing over time. The online survey with local authorities showed that the main reason for this was believed to be staffing pressures (57 per cent), although 39 per cent mentioned concerns among care homes that the survey may be used for monitoring individual care homes. It is notable that over a quarter (27 per cent) did not know what discourages care homes from facilitating participation in the survey. Local authorities vary in how many care homes they are working with. They can be dealing with over 300 care homes which makes considering the barriers faced by individual care homes difficult. However, there are local authorities which have strong relationships developed over time with care homes.

Table 4.1: What, if anything, do you think discourages care homes from facilitating the participation of their residents in the ASCS (multicode)

Response	%
They are under staffing pressures which means it is difficult for them to administer the survey	57%
They are concerned that the survey may be used for monitoring the services they provide	39%
They only have a few local authority-funded or arranged residents and it is not a priority for them	19%
They carry out their own surveys and are concerned about burden on residents	6%
The families of residents are not keen for them to participate	6%
Other	5%
Nothing discourages them from encouraging participation	4%
Don't know	27%

Base: 77

Our interview with a care home manager supported these findings. The care home manager felt that the timing of the ASCS, which tends to coincide with CQC inspections, means that:

- They have little time to engage with the survey and, support and encourage their residents to complete it;
- There can be confusion over the purpose of the survey with care homes sometimes believing it is used to monitor the services they provide. Although this is not the purpose of the research there was evidence of at least one local authority comparing the results from individual care homes with the results from CQC inspections.

⁴⁰ Letter to care home managers

4.3 Other exclusions from the sample frame

There is a lack of consistency across local authorities in the application of exclusions defined by the ASCS and SACE guidance

The NHS Digital guidance specifies that depending on the completeness and quality of the data extracted, local authorities can also exclude members of the eligible population from the sample frame. In addition to the exclusions discussed above (i.e. those known not to have the mental capacity to take part), people to be excluded from the ASCS and SACE include:

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

The guidance also says they can also consider excluding those who have recently taken part in a survey which could lead to survey fatigue, but this does not mean excluding those who have been sampled for previous years of ASCS or SACE.

Although the NHS Digital guidance for each survey includes explanations around some of those exclusions, our interviews highlighted some disparity around how they were applied in relation to the following:

- **Survey fatigue:** there can be some inconsistency between local authorities in their approach to addressing survey fatigue as reported in the in-depth interviews with local authorities. There were local authorities which remove service users who had completed the ASCS in the previous year (even though this is not in line with the guidance). Others removed service users or carers who had received another council-run survey in the few months preceding the surveys. Finally, there were local authorities which did not remove any service users and carers for this reason.
- **Dispute:** while the 2019-2020 ASCS guidance includes a definition of dispute (i.e. “a complaint that cannot be resolved by the council and moves on to be handled outside of the council by the Ombudsman”), our discussions with local authorities highlighted how the term is interpreted more or less broadly across different councils. Variations in exclusions on the basis of dispute may lead to sampling bias. For instance, one local authority participant discussed how they tend to exclude anyone with an ongoing issue.

If we would send out a survey to those who have currently got a complaint against us, you know, we don't want to skew our performance, that's our view. I don't know actually, because this is anonymised, I don't actually know whether that's right or wrong us doing that, but we do. (Local authority)

- In addition to the categories of service users and carers specified in the ASCS and SACE guidance, there were some instances reported in the interviews of local authorities excluding anyone they deemed 'problematic' (for instance those who would be 'distressed' to receive a survey).

While most of the local authorities we talked to did not include any groups that NHS Digital advise excluding, it is worth noting that:

- Some included people who are in hospital at the time of the surveys being sent out as they think they might be back at home by the time the surveys arrive.
- There could be some confusion around whether to include people living in residential care outside a local authority's boundaries but who still receive care funded by them. NHS Digital advises that in this case they should not be included if they are living in another local authority. This means they would only be included in the survey if the other local authority had the person on their records.

4.4 Exclusions from the eligible population

As described in Chapter 3, only those in the eligible population as defined by NHS Digital are included in the survey. While a defined and consistent eligible population is necessary for the consistency of the surveys, our in-depth interviews showed there are some groups excluded from the surveys which are of interest to local authorities.

Although the consensus among participating stakeholders and local authorities was that the survey in its current form might not be an appropriate or feasible way to collect feedback from those service users, there was an acknowledgment that knowing more about their experiences is crucial.

The views of short-term users should be heard

Since 2014-15, service users who only rely on local authorities for the provision of short-term care (up to six weeks per episode) have no longer been included in the eligible population. The local authorities we talked to were keen to hear about the experiences of this group. In the online survey, 27 per cent of local authorities (25 participants) said that including short-term users in the data collection would make the data of outputs of the ASCS more useful. However, the in-depth interviews showed that local authorities were uncertain that including them in the survey with its current design would be effective for two main reasons:

- **The ASCS design:** there are issues of recall when service users may have received six weeks of support up to 11 months before they receive the ASCS questionnaire 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. As such, some local authorities felt that consideration needs to be given to a rolling approach to extracting the sample for this population.

- **The content of the questionnaire:** there were local authorities which commented in interviews that many questions are not entirely appropriate for this group. A previous cognitive testing project was carried out to develop a special short-term user survey and this included a range of recommendations and solutions for this issue.⁴¹

The in-depth interviews showed that some local authorities already captured the experiences of this group using other methods. This included assessment as part of the provision of services with questions asked before and after the receipt of a package of short-term care. Furthermore, one local authority has developed a postal survey to capture short-term users' feedback between January and June every year, and another one has developed a survey carried out by senior care workers based on The Adult Social Care Outcomes Framework (ASCOF). However, this was not universal and not all local authorities have this information.

During an interview, a short-term service user commented on a suitable timeframe for being invited to take part in a survey. They felt that the more time that passes after care is stopped, the less willing they would be to provide feedback. This suggests a rolling rather than annual survey would be suitable for this group.

The views of service users receiving other forms of support from the local authority or self-funding their care are also of interest

Both local authorities and other stakeholders felt that the ASCS misses the voices of some service users by focussing on only people who have a long-term costed service and a financial assessment in that area.

Strength-based approaches adopted by many local authorities⁴² mean that they support people with signposting and using other resources such as equipment to meet service users' needs rather than providing long-term care packages. These people may use the signposting to access services which they fund themselves.

There were concerns that this group, and their carers, are not included in the ASCS or SACE, or any other standardised and/or national survey as they constitute a significant but also ever-growing group of service users.

There are a lot of people that don't go onto a long-term service but do have a considerable amount of service from social care, whether that be mental health, in response to a social worker providing a service but not a costed service (...) To be able to see that part of the social care arena as well as the long-term would give us a far better picture than just concentrating on the people that get into long-term, with all the preventative side, the reablement. I just feel that those guys, at the moment, are not getting as good a representation and voice. (Local authority)

The views of carers who are not in touch with the local authority may be of interest

The eligible population for SACE are adult carers who have been in touch with the local authority of a third party working on behalf of the local authority. This excludes those who

⁴¹ Pilley, S. et al (2017)

⁴² Strengths-based practice is a collaborative process between the person supported by services and those supporting them, allowing them to work together to determine an outcome that draws on the person's strengths and assets. As such, it concerns itself principally with the quality of the relationship that develops between those providing and those being supported, as well as the elements that the person seeking support brings to the process. (Duncan, B. L. and Miller, S. D. (2000))

have not made contact, whose needs may be of interest to the local authority who have a duty in relation to their wellbeing. However, from a practical perspective, the definition of carer is already as broad as it could be for a survey run by a local authority sending invitations to its contacts. For local authorities to understand more about carers who are not in touch with them, more general residents' surveys would be needed. The issue in relation to SACE is the availability and quality of information on the carers who are in touch with them, rather than the definition of the eligible population.

Young carers under age 18 are not eligible for the survey as their experience comes under the remit of the Department for Education, however understanding their experience may be useful to local authorities, especially if they are caring for someone supported by the local authority. In addition, the under-representation in the issued sample found among young carers aged 18-24 suggests that at the transition from childhood to adulthood, contact details for this group may be particularly problematic.

Chapter summary

This chapter has explored the causes of under-presentation in the ASCS and SACE in relation to incomplete information about the eligible population, and rules for excluding certain groups from the sample frame and initial issued sample.

It highlighted how certain issues might impact on the completeness and quality of data collected and the ability to draw comparisons across local authorities, including:

- **Lack of carers' records:** carers' records are not as complete and accurate as service users' records which can result in incomplete datasets.
- **Inconsistencies in excluding users lacking mental capacity:** in spite of NHS Digital's guidance, there seems to be a range of practices used by local authorities to engage care homes and little is known about how they determine whether services users have the mental capacity to consent to take part in the ASCS.
- Acknowledging such issues is critical as they can result in eligible service users and carers not being represented in the survey at all which can in turn lead to the under-representation of a certain user, carer, and demographic groups in the data if they are more prevalent among some of the groups excluded from the survey.

The chapter concludes discussing three significant groups of service users currently excluded from the ASCS's eligible population: short-term users and service users receiving other types of support from the local authority or self-funding. Whilst there is an agreement by local authorities that the ASCS is not necessarily suitable to gather service user feedback, the lack of a systematic method for doing so means that local authorities do not currently get the full accurate picture of the experiences of those living with care needs in their local authority.

5 Barriers and facilitators to participation in the research

This chapter explores the likely causes of differential response rates to the ASCS and SACE which contribute to some groups in the service user and carer population being well-represented and others being under-represented. This chapter considers the barriers to participation which could affect some groups more than others as well as facilitators which could promote and encourage under-represented groups to complete the surveys.

5.1 Wider evidence exploring the response rates amongst social care service users and carers

Under-representation of certain groups is found across research with service users and carers

Literature related to the representativeness of social care user surveys highlights the following response issues:

- Those lacking mental capacity are less likely to respond to surveys due to gatekeepers' uncertainties about the purpose of the surveys. Consequently, they are unwilling to conduct mental capacity checks or permit engagement, despite the ASCS providing assurances that the survey is not designed to evaluate social care services.⁴³
- Non-response rates are higher amongst younger people and people with mental health or substance misuse problems.⁴⁴
- People with learning difficulties are more likely to respond to the questionnaire. Several factors could be at play here, including the targeting of easy read questionnaires to people with learning difficulties and support to complete questionnaires being high amongst this group.⁴⁵

Many subgroups in the ASCS sample are considered to be hard to reach when conducting research. Relevant literature suggests issues with representativeness in the ASCS are not unique to this survey and there is potential to learn from other research. These groups are:

- Those with intellectual disability,
- Older adults, particularly those with dementia,
- Those with mental health conditions,
- Those from minority ethnic groups.⁴⁶

⁴³ Heath et al, (2015)

⁴⁴ Malley, J. and Fernandez, J.L. (2012)

⁴⁵ Malley, J. and Fernandez, J.L. (2012)

⁴⁶ Beadle-Brown, J. et al (2012)

Among carers, the following groups may be less likely to respond:

- 'Hidden carers' who do not realise they are using services commissioned by the council, especially when their contact is with a third party rather than local authority social services, or who do not view themselves as carers may not be included.⁴⁷
- Some carer subgroups are less likely to be in touch with the local authority (e.g. certain ethnic minority groups where there may be a stigma attached to seeking help,⁴⁸ or those with less need for support⁴⁹).

5.2 Barriers and facilitators relevant to all groups

There is confusion about how the results of the surveys are used

In-depth telephone interviews with service users and carers highlighted differing understandings of the purpose of the ASCS and SACE. There were participants whose responses indicated a correct understanding that the surveys are used to improve services generally and to identify where to focus local authority resources. Participants who understood that services as a whole (rather their own individual services) could be improved as a result of the feedback given and viewed this positively were likely to say they would take part in the surveys.

"Have got to have consistent data to create effective change." (Service user)

However, when this understanding that the survey was to provide general information for the council was expressed in negative ways (that it would make no difference to their own care) this was associated with a reluctance to take part.

"They always ask you to do things but don't do anything for you." (Carer)

Another group of participants believed that the responses they provided could impact on the services they as an individual would receive. When expressed in a positive way this encouraged participation (at least the first time).

"To find out if I need more help." (Service user)

However, among the group who believed their responses could impact on the care received, concerns around the impact of sharing certain information with the council was associated with a lower inclination to take part. For example, there were service users who believed that revealing that they had received unpaid support could lead to reduction in their care package. These findings suggest that the invitation letters need to be very clear about the purpose of the surveys and to highlight that responses will not impact on the care they receive as an individual but will improve services generally. Suggestions were made that providing feedback on the survey results or on how the findings were used could be useful in encouraging participation.

⁴⁷ Fox, D. Holder, J. and Netten, A. (2010)

⁴⁸ Gray, M. et al (2014)

⁴⁹ Gray, M. et al (2014)

"If you could see a beneficial response, would be more inclined to take part." (Service user)

"A video would be good to see how care is provided in the community as a result of the feedback given." (Service user)

Service users and carers are keen to give feedback on the services they receive

There was a general interest among service users and carers in providing feedback on individual experiences of services in a way which would impact positively on the individual services received, through the local authority being able to respond to particular issues raised. This view was found among those who misunderstood how data collected from the ASCS and SACE are used as well as those who did understand that local authorities could not alter individuals' services in direct response to the surveys. There was a suggestion that service users might choose their survey answers to reflect the occasions where they required the most help in order to avoid reductions in the services they receive. If participants fully understand that survey answers would not affect their own individual services but there are other channels to give individual feedback, it could improve the consistency of responses to the survey and improve response among those who are concerned about the impact of taking part on their own services.

"I always tell people they need to always consider, when filling out information, what your worst days are, you need to be able to give a range of experiences. Some people are proud and don't want support or help and will answer differently." (Service user)

The issues above affect response generally. In addition, if the issue of misunderstanding the purpose of the survey or seeing the local authority's role negatively affects some groups more than others it can lead to under-representation. Particular issues related to this are covered in the sections below.

Service users and carers would be motivated to take part by financial or other incentives

During the interviews, participants (both carers and service users) spontaneously suggested that incentives should be offered to take part. This could be a financial incentive or vouchers to encourage participation and show people they are valued. A comment was made that a survey would be treated as junk mail, unless there was a cheque in there.

The NHS Digital guidance discourages the use of incentives, though in 2017-18 six local authorities and in 2018-19 four local authorities used them on the SACE. There is limited evidence about the effectiveness of incentives on the ASCS and SACE, though incentives are widespread in research to improve responses rates.⁵⁰

Local authorities were not asked about incentives in the online survey or interviews. However, it was mentioned by one local authority that while a small incentive such as a gift-voucher might increase response rates, they would be concerned about offering large

⁵⁰ Aznar, C. et al (2020) Methodology Review

incentives because of the potential impact on the quality of the data, even if it improved response rates.

The content of the invitation letters is comprehensive but may not be accessible to all

Interviews with service users and carers indicated that the ASCS and SACE invitation letters were felt to be clear and comprehensive and included the information needed, such as assurances about privacy and confidentiality. It was also suggested that the invitation should include more information about how people should complete the survey to improve the services they receive (reflecting the misunderstanding discussed earlier). Since taking part in the surveys may raise concerns about services or the service user's circumstances, the letters could include more information about sources of support. On the other hand, the letter is quite long and even in its current form not all service users or carers may be able to read it all, resulting in them not taking part in the survey. It was suggested that this might impact some groups more than others (e.g. those with learning disabilities or mental health problems) which could result in under-representation of these groups. Since the content of the letter is valued and could perhaps be expanded, we recommend that the letter is restructured to include all the essential information needed for participation on the first page, with additional information for those who want to know more on the back.

5.3 Older people and those with dementia and cognitive decline

Local authorities believe that those with dementia and cognitive decline are the most under-represented in the ASCS

In our online survey of local authorities 63 per cent (53 local authorities out of 84 who responded to this question) reported they were concerned that users with dementia and cognitive decline are under-represented in the ASCS. This was the group most commonly mentioned as being under-represented. During in-depth interviews, several explanations for this were given.

- **When local authorities do not receive information that a care home resident lacks mental capacity a questionnaire is sent.**⁵¹ This results in local authorities sending the ASCS to people who may lack mental capacity and who are unable to respond. The under-representation of those lacking mental capacity comes not only from exclusions from the sample but also low response among those who are invited.
- **In community care, local authorities are unable to verify the mental capacity of service users,** resulting in them sending surveys to people who cannot complete the questionnaire. A lack of available support from family or carers to assist users in completing the questionnaire may explain a lower response rate.
- **Known difficulties in completing the paper questionnaires, due to mental capacity or visual impairments.** Interviewees from local authorities suggested the length of the questionnaire, and number of questions, may result in gatekeepers deciding it would be difficult for service users to complete. Among those who do respond, support is important with the majority of those with memory and cognition as

⁵¹ This issue is discussed in more detail in Chapter 4.

their primary support reason receiving help of some kind to complete the questionnaire. Where help is not available, they may not be able to take part.

Accessible formats such as proxy questionnaires and easy read versions may improve response rates among this group

Local authorities agreed that proxy questionnaires completed by family and friends, would be a useful tool for improving response from older people in residential care. In the next chapter we discuss the potential for introducing a proxy survey.

The other facilitators, suggested by local authorities, that would help older people with cognitive decline or dementia to complete the ASCS include:

- **Using the easy read questionnaire.** The easy read questionnaire is sent to all service users in the learning disability stratum. In the online survey of local authorities, 40 per cent reported that they sent easy read versions of the survey to those without learning disabilities on request. Those with cognitive decline or dementia were the largest group that were sent easy read versions on request.
- **Facilitating telephone interviews.** Local authorities reported directing service users to their helplines if they had questions. In some cases, the helpline assisted with telephone completions which was useful for those who had visual impairments or had issues with their literacy skills.
- **Facilitating face-to-face interviews.** One of the local authorities spoken to arranged for an advocacy group to go into care homes to help participants complete the questionnaire face-to-face. Instead of reading out the survey to participants, advocates would engage residents in conversation and ask the ASCS questions as they were talking. They said it could take between 20 minutes and one hour to complete a survey like this. The advantage is receiving responses from service users who otherwise would not be able to take part, but it is a time-consuming process.

An older service user with English as an additional language who had needed considerable support to take part suggested that the inclusion of smiley faces and images on the questionnaire would assist her in understanding the questions.

5.4 Learning disability service users

The learning disability cohort is known to be well-represented in the ASCS. Only 11 per cent of participants to the local authority online survey were concerned that this group were under-represented in the ASCS. This is interesting as those with learning disabilities are a group more generally considered to be hard to reach in research. Interviews with local authorities and other stakeholders highlighted the following reasons for a high response rate among learning disability service users:

- Service users with learning disabilities are likely to receive frequent support from professionals or advocacy groups. These groups may encourage users to engage with the questionnaire or can provide assistance in completing the questionnaire.
- Local authorities automatically send easy read questionnaires to those with learning disabilities which may improve the response rate if it is easier for them to engage with the questions and it seems that they have been sent a questionnaire targeted at their group.

- Learning disabled users are long-term users of care so the local authority would have established contact with this group. It is interesting that survey fatigue does not seem to affect this group despite their long-term use of services and likely repeated inclusion in the survey sample.

While the easy read questionnaire increases accessibility, there is concern over how appropriate it is

Despite the high response rate among service users with learning disabilities, interviewees from among local authorities and stakeholders cautioned that they had some concerns about the easy read questionnaire:

- The images used in the easy read questionnaire are considered to be dated and childish and in need of updating. One local authority *said*, “*the easy read surveys make me squirm*” and the pictures can be seen as patronising. A new version of the easy read questionnaire with updated images, questions and responses has been developed by the ASCOT team at Personal Social Services Research Unit (PSSRU) but has not yet been implemented on the ASCS.⁵²
- The questionnaires are sometimes printed in black and white which can make the images difficult to distinguish, despite the questionnaires being provided in colour. An interviewee from a local authority commented they were unable to tell whether an image was portraying someone smoking or a thermometer in someone's mouth.
- The size of the easy read questionnaire may be off putting to both service users or those supporting users complete the survey and may prevent them from completing it. A local authority mentioned that even if they removed additional questions, they are unable to change the questionnaire's formatting meaning the length would not change.
- While the easy read version may increase accessibility for many of those with learning disabilities, they may not be suitable for those with Asperger's and autism. The questions are considered too open and are not appropriate to this group as they find it difficult to relate them to their own lives. Additionally, if the easy read questions include images of ticks and crosses, those with autism may struggle to complete the questionnaire as the images can bias their answers.
- Levels of satisfaction expressed by the learning disability group are higher than any others (80 per cent extremely or very satisfied)⁵³ and it is unclear whether this relates to the use of the easy read, support from professionals in completion, acquiescence bias among this group, or levels of greater satisfaction among this group than others.

The sample for the qualitative interviews with service users and carers did not include anyone for whom the easy read questionnaire would be appropriate.

5.5 Service users living in residential care homes

Over a third (36 per cent) of those responding to the online survey of local authorities reported that they consider those living in nursing or residential or nursing homes to be

⁵² Turnpenny, A. Caiels, J., Whelton, B., Richardson, L., Beadle-Brown, J., Crowther, T., Forder, J., Apps, J., Rand, S. (2016) Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities*, 31 (1). pp. e36-e48.

⁵³ ASCS 2018-19 Annex tables

under-represented in the ASCS. Only 4 per cent reported that they consider those living in their own homes were under-represented.

The responses received from those in care homes are generally more positive than those who live within the community (69 per cent of those aged 65+ in residential care are extremely or very satisfied compared with 56 per cent of those aged 65+ living in the community).⁵⁴ This may relate to real differences in satisfaction or may result from the greater role of care and support staff in assisting with completions in care homes. ASCS data from NHS Digital show that those who have support from care workers in responding to the survey express higher levels of satisfaction with their care than those who complete the survey on their own or with the support of family or friends.⁵⁵

Local authorities feel that care and support workers and family members have a role to play in assisting service users in completing the survey

Thirty-nine per cent in our online survey of local authorities reported that care homes encouraged residents to respond to the ASCS. Interviews with local authorities highlighted that local authorities do not always send guidance to care homes and rarely provided guidance to family members about how to assist users in completing the questionnaires. However, local authorities explained that there was a tension between the need for help from care and support workers, carers and family members in supporting users in completing the questionnaire and the impact on responses from those offering support.

The local authorities felt that providing guidance materials that are too prescriptive may discourage people from assisting service users completing the survey, which would further reduce response rates from this cohort. On the other hand, if steps are taken to encourage the participation of those in care homes through support to complete the survey, consideration should be given to the impacts on the nature of responses given.

Service users who we interviewed said where help is needed, they would prefer a family member or friend to answer the ASCS on their behalf, rather than a care and support worker. They felt that if the feedback given in the questionnaire reached the care and support worker, this could have a negative impact on the care they received. The carers we talked to were prepared to complete the ASCS on behalf of service users but reported they would like to receive guidance about this. Concern was also expressed about the burden of doing this, given their caring responsibilities and the amount of form filling needed in their caring role. It was also noted that the carer may not observe all the care received and so could not provide feedback on all services. The types of help received with completing the survey mentioned during the interviews with service users and carers varied:

- Carer completing on the service user's behalf with no involvement from the service user (because the service user was not able to help, taking part might upset the service user or the carer judged that without the service user she could comment on things the service user might not feel comfortable mentioning),

⁵⁴ ASCS 2018-19 Annex tables

⁵⁵ ASCS Annex tables 2018-19.

- Carer completing on the service user's behalf with their involvement,
- The service user completing the survey with assistance from a carer on recall or to provide general support,
- Care and support worker helping with translation and explanation and noting the service user's answers, but also commenting on and influencing answers.

5.6 Ethnic minority groups, translations, language

Local authorities are more concerned about the small number of ethnic minority participants in the responding sample than whether they are under-represented

Among local authorities there was a lack of awareness over whether ethnic minority groups were under-represented in the ASCS. In the online survey of local authorities, 20 per cent reported that ethnic minority groups were under-represented. The in-depth interviews showed that local authorities tended to have limited awareness of whether service users or carers from ethnic minorities were under-represented. Local authorities were mainly aware of the small number of cases from ethnic minority groups in the responding sample. In local authorities with a relatively large ethnic minority population, the small number of cases from ethnic minority groups was thought to be a result of the service user population profile differing from the overall population profile of the local authority. This could reflect the age profile and needs of those from ethnic minority groups, as well as these groups using other forms of support and being less likely to access long-term packages of care from the local authority owing to 'perceived and internalised obligations' for family to provide care.⁵⁶

In local authorities with a small ethnic minority population, they were not surprised at the small number in their sample. Local authorities commented that it was not issues with response rates but the small number of ethnic minority participants in their eligible population which prevented local authorities from conducting meaningful analysis about their experiences, because of small sample sizes even if these groups were not under-represented.

Discussion tended to focus on ethnic minority groups as a whole, rather than looking at subgroups within the aggregated ethnic minority group because of the small numbers involved. Because of a perception that the number of service users from ethnic minority groups was small (because of small ethnic minority populations in the local authority or under-representation in access to services), limited consideration was given to over-sampling these groups, which is an option offered in the NHS Digital guidance.

⁵⁶ Blake, M., Bowes, A., Gill, V., Husain, F. and Mir, G. (2017), A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users. *Health Soc Care Community*, 25: 1090–1099.

Use of translated versions of the questionnaires is low even for groups who might benefit

For service users for whom English is an additional language, translations may be needed for them to participate in the survey. This is likely to affect people from ethnic minority groups more than people from the White group (although there are white minorities with languages other than English). Local authorities do not formally record the language spoken by service users and therefore, unlike with the learning disability cohort, cannot automatically send them an appropriate translated version of the ASCS (though the NHS Digital guidance is that they should send a translated questionnaire when the language is known not to be English). Care and support workers may record the level of English service users speak, however, if this is recorded within case notes and not in the central database, local authorities are unable to access this information.

This means that the approach taken is to send service users a translation request sheet. Local authorities vary in the extent to which this is sent out. However, even where the sheet is sent out, requests for translated versions of the questionnaire are rare. A member of the advisory group for this project has also pointed out that unless the translation request sheet is upfront in the documents that are sent, those who require translations may not see it and may assume all the documents are in English.

Other reasons for not requesting translated versions could be other issues such as literacy, lack of understanding of the purpose of the surveys or suspicion of the local authority. Also, one stakeholder interview indicated that sometimes English questionnaires cannot be effectively translated, this can be because the predominant dialect does not have a written form (e.g. Sylheti). It is possible that prior experience of poor translations may put off some groups from requesting the questionnaire.

In the online survey of local authorities, 44 per cent reported ever providing translated versions of the surveys. Among those that do not, the two main reasons given in the online survey were:

1. No one requests them or makes it known that they need them, even in local authorities where the predominant minority groups share a language other than English.
2. The social care population does not include people who need translated materials. Of the local authorities who sent out the additional translation request sheets, even those with a high population of ethnic minority groups received very few requests for translated questionnaires. A local authority with a large proportion of ethnic minority groups in its population said, *“in the eleven years I’ve done the survey nobody has ever contacted me for a translated questionnaire”*.

The questionnaire is also provided as interview scripts so that local authorities can offer face-to-face or telephone interviews to service users. Another local authority with a high percentage of ethnic minority groups said if someone who did not speak English contacted them about the questionnaire, they were able to complete the questionnaire over the telephone. However, as they did not have a dedicated team to run telephone interviews, this was reliant on someone in the local authority speaking the language and being willing to conduct the interview.

In an interview, a service user from an ethnic minority background with English as a second language explained that even if she was provided with a translated version of the ASCS she would still find it difficult to complete the survey. The participant reported that sight problems and struggling to comprehend the questions, regardless of them being translated, would make answering the questions challenging. She said her lack of understanding partly stemmed from her lack of education and partly from her age-related cognitive decline. When she took part in the ASCS, a care and support worker helped her to complete it, using the English questionnaire and translating into her language (Gujarati). She believed the questionnaire was not available in Gujarati and could not remember whether she had seen a sheet telling her which languages were available.

The participant explained that completing the ASCS with a care and support worker translating and explaining the questions had taken an hour and a half which had been tiring and unenjoyable for the participant. This example offers insights into why translations may not be requested even among users of the available languages who are not fluent in English and the further barriers faced by service users in taking part.

There are a wide range of reasons why people from ethnic minority backgrounds may be under-represented in surveys

Translations would only assist in improving response among people from ethnic minority backgrounds where literacy in English is low. The extent of non-response and underlying reasons may also vary between ethnic minority groups. The lack of awareness of response levels among people in different communities, meant that local authorities did not themselves provide insights into why ethnic minority groups may be under-represented in the surveys.

The wider literature on engagement of ethnic minority groups in service delivery and research identifies several reasons for lower response among these groups⁵⁷:

- Negative perceptions of local authorities,
- A feeling that their community is not taken seriously by health and social care professionals,
- The need for flexibility in mode and format,
- The importance of engagement with community and faith groups,
- The importance of ethnic matching in the interviewer and participant – while this may not seem relevant for a paper questionnaire, a perception that the request has come from or is endorsed by someone from their community could be helpful.

A stakeholder from an organisation with a special interest in ethnic minority groups suggested that there may be a lack of awareness of why the local authority is seeking views and whether they will make a difference to the quality of care they receive.

A non-LA stakeholder interviewed also commented that the data from these surveys do not appear on the government racial disparity website. If there is a lack of awareness among groups working with ethnic minority communities of the value of these surveys for exploring differences in the experience of social care of different ethnic groups, the potential for

⁵⁷ Aznar, C. et al (2020) Ipsos MORI (Literature Review)

engagement with these organisations may be less. Previous research has shown that in involving hard to reach groups in research, community groups play an important role in building trust and facilitating participation.⁵⁸

5.7 Mental health service users

In the online survey of local authorities, 37 per cent reported that they considered those with mental health conditions to be under-represented in the ASCS. This is supported by previous research about the ASCS.⁵⁹ Mental health services are not always provided through adult social care services as local authorities sometimes commission separate mental health services. As local authorities are therefore not always in direct contact with mental health service users, they may not hold their contact details which may limit the number of questionnaires they can send to this group. An interviewee reported that some mental health service users think they have mistakenly received an ASCS questionnaire as they are unaware the care they receive is part of the local authority's adult social care service. Local authorities publicising the ASCS alongside mental health services may help to increase response rates as users would be more likely to know how to complete the questionnaire.

As with ethnic minority groups, local authorities felt the number of responses they received from mental health service users were too small to conduct meaningful analysis. In one interview with a local authority, they were able to tell us how many mental health service users had completed the ASCS but could not say whether this meant the group was under-represented. Another local authority was aware that mental health service users are under-represented.

“Every year we have an under representation of those receiving mental health services. It is an assumption that they will be removed from the sample frame due to the capacity checks and the type of conditions that they have, which means they're less likely to complete the questionnaire even if they get it.” (Local authority).

The wider literature identifies those with mental health conditions as a group widely regarded to be difficult to reach or to engage in research. The literature⁶⁰ identifies several approaches which can facilitate research among hard to reach groups, such as:

- Respectful treatment,
- Establishing trust,
- Flexibility in the approach to gathering data and in approaching and recruiting participants,
- Partnership working with other organisations,
- Harnessing service user involvement in the design of the research.

These approaches could therefore potentially be effective in facilitating greater response of mental health service users in the ASCS.

⁵⁸ Aznar, C. et al (2020) Ipsos MORI (Literature Review)

⁵⁹ Malley, J. (2017)

⁶⁰ Aznar, C. et al (2020) Ipsos MORI (Literature Review)

In the interviews, a mental health service user commented that some people might need help to complete the survey and commented that in her case the only person she would be willing to get help from would be her husband because she would feel 'judged and labelled' if it was someone else. These comments suggest that there may be sensitivity about sharing needs related to mental health, which could impact on participation by those using services for mental health needs.

5.8 Carers

Barriers to carers taking part include not recognising SACE is relevant to them as well as practical difficulties in responding

Among local authorities, there was a lack of knowledge about the under-representation of their carer population. Thirty-seven per cent of participants in the local authority online survey reported that they did not know which subgroups of carers were under-represented in the SACE. In the interviews, local authorities discussed the following reasons for carers non-response to the SACE:

- **Carers sometimes do not recognise themselves as performing a caring role.** In some cases, carers had called local authorities to ask why they had received the SACE as they were not aware that those with informal and voluntary caring responsibilities are included in the SACE. Those not identifying themselves as carers are usually young carers, those caring for family members or those providing low level care.
- **Local authorities do not always work directly with carers and may be unaware of which accessible formats to provide carers.** NHS Digital guidance states that local authorities must ensure the following formats available if requested by carers: easy read, Braille, audio for visually impaired people and an electronic version of the questionnaire to be sent and returned via email (for those with sensory impairments).⁶¹ However, if local authorities do not work directly with carers, they may be unaware of the accessible formats to automatically provide them and must wait until these are requested. If carers do not know these other formats exist, they may decide not to complete the SACE.
- **Survey burden may prevent carers from completing the SACE.** One stakeholder noted that there is overlap between the Care Act and ASCOT questions in the survey so asking carers to answer multiple questions on similar topics may be burdensome to them and prevent them from completing the survey.

During interviews with carers, there was a mixed response from carers regarding the questions on the SACE. One participant was pleased that the SACE included questions about the mental health of carers as they felt this could be overlooked. However, another carer found these questions to be intrusive and thought that carers would avoid answering more personal questions. They also reported that the length of the questionnaire and types of questions in the SACE, including information the local authority already knows, may lead to a survey burden, preventing them from completing the survey.

“(when you are a carer), you have to repeat yourself a lot, whether it is for disability benefits, forms, surveys, personal benefits, universal credit, other forms, carers allowance. We are consistently filling forms and consistently repeating ourselves, so a survey that you don't have to do will probably also put people off as we are constant form fillers as carers.” (Carer)

⁶¹ NHS Digital (2018)

Response rates among carers may increase if other methodologies are used to collect feedback

There were multiple innovative methods suggested by local authorities and stakeholders to improve response rates among carers.

- There was an appetite for online surveys with 94 per cent of those responding to the local authority online survey agreeing that online surveys would be appropriate for carers (compared to 79 per cent who felt that a paper questionnaire by post was appropriate). As well as online surveys being more cost effective, and better for the environment, this could be time saving for carers. However, they noted that for this to be an effective method, local authorities would have to collect the email addresses of carers.⁶² Additionally, there was concern expressed in the in-depth interviews with local authorities that carers who lack digital literacy skills, access to the internet or who do not have an email address would be excluded from the SACE online. Local authorities were also worried about whether those who completed the SACE online would be different to those completing a postal survey resulting in data that would not be comparable. Therefore, this was a solution for the future when more carers were more likely to be online or as part of a 'push-to-web' methodology.⁶³ Online methods are discussed in more detail in Chapter 6.
- Although local authorities and stakeholders were aware of the expense of face-to-face interviews, they reported that collecting qualitative data through in-depth interviews would provide higher quality feedback and better response rates than a questionnaire.
- Local authorities felt it was important to share findings from the SACE with their carers. A local authority sent carers a summary of the data collected in their area. Despite this, there remained a need to demonstrate to carers that their views make a difference rather than just telling them the results from the SACE.

⁶² See Chapter 4 for discussion of challenges in obtaining carer contact details and Chapter 6 for discussion about access to email addresses.

⁶³ 'Push-to-web' is when an invitation to take part in an online survey is sent in a letter by post. A paper questionnaire is only provided later as a reminder.

Chapter Summary

- Non-response rates among those with dementia and cognitive decline are considered by local authorities to be high. This group may be automatically excluded from the survey by difficulties in completing the standard version of the ASCS. However, the introduction of other accessible formats such as proxy questionnaires or providing an easy read version may help to increase the response rate amongst this group.
- Those with learning disabilities are generally understood to be well-represented in the survey as they are likely to receive frequent support from carers and advocacy groups. However, local authorities and wider stakeholders are critical of the easy read questionnaire that is sent to the learning disability population.
- Staff in residential care homes may act as gatekeepers and may decide that residents should not complete the ASCS. If staff in residential homes help users to complete the questionnaire, they may influence the feedback provided. Local authorities are aware of this but feel there is tension in encouraging response and enabling service users to respond, while ensuring results are not affected by the support received in completing the questionnaire.
- Local authorities do not collect consistent information about the languages their service users speak, which prevents them from sending out translated versions of the questionnaire. They are reliant on service users reading the translation sheet and requesting translated versions.
- Where mental health services are provided by separate mental health services and not by the Adult Social Care Service, service users may not understand why they are receiving the survey and therefore not complete it. Additionally, mental health services may not provide local authorities with service users' contact details which limits the number of questionnaires delivered. Mental health service users are in a group often considered as more difficult to engage in research.
- Many local authorities commission third parties to work with carers, resulting in local authorities not knowing which accessible formats to send them. Online approaches were felt to offer potential advantages for this group.

6 Innovations in research methods

This chapter summarises the parts of this research that explored alternative approaches to collecting feedback from service users, recognising the many challenges and barriers reported in earlier chapters. This includes a discussion around the introduction of an online survey and a proxy survey and consideration of the feasibility of introducing qualitative approaches to data collection.

6.1 Online methods

A review of the ASCS conducted by the ONS in 2010⁶⁴ suggested that an online methodology could reduce fieldwork costs, speed up data collection and improve the data processing, but that it relies on intended participants having access to the internet and for them to have a certain level of computer literacy. The ONS review 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 therefore recommended against the use of an online mode even as part of a mixed-mode design.

Over the past ten years, however, access to the internet has improved⁶⁵ meaning the introduction of an online survey does now have the potential to both increase representativeness (among certain groups) and decrease costs. Consideration also needs to be given to digital literacy, access to suitable hardware and frequency of use. In 2020, a report showed that 13 per cent of adults age 16 and over never go online and this has remained stable since 2014.⁶⁶ This percentage is likely to be higher among the samples for the ASCS and SACE, since in 2019, 30 per cent of those aged 65-74 and 51 per cent of those aged 75+ did not go online.⁶⁷ In 2020-21 during the coronavirus pandemic NHSX offered iPads to care homes for use by care staff and residents.⁶⁸ It is possible that this and other initiatives make online surveys in care homes more feasible in the future.

The introduction of online methods may also involve initial set up costs which means savings may not be realised immediately.⁶⁹

⁶⁴ Williams, S. and Betts, P. (2010)

⁶⁵ In 2010, 73 per cent of households had internet access compared with 96 per cent in 2020. ONS Data.

<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/datasets/internetaccesshouseholdsandindividualsreferencetables>

⁶⁶ Ofcom (2020) https://www.ofcom.org.uk/__data/assets/pdf_file/0028/196408/online-nation-2020-summary.pdf

⁶⁷ Ofcom (2020) https://www.ofcom.org.uk/__data/assets/pdf_file/0027/196407/online-nation-2020-report.pdf

⁶⁸ <https://www.nhs.uk/covid-19-response/social-care/ipad-offer-care-homes/>

⁶⁹ Burton, J. and Jackle, A. (2020)

Local authorities are positive about the introduction of online for certain populations, and the potential for cost savings

In the online survey of local authorities, the majority reported that they felt online would be appropriate for carers (94 per cent), those aged 16-64 without a learning disability (90 per cent), those aged 65+ in the community (65 per cent).

Just over half (55 per cent) reported that they thought online would be appropriate for learning disability clients, and few (29 per cent) reported that online would be appropriate for those aged 65+ in residential care.

During the in-depth interviews with local authorities, it was reported that online has the potential to reduce costs and would be better for the environment. One local authority reported that in previous years they had to find temporary workers to input the paper questionnaire data. Therefore, they would welcome the introduction of online to reduce the manual data entry work involved in running the surveys.

However, in practice a push-to-web design, with a paper questionnaire included within the reminder, would be most feasible

- **The most efficient way to run an online survey is by including a direct link to the survey in an email to the sampled population.** Email records need to be completely accurate in order to be effective. This would not currently be possible for the ASCS or the SACE as local authorities records on email addresses are incomplete. The online survey of local authorities found that 63 per cent reported holding email addresses for service users. Among those, only 16 per cent reported having email addresses for more than half their service users. A quarter (24 per cent) did not know what percentage of service users they had email addresses for. A quarter of local authorities did not know what percentage of carers they hold email address for, 19 per cent reported they hold email addresses for 50-74 per cent of carers and none reported that they held email addresses for 75 per cent or more of carers. During the in-depth interviews with local authorities, they reported even where email addresses are held, there was some uncertainty about whether local authorities have permission on GDPR to use them for the purpose of sending out surveys. There was also a suggestion that many of those receiving care do not have email addresses at all.
- **Alternatively, a sequential mixed mode design could be implemented, but the cost savings are unlikely to be large.** In this design, a letter is sent to the sampled population with a URL link to the online survey, as well as a paper questionnaire enclosed in the mailing. This option does not offer the greatest potential to decrease costs, since the same amount of printing of the questionnaires is required. However, some cost saving might be observed (for example, from not needing to input the data or scan the questionnaires of those who do respond online). It may also be that some people who might otherwise have not responded on paper (if the effort to post back the questionnaire was off-putting) might respond online.
- **This suggests that the potential to decrease costs would be via a push-to-web design,** whereby a letter is sent to the sampled population and included within this is a URL link to the online survey but no paper questionnaire. If successful, savings can be made through a reduction in printing of paper questionnaires, as well as saving on data entry and/or scanning costs at the back end. This approach alone (i.e. without the

inclusion of a paper questionnaire in the reminder) will not be successful however, for two reasons:

1. The response rates will be lower than a direct paper survey⁷⁰
2. The response will be less representative because there will be people who may not wish to take part online, as well as those who are not able to (either because they do not have access to the internet, or cannot use it even if they do). This could disproportionately affect certain groups in the sample such as older people living in care homes.

- **Thus, a flexible mixed mode and push-to-web design, with different approaches for different strata appears to be the most feasible approach for the ASCS.**

- Working age service users and those aged 65+ living in the community without learning disabilities could be sent an initial letter with the URL (push-to-web) and no questionnaire, with a paper questionnaire included with the reminder.
- Learning disabled service users could be sent an easy read questionnaire with a link to an online easy read questionnaire (sequential mixed mode).
- Older people living in residential care could be sent a paper questionnaire together with a URL link to the online survey (sequential mixed mode).

- **For the SACE where there are no strata, push-to-web could be used for the whole sample with a questionnaire included with the reminder**

The approach to determining who gets which type of invitation would need to be kept simple to maximise efficiency (e.g. based on stratum or used for all carers). However, testing would be needed to explore whether push-to-web is effective in all age groups in among those 65+ living in the community. Cost savings can be made initially, from those who take part online, meaning fewer letters and questionnaires need to be printed and posted for the reminder.⁷¹ In addition, SMS text reminders have been shown to be a low-cost means for boosting response⁷² so this is a strategy that could be considered. Coverage of mobile phone numbers varies with 81 per cent reporting in the online survey of local authorities that they have mobile numbers for service users and among them 63 per cent reporting they have a landline or mobile for at least half their service users.

- **However, while the push-to-web design has the potential to improve representativeness of certain groups (younger people for example), it may not increase response rates overall**, when compared to a straight paper survey. A review of experiments in the USA showed mean response rates from push-to-web surveys was lower than the mail only comparisons.⁷³ Although response may increase among some previously under-represented groups, it might decrease among others.
- **A move to online could improve the quality of the data.** On online questionnaires it is possible to include validation rules (for example, not allowing those responding to

⁷⁰ Ipsos MORI (2020) NHS Adult Inpatient Survey: Findings from the mixed-mode methodology pilot. <https://nhssurveys.org/wp-content/surveys/06-development-work/06-engagement-work/2020/Adult%20Inpatient%202019%20Mixed-mode%20pilot%20results.pdf>

⁷¹ We have seen promising results in our push-to-web design for the Adult Inpatient Survey for CQC, which is an older survey population.

⁷² Ipsos MORI (2020) GP Patient Survey Technical Annex. https://www.gp-patient.co.uk/downloads/2020/GPPS_2020_Technical_Annex_PUBLIC.pdf

⁷³ Dillman, D. (2017) <https://www150.statcan.gc.ca/n1/pub/12-001-x/2017001/article/14836-eng.pdf>

choose a substantive response *and* a don't know response, whereas they could tick both on paper) which improves data quality. Furthermore, as the data are captured automatically there is no need for manual entry or scanning of questionnaires which can introduce errors.

- **The switch in modes and mixing of modes can cause problems with survey trends.** In the Survey of Inpatients for the CQC,⁷⁴ for example, we have observed overall, less positive results from the push-to-web design, compared to the straight paper survey. The reasons for this are unknown but could be explained by a perception that it is more secure to report lower satisfaction online, without the risk of the paper questionnaire being shown to those who provide the care. There are also practical issues associated with integrating data from online questionnaires and paper questionnaires. There are also mode effects when amalgamating data from different modes.⁷⁵
- **Smartphone use is increasingly important, and any online survey needs to be 'mobile first' so it can be completed as effectively on a mobile phone as a computer.** In the UK in September 2019, 81 per cent of measured time spent online was on a mobile or tablet device.⁷⁶
- **There is an appetite for online surveys among service users and carers who are confident with using technology.** In the interviews with service users and carers, among those who could access them, online surveys were felt to be more convenient than paper surveys. The view was also expressed that participants could be more reassured about confidentiality and privacy in an online survey than in a paper survey. However, it was noted that having a paper questionnaire could act as a visible reminder to take part. It should be noted that the sample for the interviews with service users and carers may have been more digitally literate than is typical of service users and carers generally.

An online option also has the potential to offer more accessibility options

The suite of accessibility options for online also offers the potential for those currently excluded from a pen and paper format to take part.

In the GP Patient Survey, for example, there is an option to change the size of the font and the colour of the background, and the survey is also screen reader compatible. These are all standard features, available at no additional cost, and are helpful to those with visual impairments. There is also an option (which does come at a cost) to add BSL translations, for those with hearing loss, and the questionnaire is programmed in alternative languages meaning that people can automatically complete it in a language of their choice, without requiring any effort on their part.

⁷⁴ CQC

⁷⁵ Dillman, D. (2017) <https://www150.statcan.gc.ca/n1/pub/12-001-x/2017001/article/14836-eng.pdf>

⁷⁶ Ofcom (2020) https://www.ofcom.org.uk/__data/assets/pdf_file/0028/196408/online-nation-2020-summary.pdf

The future of the surveys must learn from online pilots of the ASCS and SACE

In 2018-19, two local authorities piloted an online version of the ASCS and SACE questionnaires. We have information about the precise approach used in one of these local authorities. There, a 'push-to-web' methodology was used for the SACE. In these two local authorities, 29 per cent of responses received on SACE were received online. For the ASCS a mixed mode sequential design was used where the initial invitation included both the online URL and a paper questionnaire. The number of ASCS responses received online was small (1.4 per cent or 19 questionnaires across the two authorities).⁷⁷

In both local authorities, those who responded online had a younger age profile than those completing on paper. If local authorities move to an online mode in the future, it may yield a higher proportion of responses from those aged under 65, compared to using the postal method.⁷⁸ Given that 18-64 year olds are under-represented in the responding sample for SACE, the introduction of an online mode may improve representativeness of the survey, even if overall response rates are not improved. Given that the ASCS and SACE were tested online in two local authorities and response rates vary from year to year, it is not possible to draw firm conclusions about the overall impact on response of the introduction of online methods in these surveys. There was certainly no evidence that response rates were increased by the introduction of the online survey in these two local authorities.⁷⁹

Further evidence is needed about the impacts of different approaches to the online mode, particularly from the ASCS, where the numbers responding online in the previous pilot were small. At the time of writing this review, an online pilot is planned for the next wave of the SACE. The pilot, managed by NHS Digital, intends to test three variables across at least ten local authorities:

1. Questionnaire management – centrally and by the council,
2. Questionnaire design – with a mobile friendly version of the questionnaire and a questionnaire online which mirrors the paper version more precisely,
3. Variation in the invitation – where five different groups receive a paper questionnaire included in the mailing at different points.

Among service users and carers, there is awareness of the use of Apps for research. More innovative methods such as using an app to track feedback was thought to work well among those who were familiar with using this technology, including those who were familiar with apps from their health care (e.g. diabetes apps). However, a service user commented that they had previously used an app to give feedback and while it was good at first, his participation fell off because of the effort involved and felt an appropriate incentive was necessary for this type of methodology.

6.2 Other survey modes

Participants in the service user and carer interviews expressed a preference for telephone interviews as they were considered to be more personal than paper or online questionnaires, especially for carers who may be regularly filling in forms. This included those for whom

⁷⁷ NHS Digital (2019)

⁷⁸ NHS Digital (2019)

⁷⁹ Aznar, C. et al (2020) Methodology review

online was not suitable as well as those who could do an online survey but would still prefer telephone. Telephone calls were suggested for completing the survey, or alternatively, to warn the participant that the survey would be sent and to check this would be OK, potentially with a positive impact on participation. Telephone interviews were also preferred over face-to-face interviews, which were felt to be time consuming and tiring for service users and carers. However, one carer noted that if a service user was hard of hearing, a paper questionnaire would be more appropriate.

6.3 Proxy methods and research in care homes

There is a need to consider alternative ways to capture the experiences of those who lack mental capacity

Chapter 5 outlined some of the reasons for the under-representation of those lacking mental capacity in the survey. Given the importance of this group and the need for local authorities to understand their experiences and outcomes, consideration needs to be given to whether a proxy approach, where someone else responds on their behalf, is feasible and ethical.

Although there is no formal proxy version of the ASCS questionnaire, information on help received in completing it shows that, overall, 10 per cent of questionnaires are completed by someone other than the service user. Among those receiving care for memory and cognition problems, 26 per cent are completed by others on their behalf. However, in the current questionnaire it is not clear whose view is being collected. The covering letter makes it clear that the views of the service user are being sought but the questionnaire refers to 'you' throughout which causes confusion when a carer is completing it on behalf of a service user.⁸⁰

Given that proxy responses are already being received from the ASCS, and the challenges and inconsistencies in the current approach, 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.

A proxy survey could be a low-cost means for including the voices of those who lack capacity but there are practical challenges

The development of a formal proxy version of the questionnaire could be an affordable and efficient means for including the voices of those who lack capacity. There has been work carried out on the development of a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT) scale.⁸¹ 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.

⁸⁰ Gray et al (2014)

⁸¹ Caiels, J. et al (2019)

The appetite for this was explored in the in-depth interviews with local authorities, and the feasibility carefully considered. While the general feedback was that a proxy version of the questionnaire would be welcomed, several challenges were also highlighted.

- **The difficulty in targeting proxy participants.** It is unlikely that local authorities would be able to suitably target proxy responses, even if they log when a service user loses capacity so *could* do so in some case. The existing questionnaire may need to accommodate a separate set of questions for proxy participants. This would be feasible and easy enough to do in an online version, however it would need to be incorporated into an already long paper version.
- **There are ethical considerations and proxy responses must be analysed separately from responses from users.** It cannot be assumed that a proxy response is equivalent to a self-report, and therefore proxy responses would need to be separated out and analysed and reported on separately. Stakeholders, during interviews, cautioned this, calling for these to be excluded from, or separated out from the service user responses.
- **There needs to be clarity on whose perspective the proxy participants being asked to provide.** There can be ambiguity around how to answer the questions and from whose perspective. Additionally, it could be that certain items (for example, about ‘dignity’) are perceived to be more abstract and therefore will be more difficult to answer as part of a proxy survey.⁸² A carer of a service user with learning disabilities who was interviewed was willing to complete the ASCS on her behalf, however, felt it would be difficult to accurately complete the survey. Although he said “*I kind of speak for her*” he did not feel qualified to speak about what she thinks generally about the care received, and would not be able to ask her as she was not able to express general thoughts about her experiences. Previous research,⁸³ however, has found that such challenges can be mitigated through using various framing questions to help minimise bias. For example, previous suggestions have included providing two sets of response options for each proxy perspective (one for the proxy and one from the view of the care recipient) and a comments box to help people explain why they have selected a given response option (especially where these indicate unmet need).
- **Even when it is clear whose response it is, there is potential for bias and there should be clear rules about who should act as a proxy.** Given that the people likely to act as the proxy may also be the people providing the care, there is a risk that the responses will be biased, particularly if the proxy is a care and support worker providing the care which is being asked about in the questionnaire.⁸⁴ Bias of this kind is less of a problem for unpaid carers, though there is evidence that unpaid carers tend to underestimate the quality of life of the person they care for.^{85,86} Careful thought to the design of the instrument would be needed to ensure that the potential for bias is reduced in the design and that proxy responses from those providing professional care and support are avoided. In previous research, both paid and

⁸² Caiels et al, (2019)

⁸³ Caiels et al, (2019)

⁸⁴ ASCS data show higher levels of satisfaction among those who receive help from care and support workers.

⁸⁵ Brooks et al. (2016)

⁸⁶ Smith, N. & Malley, J. (2012)

unpaid carers agreed that any person acting as a proxy would need to be very familiar with the care recipient, as well as their needs and care provision. It would be important to record the relationship between the proxy and the care recipient in the proxy questionnaire. Clear guidance is needed setting out exactly what is expected of the proxy participant and how they should complete the questionnaire.⁸⁷

In introducing a proxy approach consideration needs to be given to the process of consent

The current ethical approval for the ASCS and SACE stipulates that only those with mental capacity to give consent should be included in the research. If a proxy approach is introduced, the issue of consent remains. The proxy not only has to respond on behalf of the service user, but also needs to give consent on their behalf. Under the Mental Capacity Act (2005) there are clear rules about how this can be done. On the English Longitudinal Study of Ageing,⁸⁸ when existing panel members lose capacity to take part, consent is obtained from a consultee who is asked 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. It would be feasible to build this into the process through a question on a proxy version of the ASCS and SACE questionnaires by explicitly asking for consent from a consultee. This issue is greater for the ASCS, where the sample is more likely to include those who lack capacity, than the SACE where all sample members are caring for someone else and so less likely to lack capacity (though some may).

6.4 Qualitative approaches

Although the structured nature of a questionnaire is not suitable for some people, a more qualitative, conversational approach could be a means for gathering the direct views of those who otherwise could not take part in a survey. This would increase accessibility and overcome some of the issues associated with relying on proxy responses. In this section, we consider whether alternative qualitative approaches could be used to gather the views of those who are otherwise excluded from the surveys (such as those lacking mental capacity).

There have been some developments already with such approaches, for example, a version of Talking Mats for ASCOT⁸⁹ has been developed.⁹⁰ However, subsequent findings suggest this is not an appropriate tool in the context of the ASCS and obtaining feedback on outcomes from service use. The same team at PSSRU⁹¹ have also explored and developed an approach (as part of the ASCOT) to use in care homes with people who may not be able to complete a standard questionnaire. Qualitative interviews with and observations of residents are conducted to determine quality of life.

There has also been work in the UK and Australia to explore the use of the ASCOT tool in residential care planning. The tool which is suitable for those with dementia enables staff to initiate and hold conversations with residents about their emotional and social wellbeing and

⁸⁷ Caiels et al, (2019)

⁸⁸ Bridges, S. et al (2015)

⁸⁹ Adult Social Care Outcomes Toolkit <https://www.pssru.ac.uk/ascot/>

⁹⁰ Smith and Towers (2015)

⁹¹ Personal Social Services Research Unit

quality of life using a 'circle of care' approach involving residents, family members and a care worker.⁹² Although developed as a planning tool, the principles and approaches could also be adapted for gathering feedback and exploring outcomes.

There is appetite within local authorities for qualitative approaches to supplement the survey data, although given that resources are limited, this may not be feasible across all local authorities

Local authorities value the quantitative aspect of the surveys. The consistency and scale allow for benchmarking and capturing any change over time in self-reported satisfaction with the services. However, structured surveys exclude the voices of those unable to engage with such an approach.

Local authorities were asked about the ways in which the data or outputs from the surveys (ASCS and SACE) could be made more useful in the online survey of local authorities. Over a third (38 per cent) reported that the opportunity to supplement the survey data with other types of feedback (e.g. qualitative research) would make the survey findings more useful. There were suggestions for more 'narrative' and the collation of people's 'stories' to explain the survey data, as well as software to be made available to them to analyse this against the corresponding questions.

"The tick box nature of the questions makes responding easier but doesn't give us the qualitative feedback and 'people's stories'." (Online survey of local authorities, open response)

During the in-depth interviews, representatives from local authorities talked about how it is difficult to interpret the numbers and how qualitative feedback (written on blank spaces on the questionnaire, or in letters sent with the questionnaire as no comments boxes are offered) can be helpful. These comments are useful to explain why people have answered in the way that they have and help bring to light stories, perceptions and issues which service users and carers want to flag, even if not asked about in the questionnaire. There were examples of local authorities carrying out their own follow-up research to understand more about some of the issues raised by the survey, so that they could act on the findings. Finally, local authority participants discussed during the in-depth interviews how they tend to find most value in the collection of spontaneous qualitative data.

The inclusion of open text boxes was suggested during the interviews with service users and carers. This would allow participants to elaborate on their answers or raise topics which were not included in the survey. However, given the general confusion over how local authorities use the information, open boxes should only be included if the information would be actioned by the local authority, or it is made very clear that specific concerns the local authority needs to take action on should be raised in another way outside the survey.

When discussing the use of qualitative approaches as a potential option, interviewees from local authorities cautioned that a lack of resource would be a serious limiting factor to gathering feedback from service users in this way. Instead suggestions were made for how some qualitative feedback could be captured as part of service provision (i.e. at the end of a

⁹² Towers et al (2019)

face-to-face session), which is already being used for short-term users by some local authorities.

Although there were concerns about the resources involved in this approach, one local authority reported that it commissioned someone from a local organisation to go into care homes and complete the ASCS questionnaire face-to-face. If this approach is feasible with the survey questionnaire, then there may also be potential for qualitative research tools to be provided as well. Standard qualitative feedback tools could be provided by NHS digital as an option for local authorities to use on a small scale to explore some of the issues raised by the survey data in more depth locally, or to hear the views of those excluded from the survey.

The addition of a comments box would help with the consistent collation of qualitative feedback. This would need to be signposted upfront in the questionnaire so that those completing the questionnaire could save their open feedback for the comments box, usually located at the end of a questionnaire.

6.5 Weighting and statistical innovations

It is common for survey data to be weighted to correct for differences between the target and achieved samples. Weighting relies on information being available on the characteristics of both groups. Chapter 3 included analysis which showed that weighting to correct for identified under-representation did not change survey estimates (sections 3.3.1.4 and 3.3.2.4). However, this analysis was limited to the variables available from the survey data and for the eligible population. There are groups under-represented by response for which information is not available in the eligible population (e.g. ethnic groups, the primary support need of the person a carer helps). In addition, the data available for the eligible population is summarised in a way which can limit its usefulness. For example, for ASCS age is provided by a two-way split in the eligible population which means that important patterns by age (e.g. that response is highest in the middle age groups) cannot be corrected for by this weighting.

Chapter Summary

- Local authorities are positive about the introduction of an online mode for certain populations, and the potential for cost savings. However, given the fact that they do not routinely collect and store up-to-date email addresses and that online is not suitable for all service users, in practice a flexible design would be most feasible.
- The suite of accessibility options for online is also attractive. For example, the option to change the size and font and the colour of the background and make the survey screen reader compatible. There would also be an option to add BSL translations, for those with hearing loss, and the questionnaire is programmed in the alternative languages meaning that people can automatically complete it in the language of their choice, without requiring any effort on their part.
- While a move to online will improve the quality of the data (from the online responses) because of the ability to include validation rules (for example, not allowing those responding to choose a substantive response and a don't know response, where they could tick both on paper), the switch in modes can cause problems with survey trends.
- A proxy survey could be low-cost means for including the voices of those who lack capacity. However, the addition of a proxy version of the questionnaire presents several challenges, including the difficulty in targeting proxy respondents and the ethical considerations meaning that proxy responses must be treated separately. There is also a question mark over whose perspective is the proxy respondent being asked to provide and even when it is clear whose response it is, there is potential for bias. Thus, the importance of clear rules for whom should act as a proxy would be needed.
- There was appetite for qualitative approaches to supplement the survey data though given that resources are limited, this would need to be offered as an option rather than a required part of the protocol. Suggestions were made for how some qualitative feedback could be captured as part of service provision (i.e. at the end of a face-to-face session). As well, the addition of a comments box would help with the consistent collation of qualitative feedback – though this would need to be signposted to upfront in the questionnaire so that those completing the questionnaire could save their open feedback for the comments box, usually located at the end of a questionnaire.

7 Other issues related to running the surveys

This chapter discusses the insight gathered during the interviews, focused on how the surveys are run in practice. It looks at survey fatigue and how data around safety are used to inform safeguarding alerts. It also reviews the resources and capacity required to run the surveys and closes with a discussion around the running of the surveys (whether this should be central or continue to be local) and the frequency of the surveys.

7.1 Value of the surveys for local authorities

The online survey and interviews with local authorities showed that the surveys are felt to be worthwhile and serve multiple purposes.

Three quarters of the online survey participants⁹³ thought that conducting the ASCS and SACE were worthwhile. Overall, the local authorities we talked to felt that both surveys constitute a good (and sometimes the only) opportunity for service users and carers to give feedback about their experiences of social care.

It's one of the few opportunities that the people who actually use our services get to have a voice. So, it's direct client feedback. They've got the opportunity to say what it is they want to say about it. Particularly with the carers' survey, they're sort of a hidden group. So, unless they're also receiving services from us directly, if they're, you know, like a carer in the purest sense with no provision of service from the authority, it's difficult to see how else they would get a voice. So, it is useful from that point of view. (Local authority)

Other reasons given for conducting the ASCS/SACE surveys included monitoring the success of local interventions, identifying and sharing best practice and informing strategic policy and ensuring public accountability. The consistency of the surveys across local authorities which enables benchmarking and comparison with national, regional and similar local authority figures was felt to be valuable (80 per cent in our online survey reported using the data in this way). This, combined with consistency over time, means local authorities can look at trends, and identify areas for development and improvement. There were instances where, as a result of findings from the survey, local authorities were able to report back to service users 'you said – we did' to show service users how their feedback is used.

Both surveys are also sometimes used as part of local authorities' safeguarding processes, whereby certain responses are flagged for immediate help and targeting while the surveys are ongoing. Although the survey is not intended for this purpose, there was evidence from the in-depth interviews that local authorities can use the findings to assess the performance of individual care homes, including comparing survey results with CQC inspection evidence.

⁹³ In the online survey of LAs conducted as part of this research

They did not report using this for any particular purpose, but it was clear that use is made of service level data.

While finding the survey worthwhile, many local authorities do not make full use of their results. During interviews, local authorities varied in the extent to which they considered the ASCS and SACE helpful for informing local decision making. In the survey, just 49 per cent in the online survey reported that they use the data from the ASCS to plan improvements to services, although 65 per cent reported using the data to explore areas of concern in the provision of services. Local authorities understood NHS Digital's need for national consistency in the design of the survey, but highlighted that additional local follow-up was needed to fully understand some of the issues raised by the survey.

In our interviews, local authorities revealed how conducting the surveys could sometimes feel a bit like a tick-box exercise. Although it offers huge potential, the full benefits were not always realised. They felt they were not always able to dedicate enough time and resources into data collection and analysis, partly as a result of the financial and resource cuts they have experienced in the last decade which have led to loss of staff and expertise. This meant that limited or no analysis was carried out to understand how well the surveys were running locally and which groups may be under-represented.

Although tools such as Power BI provided by NHS Digital for analysing the data were found to be useful, there were limitations in what they could offer locally. These limitations included sample sizes which were too small to explore subgroups of interest within the local authority and difficulty in interpreting the findings against other sources of data such as CQC inspection reports.

7.2 Survey fatigue

Given that the service user and carer populations are relatively small in each local authority and people may use services or be in contact with the local authority across several years, the same people may be sampled in consecutive survey years. This is more of an issue for the ASCS which takes place annually, than for the SACE which takes place every two years.

Survey fatigue is an issue in some local authorities, and amongst certain groups in particular

Survey fatigue may impact on response rates to the survey, and because of the risk that those in the small strata are even more likely to be sampled every year, this could lead to lower response rates among certain groups. The percentages of eligible service users sent a questionnaire by stratum in the 2018/19 ASCS survey year shows that the 'age 18-64, excluding learning disability' group was the most likely to be affected by repeated sampling. This, incidentally, is one of the groups that is under-represented in the survey data.

In 2018-19, 26 per cent of local authorities included 75 per cent or more of the eligible population in this stratum in the issued sample.⁹⁴ Assuming people remain long-term users for more than one year, the chance of being sampled in consecutive years is high. The

⁹⁴ Aznar, C. et al (2020) Review of survey methodology for ASCS and SACE

higher the percentage who are asked to take part every year, the greater the potential impact of fatigue on response rates.

During the in-depth interviews, some smaller local authorities reported that the requirement to achieve a certain sample size and confidence intervals does mean that most years they have no other choice than to invite the same people to complete the survey again. In addition, the local authorities carry out their own surveys, or other organisations such as Healthwatch do and this can contribute to survey fatigue. Generally, as per the guidance, that local authorities are correctly not using fatigue as a reason to exclude people from the sample frame. However, local authorities also mentioned in interviews that those who have explicitly informed the local authority that they do not wish to be contacted again about the survey are excluded from the sample frame.

Survey fatigue relates not just to the frequency of taking part, but the burden involved in doing so, how long the questionnaire is (or is perceived to be) and how worthwhile the survey is felt to be. Service users and carers expressed a willingness to provide feedback more often, but not necessarily in the form of the current surveys, rather to provide updates on the care they are receiving.

7.3 Identification of safeguarding issues

The ASCS asks service users how safe they feel and whether their care and support services help them in feeling safe. It is not known how this is interpreted by those completing the survey – for example, if this is assumed to mean living safely independently or personal safety for reasons unrelated to social care needs such as fear of crime. However, the information gleaned from quantitative responses to this question and from comments beside it is used in local authorities as a means for flagging safeguarding issues which are followed up during fieldwork. The safety question was one example provided when local authorities talked about not being equipped to know how to respond to poor service user/carer ratings in certain areas, owing to a lack of clarity about how participants interpreted the question.

There are opportunities, harnessed currently by some but not all local authorities, to make better use of the data locally

In one local authority, responses to the question about safety, as well as the question about access to timely food and drink, are a trigger to inform the access point team. This council performs daily checks on the data to identify these flags, using responses to these two questions. Another local authority, which carried out some work to establish how its users were interpreting safety, found that it was interpreted as fear of falling. This local authority then used the data to promote its Telecare Safe and Sound equipment in response.

Where the survey data were being used locally in these ways, local authorities cautioned against the idea of the surveys being centralised (and run from NHS Digital rather than the local authority) as this could limit the ability of local authorities to respond quickly to such issues.

7.4 Resource and capacity for running the surveys

Running the surveys is a big undertaking for local authorities and is resource intensive. The in-depth interviews showed there were local authorities which welcomed the fact that the SACE is run bi-annually for this reason. In some interviews, local authority representatives were keen for the surveys to be run centrally by NHS Digital as this would free up resource within the local authority. However, this was not the view held by all (see section 7.5 for a discussion about running the surveys centrally).

There is appetite to implement more measures to improve the running of the surveys, but a lack of resources limits what can currently be done

In the context of teams that are stretched to deliver the surveys currently, there were several activities that local authorities we interviewed reported that they would like to do but are unable to because of limited resources and capacity. These include the following activities.

- **Carrying out capacity checks with care homes.** Currently, as previously noted, local authorities rely on care homes to assess the capability of service users in their care for taking part in the survey. Some councils we spoke to suggested that they do not think that care homes always perform capacity checks (because they only hear back from a minority of homes), or if they do, they are not consistent as care homes interpret capacity in different ways and do not provide information on the reason for their decisions. Thus, this was one of the areas that councils would like to have the resource to be more involved in.
- **Issuing reminders to boost response rates.** 79 per cent of those who responded to the online survey of local authorities reported that they send out the questionnaire with the reminder letter (which is a requirement in the guidance). Where they did not do this as standard practice, one reason was a feeling that the reminder did not have much of an impact and including the questionnaire was viewed as a waste of resource. However, other local authorities which did include the reminder, found the reminder letter had a greater impact (30-40% increase in response).
- **Sending out a summary of the survey findings** to service users / carers or to anyone who had asked for this, to help show how taking part in the research is useful, particularly if the summary could include details of how the results were used.
- **Re-interviewing some of those who had completed the surveys** to explore how they had understood the questions or to follow up on some of the issues raised, then using this information to initiate service changes.
- **Making better use of the data locally, for ,to understand more about the groups that are currently poorly represented in the survey** so that those involved could focus on how to improve response among these. There is also an appetite for being able to delve deeper into the findings and cross analyse these by subgroups.

7.5 Running the surveys centrally vs locally

Currently, local authorities have some flexibility in how they run the surveys, although NHS Digital provides clear guidance and distinguishes between elements of the protocol which are compulsory and those where there is flexibility. For example, there is an option for local

authorities to include additional questions or open-ended questions for local research purposes, however, these amendments are subject to NHS Digital approval.

The research explored the arguments for and against centralising the surveys, which would mean that local authorities would have less involvement and control in running the surveys.

Local authorities were split on the idea of NHS Digital centralising and running the surveys

In the online survey of local authorities, 40 per cent reported that they felt that carrying out the surveys should remain the responsibility of individual local authorities. During the in-depth interviews, several reasons for this were given.

1. **There is a need to use local intelligence held by the council** (for example, up-to-date information about deaths and contact details), as well as the opportunity to promote the surveys locally.
2. **There is a requirement for certain data from the survey to inform safeguarding flags** (and if the surveys were centralised, the delay in being able to respond to this, if at all, would put people at risk).
3. **There was some reticence around taking resources away from local authorities.**
4. There was a perception that the survey may appear **less attractive to complete** from the service users' point of view, if it were **not 'owned' by the local authority.**

A similar percentage (42 per cent) of local authorities surveyed reported that the survey administration should be centralised and 18 per cent had mixed or uncertain views. During the in-depth interviews, those who held the view that the surveys should be centralised suggested that this would enable the surveys to be run more consistently and efficiently (for example, scanning the survey responses could also be centralised, rather than each local authority entering them manually). Assuming, that funding to the local authority was not reduced, this would also free up local authority staff from the onerous job of running the surveys, allowing them to take on other tasks, including more analysis of the data.

The advantages of centralised running in terms of efficiency would rely on consistency between local authorities in terms of the questionnaire content, invitations and sample information. The group who felt the surveys should be centralised included the 28 per cent of participants who reported that they felt that local authorities should be able to add questions from a standard list. This suggests that even if the surveys were centralised, local authorities might still expect to be able to include local variation which would be challenging on a centralised postal survey, though easier on an online survey.

7.6 The frequency of the surveys

The research also sought to understand views around how frequently the surveys should be run, from within local authorities and among wider stakeholders (some of whom are users of the survey data). The ASCS is currently run as an annual survey, while the SACE is run bi-annually.

There were concerns about changing the frequencies of both the ASCS and SACE

Among wider stakeholders interviewed, there was caution over altering the frequency of the surveys and having them run less frequently. For example, data users reported that the key indicators (for example, to inform ASCOF) would become less useful if the ASCS became bi-annual. They would have access to less up to date information to react to problems using recent evidence. There was also a sense from some stakeholders that given the importance of carers and the value of their work, the SACE should also be run annually.

Within local authorities, some were attracted by the possibility that less frequent surveys would reduce the burden on users, especially those who are asked to complete it every year. Less frequent surveys would also give local authorities a break from administering the survey, potentially allowing them to use the data in more detail or carry out other feedback activities in between. It could also allow the ASCS and SACE to alternate to avoid the pressures which occur in years when local authorities have to run both surveys. These local authorities felt that running the SACE bi-annually is a good thing as it would be too resource intensive to run it every year.

However, other local authorities were against the idea of less frequent surveys, given the importance of collecting regular feedback from their users. Several other suggestions were provided by wider stakeholders and local authorities, during the in-depth interviews. These included having a rolling survey, being run at different points of the year and including more frequent, but shorter, surveys, for example, every six months, potentially administered as part of service delivery. A suggestion was also made about the timing of the annual survey and whether after Christmas is the best time, whilst also recognising the potential impact on results of changing the timing.

There is an appetite for giving more frequent feedback among users and carers, but not necessarily through the current surveys

There was also an appetite among service users and carers for providing feedback more frequently. There were mixed opinions on how frequently this should be, with suggestions ranging from every three months to annually. This desire to give more frequent feedback stemmed from an awareness that the health and social care needs of a service user or the responsibilities of a carer can change quickly. They felt that more frequent surveys would ensure that these changes are recorded by local authorities. This stemmed from a misunderstanding about the survey being a way for them to provide feedback about their individual situation which the local authority could act on.

A service user who suffered with neurological issues noted that the survey was lengthy and would require effort to complete. If feedback was collected more often, they felt the survey could be shortened and focus on changes to care.

"The sort of snapshot they receive depends on when the survey is being filled out, I could have filled the survey out 6 months ago and I would have given very different answers than today." (Service user)

These findings do not necessarily suggest that the surveys should be carried out more often but rather that there should be alternative mechanisms for service users to give individual

Chapter summary

- Survey fatigue is an issue in some local authorities, and among certain groups. While we did not find evidence to suggest that local authorities exclude people from the sample frame because of survey fatigue, they do exclude those who explicitly request that they should not be contacted about the survey. Survey fatigue was a suspected reason for these requests.
- There are opportunities, currently harnessed by some but not all local authorities, to make better use of the data locally. There was evidence of councils using survey data to inform local intervention and changes. The data from the question about safety has been used to inform a safeguarding alert process and promote a telecare service.
- There is appetite to implement more measures to improve the running of the surveys, but a lack of resources limits what can currently be done. Some of the activities that councils are keen to do include working more closely with care homes on mental capacity checks, sending out a summary of the survey findings, re-interviewing some of those who have completed the survey to understand their answers and making better use of the data locally, for example, to understand more about the groups that are currently poorly represented in the survey.
- Local authorities were split on the idea of NHS Digital centralising and running the surveys. Those in support of this were keen to standardise the surveys and having them run more consistently and efficiently. This would also free up council staff members from the onerous job of running them, meaning that they could take on other tasks. Though, those against the idea of NHS Digital running the surveys centrally cautioned the need for local intelligence held by councils to inform the running of the surveys as well as a need to promote them locally. There was also a concern from those who use the data to inform safeguarding flags, as well as some reticence around taking resources away from local authorities. There was also some perception that the survey may appear less attractive to complete from the service users' point of view, if it were not 'owned' by the local authority.
- There were concerns over moving the ASCS to a bi-annual survey. The data would become less useful to those who make good use of it, and it is important to capture regular feedback from service users. While from the perspective of local authorities, the continued bi-annual running of the SACE is welcomed, because it would be too resource intensive to run this one annually too, some wider stakeholders noted that data about carers should be collected more regularly.

feedback more often so that local authorities know whether the services they are providing are effective in meeting needs.

8 Other developments in Social Care Statistics

8.1 Context

This research was commissioned to explore the issues of representativeness in the ASCS and SACE, the extent to which the surveys are effective in reaching hard to reach groups, issues surrounding the exclusion of those who lack mental capacity and the potential of innovations methodology to address some of these issues.

In this section we consider other research and developments on the ASCS, SACE and wider social care statistics to ensure that findings and recommendations from this project are prepared with an awareness of this wider context.

8.2 ASCOF Refresh

The Adult Social Care Outcomes Framework (ASCOF) is used locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability. The framework is designed to inform, and support improvements led by local authorities and the social care sector. NHS Digital publishes data on performance against the ASCOF nationally, and for individual councils, annually. Data from the ASCS and SACE feed into ASCOF but are only some of the measures included. The ASCS includes eight measures which feed into the social care-related quality of life score, measures of overall satisfaction and ease of accessing information about support, and measures of the proportion who feel safe and who say social care services have made them feel safe and secure.⁹⁵

In 2019, ADASS (Association of Directors of Adults Social Services) commissioned The Institute of Public Care at Oxford Brookes University to carry out a project (currently ongoing) to review the effectiveness of ASCOF in measuring issues of importance to adult social care leadership. The research has been funded by the DHSC. The aim of the project is to recommend the key components and indicators of a refreshed ASCOF.

That research looks at what should be measured with a particular focus on measuring what people value about adult social care and its impact on their lives in relation to independence and wellbeing and the impact of social care in meeting the objectives of the Care Act 2014, which came in after the ASCOF was implemented. The research also explores the purpose of adult social care support and therefore how outcomes which indicate the success of its aims can be measured. Revisions to ASCOF may have an impact on the ASCOT measures and other questions included in the ASCS survey. Conclusions from the ASCOF refresh which relate to the need to explore the impact of social care on independence may lead to recommendations in relation to the definition of the eligible population in order to be able to

⁹⁵ Cory, G. (2019)

explore the impacts of reablement, equipment and signposting to services which are core elements of a strength-based approach.

Findings from the ASCOF review may influence final recommendations made by this research in relation to the most appropriate mode and approach for capturing information about the desired outcomes, approaches to including short-term users and other groups outside the eligible population and priority given to tackling issues such as how to capture the experiences of those who lack mental capacity.

8.3 Office for Statistics Regulation Report on Adult Social Care Statistics in England

In January 2020, the Office for Statistics Regulation published a review of adult social care statistics which emphasised the importance of good data to support the delivery of adult social care through solving problems, supporting efficiency and maximising outcomes.⁹⁶ It identified under-investment in data and analysis as a result of funding shortages. The review recommended the need for collaboration between government departments, local authorities and between private and public sector to ensure statistics meet user needs, address gaps in what is collected and improve statistics. The review highlights the fact that local authorities only collect data on local authority funded social care, but the lack of other data sources mean this must act as a proxy for the whole social care sector, and also, excludes information on experiences of unpaid care. The review concludes that:

“Now that a much wider service is being delivered, the traditional route of relying on aggregated data collected only by local authorities is not enough and statistical producers must expand and transform their data collections.”

In deciding on appropriate actions resulting from the recommendations of this research on representativeness, DHSC and NHS Digital should consider how the recommendations fit into wider discussions.

8.4 National client level dataset for adult social care

DHSC has been planning to convert the aggregate approach to social care data returns to client level. This would provide a wider and more flexible availability of social care data, make the return simpler, and facilitate the integration of social care and health data. In a letter to Adult Social Care directors in 2019, it stated the intention for this to be in place for 2021-22.⁹⁷

This is relevant to this project, since the provision of client level data to NHS Digital may make centralised data collection more feasible than it is at present where client level data is held locally within each local authority using a variety of systems and approaches.

It is also possible that a national client level dataset could lead to requests for greater consistency in the client level data held which would assist with the administration of the surveys. For example, if information on language needs of users or email addresses were

⁹⁶ Office for Statistics Regulation (2020)

⁹⁷ Office for Statistics Regulation (2020)

routinely collected in a consistent manner this could be valuable in targeting appropriate questionnaires or moving to a cost-effective online approach.

9 Key findings and recommendations

9.1 Defining the eligible populations and creating the samples

The eligible populations for the surveys do not cover all those of interest to local authorities (4.4)⁹⁸

The adult social care support provided by local authorities has evolved with the introduction of the Care Act, funding limitations and the growth of strength-based approaches since the ASCOF was developed and the ASCS and SACE started. Questions are now being raised about the extent to which the eligible population defined for the ASCS which covers those with long-term packages of support from the local authority, fully reflects the populations of interest to local authorities. The carer population for SACE covers only a subgroup of those with unpaid caring responsibilities. Other parallel work has also examined this and has shown the limitation on adult social care statistics from the relatively narrow focus of the two surveys.

Maintaining accurate data about the eligible populations as currently defined is challenging (4.1)

Our research has shown the challenges and resource involved for local authorities in maintaining up-to-date and accurate data of their service user and carer populations. The systems used to hold the data, and information held vary between local authorities. There are particular problems for data on the carer population and some subgroups of the service user population (e.g. mental health service users) because of the role of third parties in providing services. Additionally, the implementation of GDPR has led to concerns about what data can be held and how it can be used. This means that extending the remit of the surveys to include those receiving just advice and support or equipment, or those who are not in contact with the local authority at all (e.g. self-funders) would range from challenging to impossible.

Short-term users can be identified in the ASCS eligible population but there are other challenges to their inclusion in the survey (4.4)

Short-term users are a group of interest to DHSC, NHS Digital and local authorities. This population was initially included in the sample frame but with the move to SALT, and the change in the definition of short-term users since 2014, they are now excluded from the eligible population. Local authorities do have information about this group in their records so that the difficulties with their inclusion lie less with creating a sample frame and more with timing and content of a survey for this group. This is discussed in section 9.10.

⁹⁸ In this chapter, the section numbers where more detail on the key findings can be found are shown next to each heading.

Exclusions from the ASCS and SACE sample frames are not always applied consistently (4.2 and 4.3)

Certain exclusions from each survey's sample frame are permitted under the NHS Digital guidance. These are generally well-understood by local authorities but, given the 151 authorities involved, these are not applied completely consistently, particularly where judgements are required. Finally, they also face challenges in the exclusion of those who lack mental capacity from the ASCS sample frame, which is discussed in section 9.2.

Some groups of interest to local authorities are too few in the eligible population for subgroup analysis (5.6)

Local authority concerns about under-representativeness of ethnic minority groups and mental health service groups in the surveys relate more to the absolute small numbers in the eligible population rather than poor response from these groups. While the issue of under-representativeness may be relevant at a national level, concerns may be different at a local level, meaning greater communication is needed with local authorities about how to assess under-representativeness and why this is important.

Recommendations

- DHSC and NHS Digital to ensure that any recommendations from this research are applied in the light of wider decisions about social care statistics and how feedback can be gathered from groups not currently in the ASCS and SACE eligible populations.
- NHS Digital to work with local authorities to bring greater consistency to the data held on service users and carers for service delivery which would also be of value for survey administration. This will involve input from wider adult social care teams, not just those involved in survey administration. This includes consistency in:
 - fields recorded (e.g. ethnicity, language needs, preference for easy read or standard format materials, mental capacity, email address);
 - the way in which they are held (e.g. whether carers are held as records in their own right);
 - permissions obtained from service users about the use of their personal information under GDPR;
 - data sharing contracts with third parties to permit sharing of data on service users funded by the local authority.
- NHS Digital to ensure that the requirement for client level data flows for the SALT return from 2021-22 aligns with the information needs for the ASCS and SACE so that the data records for SALT, the eligible population and issued sampled are consistent.
- NHS Digital to consider whether client level SALT records could be used to centralise the sample selection and survey administration in future.
- NHS Digital to provide more detailed guidance to local authorities about the exclusions from the sample frame, perhaps with examples, in a supplementary document⁹⁹ or as links from the guidance. The guidance should also be updated to include new categories which local authorities are legitimately excluding such as those who have requested that they are not sent the surveys.

⁹⁹ For SACE an additional document 'SACE eligible population: Further information on definition' provides worked examples for determining the sample as this is so complex. An additional document of this kind could be provided on exclusions.

- NHS Digital to provide additional guidance and examples to local authorities on the definition of carers, and what information should be collected from carers to ensure consistency in the definition across local authorities. This should include guidance on recording the contact details of carers in their own right, not just with reference to a service user.
- NHS Digital to consider alternative ways in which local authorities could make use of and understand experiences of small subgroups in their user population, perhaps through amalgamation of data with a nearby similar local authority or by greater use of over-sampling where this is feasible and would be effective.
- DHSC and NHS Digital to recognise that for some local authorities, the under-representation of certain groups will never be a key concern, while in others there is more that can be done to address under-representation and greater value in doing so. Improved local authority level information about the issue could be used to enable local authorities to take some of the steps which follow to improve representativeness.

9.2 Service users lacking mental capacity

Excluding those lacking mental capacity to consent from the ASCS sample is challenging for local authorities (4.2)

The guidance from NHS Digital requires local authorities to exclude those living in residential care who lack mental capacity from the sample. However, difficulties with engaging care homes and receiving this information, lack of time to carry out the checks, and differences in understanding about how to deal with the fluctuating nature of capacity means this is not applied consistently. As a result, questionnaires are sent out to those lacking mental capacity.

Recommendations

- NHS Digital to help local authorities allow a longer timeframe for the mental capacity checks to allow care homes more time to respond to local authorities, while recognising that the decision should be based on current capacity (as capacity can vary).
- The ASCS guidance should encourage local authorities to engage with care homes face-to-face or by telephone rather than by email and letter which are not always effective with care homes.
- NHS Digital should make it clear that local authorities should not use the survey to assess the performance of individual care homes. The engagement with care homes could include emphasising that the research is not used for this purpose, to reduce concerns by care homes about the impact of their residents taking part in the survey.
- NHS Digital to provide more detail to both local authorities and care homes on assessing mental capacity, and what this means in the context of consent for research, either in written form or in an online or face-to-face training session, with examples and scenarios. There is also potential for families to be involved in assessing capacity, especially if they could be involved in assisting a service user with completing the survey.
- NHS Digital to provide local authorities with standard example questions which could be used with service users to assess capacity.
- NHS Digital and local authorities to consider engaging with umbrella bodies (e.g. Care England) or providers as well as individual care homes to explain what is

involved and the importance of the assessment of mental capacity in the context of the whole survey.

Exclusion of those who lack mental capacity from the ASCS sample, or through inability to respond means the views and experiences of a key group of service users are being missed or captured in inconsistent ways (5.3)

Even where mental capacity checks are being applied correctly, there is an issue for the ASCS since the views of this important group are not captured. Where mental capacity checks are not carried out, and questionnaires are sent, this can result in non-response if someone cannot respond, or completion of the questionnaire on the service user's behalf by a family member or care worker. The survey is designed to be completed by the service user and so completion by others, particularly those involved in delivering care is problematic. On the other hand, if help is needed to take part and that help is not available, the voices of this group are excluded. Proxy versions of ASCOT¹⁰⁰ which forms a core part of the ASCS questionnaire are being developed and could provide an approach which addresses this tension in a consistent and robust way.

Recommendations

- Where possible, local authorities should encourage a qualified advocate to assist people with cognitive impairment to complete the ASCS questionnaire themselves and consider proxies only when the service user could not take part, even with assistance.
- NHS Digital to consider alternative formats and modes which would allow those with mental capacity to consent, but who have insufficient capacity to complete the standard questionnaire, to take part.
- DHSC and NHS Digital to review the developments of the proxy version of ASCOT, and work with PSSRU to integrate it with the ASCS. Pilot this approach for those who could not take part even with adapted versions or support. Include clear guidance on who would be an appropriate proxy.
- NHS Digital to consider how improvements to the records held by local authorities could facilitate the introduction of proxies through better records on mental capacity and alternative contacts.
- If a full proxy version is not possible, NHS Digital to update the cover letter and wording on the questionnaire to make it clearer to carers assisting with completion as to whose views are being collected and how to respond to questions which refer to 'you'. This would also be relevant to those providing help to other groups in completing the questionnaire. The need to avoid care and support workers assisting with the survey completion should be emphasised further.
- NHS Digital and DHSC to liaise with the Social Care Research Ethics Committee (REC) to identify ways in which family members or carers could consent on behalf of a service user through the consultee process in a way which is robust, consistent and fully in line with the Mental Capacity Act 2005.

¹⁰⁰ Adult Social Care Outcomes Toolkit

9.3 Weighting and correcting for under-representation (6.5)

At present, the weighting of the ASCS data takes account of local authority and the four strata used in sampling.¹⁰¹ This means that the weighting does not correct for the disproportionate exclusion of certain groups from the sample frame, or for differential non-response for groups other than those defined by the strata. As a result, the weighting does not correct for under-representation of groups such as those with mental health conditions or certain ethnic minority groups. Nor does it correct for the age patterns in response which do not lie along the two-way age split in the strata.

Recommendations

- Before developing a weighting scheme we would recommend that the way in which local authorities provide information about their eligible population is reviewed by NHS Digital to ensure that all the data needed to understand and correct for under-representation is available including detailed enough age groups, ethnicity, and primary support reason for carers.
- Once this information is routinely available for the eligible population, then a weighting scheme which takes account of the factors affecting likelihood of being issued and response rates could be developed and tested.

9.4 Tools for data collection

The effectiveness and use of the easy read version of the questionnaire could be improved (5.4)

The ASCS currently offers an easy read version of the questionnaire to all those with a learning disability and to those who request it. The relatively high response rate from the learning disability group suggests that this is an effective tool. There is also potential for some of the principles of easy read to be applied to questionnaires for other groups such as those with cognitive decline. The current easy read questionnaire is perceived to be outdated and not suitable for all groups, but there is an updated ASCOT easy read questionnaire which could be adopted.

Recommendations

- DHSC and NHS Digital to liaise with PSSRU at the University of Kent over their work on the updated easy read version of ASCOT and consider how this can be adopted and integrated in the ASCS.
- DHSC and NHS Digital to develop a separate adapted easy read version suitable for those with cognitive decline, which could enable the inclusion of those who have capacity to consent but would struggle with the standard questionnaire.
- NHS Digital to update the guidance to make it clear that the easy read version must be printed in colour or ensure that the easy read version is clear when printed in black and white.
- NHS Digital to liaise with service users and professionals who are experts in autism and Asperger's to identify how format preference could be recorded, and to understand the range of appropriate formats for people with different needs. This

¹⁰¹ 1. Learning disability; 2. Age 18-64 non learning disability; 3. Age 65+ non learning disability in community; 3. Age 65+ non learning disability in residential care

could be followed by work with local authorities on the best procedures for capturing and recording this information.

Translated questionnaires are not well-used on the surveys (5.6)

Although a wide range of translations are offered in the ASCS and SACE through the translation request sheet, uptake is low. While the translations are not suitable for all ethnic minority groups, greater uptake of the translations could assist in improving response from some communities.

Recommendations

- NHS Digital to work with local authorities to ensure that preferred language for communication is recorded as standard by local authorities for service users and carers which would enable targeting of the appropriate language.
- NHS Digital guidance to further emphasise the importance for local authorities of sending the appropriate translated questionnaire with the initial mailing.
- NHS Digital guidance to require that the translation request form is placed upfront in the invitation package so that on opening the mailing it is seen first, so that it is accessible to those who cannot read English.
- DHSC and NHS Digital to review the language questionnaires with service users and carers from the appropriate communities to ensure they are fit for purpose and accessible. Work with community representatives to identify any barriers to completion even when translations are available, and work together on approaches for overcoming them.
- If an online version of the questionnaire is offered, NHS Digital should ensure that translations are built into this and that it is clear in the invitation letter that translated online versions are available.

Face-to-face and telephone versions are offered but not used consistently (6.2)

The NHS Digital guidance suggests that the interview scripts should be used occasionally where there are reasons such as sight impairments, or where language support is needed. Resource constraints mean that use of these approaches is low in most local authorities. However, there are examples where their use is more widespread, for example, through an advocate from another organisation. Where used effectively, this can allow those who cannot complete the surveys otherwise to have their views heard.

Recommendations

- NHS Digital to carry out a systematic pilot of using face-to-face approaches in care homes, in a sample of local authorities to explore the impact on sample profile, the quality of data and the range of responses.
- Since local authority and care home staff could not carry this out independently, DHSC and NHS Digital to explore the range of options available for independent third-party organisations with the advocacy skills to do this, while considering the cost implications and funding options.
- NHS Digital to update the guidance to broaden the circumstances in which face-to-face or telephone approaches can be used but with clearer guidelines on who can carry out these interviews.

9.5 Online surveys

A flexible online approach offers potential for both surveys (6.1)

Although a review of the surveys in 2010¹⁰² concluded that an online approach was not suitable for the ASCS and SACE, use of the internet has increased considerably since then. This means that online approaches should be seriously considered and revisited. Local authorities are open to this because of a perceived potential for cost savings (though this would not necessarily be realised immediately). There is also an appetite for online surveys among service users and carers who use technology. The suitability of an online approach varies for different groups of service users and carers, so any approach needs to be flexible to ensure that groups are not excluded as a result.

Recommendations

- NHS Digital should ensure that the pilot of online approaches carried out on the SACE is future focussed and reflects the ways in which online surveys will be completed in the future (e.g. as a default it must be suitable for mobile completion). The pilot should be carried out in such a way as to allow understanding of the impact on overall response and among particular groups.
- The online versions should take advantage of the flexibility which could address some of the other challenges faced by the survey such as targeting translations, easy read versions and proxy versions.
- NHS Digital should ensure that any developments to the questionnaire resulting from other parallel work such as the ASCOF review are designed to be unimodal and suitable for online, paper, face-to-face or telephone completion.
- NHS Digital should work with local authorities to ensure that any updates to the standard information held by local authorities is designed to facilitate future online surveys or online contact from local authorities. This would include ensuring accurate email addresses are collected where available, contact method preferences are recorded and that GDPR compliant permissions for using different contact methods are recorded.

9.6 Guidance for local authorities

The decentralisation of the surveys presents challenges, but the guidance and support provided by NHS Digital is key to its success (7.5)

The surveys are run by local authorities, sometimes by people who have been doing so for years and sometimes by those who are relatively new to the activity. The guidance from NHS Digital sets out how they should be administered. As there is so much information, sometimes details get missed and NHS Digital keep a record of protocols which have not been followed and could impact on response or data quality. There are areas where additional guidance could be valuable and NHS Digital updates the guidance each year. There is also variation in practice by local authorities, some of which could have a detrimental impact on response, or the data collected and some of which may provide good ideas which could be implemented more widely.

¹⁰² Williams, S. and Betts, P. (2010)

Recommendations

- NHS Digital could make it more explicit in the guidance that the term ‘must’ refers to guidance which has to be followed, and that ‘should’ is advisory. Consider the use of icons or other signals or symbols to highlight those things that must be done.
- NHS Digital to provide explanation and evidence about issues where it is known that local authorities do not follow the guidelines or where survey teams may be under pressure to save money (such as when they do not include a questionnaire with the reminder or do not send out translation request sheets). The guidance should be arranged to allow local authorities to access the key information as well as drill down into topics in more detail as needed. This should be done in consultation with local authorities to ensure that the information is provided in a way which reflects the way it is used. NHS Digital could supplement the written guidance and information with other forms of communication such as webinars on challenging topics which are recorded and available for viewing afterwards.
- NHS Digital could strengthen the means by which local authorities can share experiences and good practice, such as in the example of using advocates to support completion which is more widespread in some local authorities than others. This would need to be carefully moderated to ensure that only good and compliant practice is shared.
- There has been excellent engagement from local authorities in this research with half of local authorities having some input through the online survey. There is, therefore, an interest in this and an appetite to consider the recommendations despite the likely challenges. DHSC and NHS Digital should find ways to communicate the recommendations which involve local authorities at an early stage so that any actions taken by DHSC and NHS Digital as a result are realistic and supported by local authorities. Online workshops could be a useful tool here. The engagement needs to be with directors of adult social care as well as those involved in the running the surveys.

9.7 Means to encourage participation in the surveys and tackle fatigue

The annual nature of the ASCS and the finite population of service users means survey fatigue can be an issue (7.2)

The response to the survey has declined over the years. While this is in line with survey response rates generally, it is also possible that the repeat of the same survey with the same service users has an impact. Although local authorities provided examples of how the findings from the survey had been used to improve service delivery, the standard wording of the cover letter limits opportunities for local authorities to show service users how the results make a difference. There was also variation in the use of standard tools for encouraging response which could be applied more consistently.

Recommendations

- NHS Digital to adapt the survey cover letters to it make clear:
 - which sections are essential and must be included as worded (e.g. to comply with ethical approval and GDPR);
 - which sections could be adapted locally to demonstrate the importance of the survey for that specific local authority, and how the results are used and why it is important to take part (‘you said – we did’ rather than a description of findings);

- that taking part is a positive thing, rather than something which is burdensome (while providing information about what is involved);
 - to thank those who may have taken part in the past (and acknowledge this may not be the first time they are taking part, but that repeated participation is useful);
 - including a link to an online summary of local results.
- NHS Digital to re-arrange the cover letter content so that essential information is on the first page and the second page covers additional information for reference so that those who find reading difficult can access the key information.
 - NHS Digital and DHSC to consider whether rules about the use of white space on the questionnaire could be relaxed to ensure the questionnaire looks less long (while setting guidelines to prevent it becoming too cluttered and small). Look at examples such as the GPPS which offers a short and compact layout.¹⁰³
 - NHS Digital to add a comments box to the questionnaire to enable people to provide any qualitative feedback they may wish to. Make it clear on the invitation that they will be able to do this and that it is their chance to make their voices heard. If this is offered, then provide support and guidelines to local authorities on how to use and analyse this information (particularly in relation to safeguarding flags).
 - DHSC and NHS Digital to review the questionnaire content, and item non-response in consultation with local authorities to identify questions where there is uncertainty about how the findings should be interpreted and carry out cognitive testing to test improvements to the questions on both surveys (e.g. question about feeling safe on ASCS).
 - DHSC and NHS Digital to consider whether any of the survey content could be removed to reduce the length and burden on participants (bearing in mind the recommendations of the ASCOF refresh).
 - NHS Digital to remind local authorities of the benefits of including a questionnaire with the reminder letter and the importance of doing so.
 - NHS Digital and local authorities to learn from and share the experience of local authorities on what works well in practice in terms of encouraging participation such as the best time in the week for questionnaires to be sent.
 - DHSC and NHS Digital could consider the introduction of incentives on the survey to improve response rates overall and potentially reduce under-representation. However, an incentive scheme would need to be thoroughly tested in an experiment to assess impact on overall response rates, representativeness and impacts on data quality.

Community groups and advocates have a potential role to play in the administration of the surveys (4.2, 5.6)

The good response rates from the learning disability population in the ASCS was attributed by some to the role of support groups and advocates in supporting their participation. There are other groups in the ASCS and SACE samples for whom a similar approach could encourage their participation and support their inclusion. This is particularly important where there may be mistrust of local authorities, lack of understanding of the survey's relevance, difficulty accessing written materials, reluctance to engage in activities not endorsed or supported by a particular community or faith groups or a general lack of understanding of the care system. Carers were not always clear that the SACE was relevant to them if they did

¹⁰³ https://www.gp-patient.co.uk/downloads/2019/qandletter/GPPS_2019_Questionnaire_PUBLIC.pdf

not receive services from the local authority. Now use of advocates is only recommended where the service user has an existing relationship. However, in at least one local authority advocates are used more generally than this to facilitate completion.

Recommendations

- NHS Digital to suggest local authorities engage with a range of community, faith and support groups in promoting the surveys, building trust and encouraging them to support engagement among their communities. Groups where this could be particularly valuable include:
 - mental health support groups;
 - community and faith groups for different parts of the ethnic minority community;
 - carers groups;
 - health services such as GP surgeries which may support carers who do not recognise themselves as such.
- NHS Digital to provide local authorities with materials and ideas to assist them in promoting the surveys to the wider community and with certain groups.
- NHS Digital to provide greater guidance to local authorities on how advocates can support service users and carers in completion, potentially beyond the current guidance to use only advocates with established relationships. Guidance could be provided on the following:
 - groups providing advocates;
 - how to direct individuals to an appropriate advocate;
 - highlighting the importance of advocates being independent (of the individual participants but also of local campaign groups);
 - on the potential benefits of ethnic or other matching in advocates to build trust, while recognising this may often not be realistic;
 - on the potential arrangements for the funding of advocates for completing the survey.
- There would also be potential to work with local organisations such as Healthwatch to provide support in completing the surveys. NHS Digital to explore whether this would provide enough independence and the cost implications of this approach.
- NHS Digital to update the SACE invitation letter to carers to make it clear that it is relevant to those who provide help and support, not just those who identify themselves as ‘carers’.
- NHS Digital to engage with and include organisations which work with under-represented groups in the planning of the survey. This could involve inviting key organisations to join the SSUSG and to be involved in any developments on the survey in terms of questionnaire content, invitation materials, survey purpose and how the data could be used. Webinars could be held on the survey results and how to use them. These organisations could also potentially use their local structures to promote and facilitate the survey.

9.8 Frequency and organisation

Views on the appropriate organisation of the surveys are mixed (7.5)

At present the ASCS and SACE are carried out by local authorities using guidance from NHS Digital and a nationally determined approach. This offers the advantages of local control over the sample, the scope to engage with local community groups, and options to

follow-up on safeguarding concerns while the surveys are in the field. However, it can lead to inconsistency and a burden on local authorities in carrying out manual tasks such as data entry which could much more easily be done by scanning the surveys centrally. While the surveys represent a burden to local authorities the financial costs of administering them are provided to local authorities. When asked about whether the surveys should be carried out locally or centrally, views of local authorities were mixed. There was a sense that the task required in running them locally at the current frequency leaves little time for analysis and consideration of what the data mean and what could be done as a result which limits the impacts of the surveys on service delivery.

Views on the appropriate frequency of the surveys are also mixed (7.6)

At present the ASCS is carried out annually and the SACE bi-annually. There are local authorities which express the view that less frequent completion would be advantageous as it would reduce burden and enable better use to be made of the data. However, external stakeholders tend to have a greater desire to maintain annual data collection. Since the surveys feed into ASCOF, there is an advantage to annual data collection and an argument for more frequent data collection from carers.

Several local authorities and service users and carers expressed the view that a more flexible or rolling approach to data collection with more frequent but shorter feedback could be effective, perhaps facilitated by service providers or social workers. This is also relevant when considering the potential for short-term users to provide feedback.

Recommendations

- DHSC and NHS Digital to consider the best timings for the surveys, particularly the ASCS to avoid clashing with CQC inspections and other local surveys which may impact on the engagement with care homes.
- If centralisation or less frequent surveys are introduced, DHSC and NHS Digital should consider how the advantages of local administration can be maintained or enhanced. It is also recommended that community groups and advocates play a greater role in facilitating the participation of under-represented groups. This suggests that administration would benefit from remaining local. However, if administration was centralised, with the correct set up and local tailoring of communications coming from NHS Digital, there may be more resource and scope for local authorities to focus on locally-based activities such as working with care homes and community groups.
- DHSC and NHS Digital to consider the question of central administration and frequency in the light of other recommendations such as the introduction of online surveys. If some or all surveys were online, there is greater scope for local tailoring through local authority specific URLs, meaning that central administration would not necessarily result in the loss of additional locally chosen questions.
- DHSC to recognise the importance of the staffing and costs involved in full analysis and interpretation of the findings of the surveys. If the surveys continue on their current frequency and organised locally, consider the need for additional resource for analysis. If the frequency is reduced or the surveys are centralised, maintain existing resources in the local authority to allow for additional analysis and generating more value from the surveys.

- Even if administration is centralised, local authorities will have a key role to play in updating and quality controlling the sample frame, but developments in the client level dataset from 2021-22 may assist with this. NHS Digital to ensure this development keeps in mind the requirements of the ASCS and SACE so that the advantages of central client level data for administration of the surveys can be realised.
- NHS Digital should update the information requirements from local authorities to ensure that data needed for assessing and understanding under-representativeness is readily available in a form which can inform survey processes.
- NHS Digital to ensure that any centralisation is set up in a way which facilitates real-time or at least weekly feedback to local authorities so they can deal with any safeguarding issues (which would be easier if the mode is online).

Although the surveys are carried out locally greater support could be provided from NHS digital in how to monitor response, and feedback from previous years about which groups are under-represented (5.1)

There was a lack of awareness in many local authorities about which groups are under-represented and why. Local authorities tend to be focussed on achieving set numbers of responses to meet margin of error requirements rather than on high response rates and avoiding sample bias. Where local authorities were aware of well- or under-represented groups, this tended to be a result of anecdotal observation rather than a systematic analysis of response rates. A greater understanding of this issue nationally and within their individual authority could assist local authorities in taking steps to tackle bias and identify groups which would be suitable for over-sampling.

Recommendations

- Using data from previous years, provide local authorities with evidence about under-representation nationally and locally in a way where it can be used to address this locally. NHS Digital could publish key indicators at local authority level showing response rates for key groups known to be under-represented.
- This could be supplemented with practical suggestions from NHS Digital provided alongside evidence on under-representation of ethnic groups. This could include suggestions on over-sampling and how to improve response through engagement with local groups. Where local authorities have been successful in achieving a good response among particular groups, local authorities to provide case studies on how this was achieved to enable sharing of good practice.
- NHS Digital to use the guidance document to link evidence on under-representation with reminders of the importance of following new and existing guidance to tackle these issues (e.g. importance of including translation request sheet as the top item in the mailing).
- It would be valuable for DHSC and NHS Digital to review the current processes and protocols in the light of the GDPR legislation to overcome difficulties presented by sharing data between organisations. This is relevant for under-representation since some groups of service users and carers are affected by this issue more than others (e.g. those with mental health needs).

9.9 Other approaches to feedback

Large scale standard surveys offer advantages for benchmarking and comparison over time but can be blunt instruments (7.1)

Local authorities and stakeholders value the way in which data from the ASCS and SACE enables them to compare themselves with other local authorities and the national picture and assess their performance over time. This means there is an important role for a standard survey using ASCOT and other measures.

The ability of local authorities to make use of the findings is sometimes limited by lack of detail and uncertainty over what the responses to the questions mean and how they relate to user experience of the services provided. Local authorities value the open responses provided in the white space in the questionnaires as well as smaller scale follow-up exercises they carried out themselves.

There are groups who are excluded from the surveys altogether or whose numbers in the eligible populations are too small for surveys' results to be meaningful (5.6)

There is an appetite among local authorities to supplement the surveys with additional qualitative approaches to data collection for certain subgroups. An important reason for carrying out the surveys was to give service users and carers a voice, and there was a recognition that the current approach means some are excluded from having their voice heard. At the same time, there are resource constraints on local authorities which mean the scale of this would be limited and it could not become a requirement.

Recommendations

- DHSC and NHS Digital should ensure that when any changes are made to the survey design and questionnaire content as a result of these reviews, the issue of continuity and benchmarking over time is considered. If a change is needed, look at ways it can be implemented with a transition year so that there is continuity with past and future data collection.
- DHSC and NHS Digital to develop some qualitative research tools to enable local authorities to explore findings from the surveys in more depth and to understand the experiences of groups with numbers which are too small for quantitative analysis in the local authority. Qualitative approaches could also be used for local authorities to hear from groups whose voice is not heard effectively because they are unable to take part in the survey (e.g. those with limited mental capacity) but may be able to take part using a more flexible approach, drawing on ASCOT tools developed for this purpose. The tools would include invitation materials, topic guides and stimulus materials and analysis tools which have been approved by the Social Care REC as part of the approval for the ASCS and SACE to ensure quality and consistency and to minimise burden on local authorities. There could be several versions targeted at obtaining feedback from groups for different purposes.

9.10 Short-term users

Local authorities are keen to hear the views of short-term users of social care services (4.4, 9.1)

It is not practical to integrate short-term users into the current surveys, but feedback from this group is important to local authorities. In some cases, local authorities already collect information from short-term service users as part of their service delivery process at the end of the package or through their own standalone survey, sometimes using ASCOT measures. However, the issue with this local approach is a lack of consistency and benchmarking across local authorities.

Recommendations

DHSC and NHS Digital to revisit NatCen's short-term user ASCS questionnaire and cognitive testing report (NatCen Social Research, 2017)¹⁰⁴ and use this as a starting point for a short-term user questionnaire, addressing the points raised by their findings and engaging with local authorities on the questions they already ask short-term service users to ensure they are also covered. To ensure compliance and good response, the short-term user questionnaire should be kept as short as possible to maximise the chance that local authorities would be willing to replace their own local approaches with a national survey.

- DHSC and NHS Digital to work with local authorities to develop a sampling protocol which generates a large enough sample in each local authority, which can be administered on a rolling basis, while allowing for issues such as repeated episodes of short-term care and transition into long-term care.
- Given the demands on local authorities, we recommend that an approach which works with, rather than against the approaches currently used in local authorities would be most effective.

9.11 Summary

This research was intended to be focussed on the issues of representativeness of the ASCS and SACE. The reviews of the methods and literature, and the discussions with local authorities and other stakeholders have uncovered a wide range of related issues which have resulted in a series of recommendations.

It is hoped that the organisation of recommendations in the previous sections will assist readers in identifying those which are relevant to them or address particular issues. However, it is worth highlighting some general points about these recommendations:

- In making decisions about next steps, the recommendations need to be considered as a whole, and in the light of recommendations from other recent reviews. Under-representativeness is just one of many issues facing these surveys and adult social care statistics in general. Decisions on one aspect will affect the appropriate action as a result of other recommendations. Decisions about which outcomes should be measured and how will affect how the recommendations of this research should be implemented. Decisions about the extent to which the surveys could be moved online will affect the decisions about centralising of the surveys.

¹⁰⁴ Pilley et al (2017)

- While there are recommendations which directly address the issue of under-representativeness (for example, encouraging the support of community groups in reaching under-represented subgroups), some may have both positive and negative impacts on representativeness. For example, moving the surveys online might improve representation among some groups but reduce it for others. Any changes to the surveys' methodology therefore need to be fully tested, considering a wide range of issues including representativeness.
- There is enormous commitment to these surveys, and to adult social care statistics generally, among local authorities and any changes resulting from these recommendations should be developed in partnership.
- There are no quick fixes, but a variety of tools and approaches can be used to improve representativeness while having wider benefits for data quality and the value of the surveys to local authorities.

Bibliography

Aznar, C., Blake, M., Mackie, M., Morris, L., Rehsi, A. (2020) Review of Survey Methodology for ASCS and SACE. Ipsos MORI.

Aznar, C., Blake, M., Juliette, C., Rehsi, A. (2020) Literature Review related to the review of ASCS and SACE. Ipsos MORI.

Adult Social Care Outcomes Toolkit (ASCOT) developed by the Personal Social Services Research Unit (PSSRU). <https://www.pssru.ac.uk/ascot/> [accessed 22/4/20]

Beadle-Brown, J., Ryan S, Windle, K., Holder, J., Turnpenny, A., Smith, N., Richardson, L. and Whelton, B. (2012). "Engagement of people with long-term conditions in health and social care: barriers and facilitators to capturing the views of seldom-heard populations." QORU.

Blake, M., Bowes, A., Gill, V., Husain, F. and Mir, G. (2017), A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users. *Health Soc Care Community*, 25: 1090–1099.

Bridges, S., Hussey, D., Blake, M. (2015) The dynamics of ageing: The 2012 English Longitudinal Study of Ageing (Wave 6) Technical Report. (NatCen Social Research) https://www.ucl.ac.uk/drupal/site_iehc/sites/iehc/files/5050_elsa_w6_technical_report_v1.pdf

Brooks, J., Savitch, N., Gridley, K. (2016) Removing the 'gag': involving people with dementia in research as advisers and participants. *Social Research Practice: Volume 3*. Social Research Association.

Burton, J. and Jackle, A. (2020) Mode Effects Understanding Society Working Paper Series No. 2020 – 05

Caiels, J. and Rand, S., Crowther, T., Collins, G., and Forder, J.E. (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).

Cory, G. (2019) How can data improve the social-care system in the UK? Better Evidence for Better Care for Doteveryone.

Dillman, D.A. (2017) 'The promise and challenge of pushing respondents to the Web in mixed-mode surveys' *Survey Methodology*, June 2017. Vol 43, No 1: 3-30.

Duncan, B.L. and Miller, S.D. (2000) The client's theory of change: Consulting the client in the integrative process. *Journal of Psychotherapy Integration*, 10(2), 169–187. [accessed 24/4/20]

Flanaghan, S.M. and Hancock, B. (2010) 'Reaching the hard to reach' - lessons learned from the VCS (voluntary and community Sector). A qualitative study. [BMC Health Serv Res](https://doi.org/10.1186/1471-2288-10-92). 2010; 10: 92

Fox, D., Holder, J., Netten, A., (2010) Personal Social Services Survey of Adult Carers in England – 2009-10: Survey Development Project. PSSRU Discussion Paper 2643

Gill, V., Husain, F., Vowden, K., Aznar, C. and Blake, M. (2014) Satisfaction with social care services among Black and Minority Ethnic populations. Exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people. NatCen Social Research

Gray, M., Lepps, H., Blake, M. (2014) Exploring Satisfaction with social care services among Pakistani, Bangladeshi and white British populations: Findings from cognitive interviews. <http://natcen.ac.uk/media/563051/BME-social-care-satisfaction-cognitive-report-2014.pdf> [accessed 25/1/19]

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.

Heath, C., Malley, J., Razik, K., Jones, K., Forder, J., Fox, D., Caiels, J., and Beecham, J., *How can MAX help local authorities to use social care data to inform local policy? Maximising the value of survey data in adult social care [MAX] project [Executive Summary]*. Working paper. Personal Social Services Research Unit, Kent, UK (KAR id: [58852](#))

Ipsos MORI (2020) NHS Adult Inpatient Survey: Findings from the mixed-mode methodology pilot. <https://nhssurveys.org/wp-content/surveys/06-development-work/06-engagement-work/2020/Adult%20Inpatient%202019%20Mixed-mode%20pilot%20results.pdf> [accessed 30/9/20]

Ipsos MORI (2020) GP Patient Survey 2020 Technical Annex. https://www.gp-patient.co.uk/downloads/2020/GPPS_2020_Technical_Annex_PUBLIC.pdf Liljas, A.E.M., Walters, K. Jovicic, A., Iliffe, S., Manthorpe, J., Goodman, C., Kharicha, K. (2019) 'Engaging hard to reach groups in health promotion: the views of older people and professionals from a qualitative study in England' BMC Public Health 2019; 19: 629

NHS Digital. (n.d.). *Adult Social Care Outcomes Framework*. Retrieved from <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/upcoming> [accessed 21/4/20]

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 [accessed 23/4/20]

NHS Digital (2018) SACE Eligible Population: Further information on definition.

NHS Digital (2019) ASCS 2018-19 Annex tables.

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

NHS Digital (2019) 'Personal Social Services Adult Social Care Survey, England – Information and guidance for the 2018-19 survey year, published Sept 2019.

Malley, J. '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.

Malley, J. and Smith, N. (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-Centered Care Research Unit.

Malley, J., Fernández, J-L (2012) Patterns and effects of nonresponse in the English adult social care survey. Full report, QORU working paper 2841, Canterbury / London <https://www.qoru.ac.uk/about/research/engagement/non-response-and-under-representation-in-the-adult-social-care-survey-2/>

Malley, J., Fernández, J-L., Smith, N., Netten, A., Sato, A., (2014) Non-response and under-representation in the Adult Social Care Survey. QORU working paper, London, <https://www.qoru.ac.uk/about/research/engagement/non-response-and-under-representation-in-the-adult-social-care-survey-2/>

Mansell, J., and Beadle-Brown J. (2012) Active Support Enabling and Empowering People with Intellectual Disabilities. London: Jessica Kingsley

Ofcom (2020) Online Nation: 2020 Summary Report. https://www.ofcom.org.uk/_data/assets/pdf_file/0028/196408/online-nation-2020-summary.pdf [accessed 30/9/20]

Office for National Statistics (2020) Internet access – households and individuals, Great Britain: 2020. <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2020> [accessed 30/9/20]

Office for Statistics Regulation (2020) Adult Social Care Statistics in England.

Pilley, S., Comanaru, R., Fenton, C., Maun, E. and d'Ardenne, J. (2017) 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.

Smith, N. and Towers, A-M. (2015) Using ASCOT with older adults living with dementia. QORU presentation

Stedman, R.C., Connelly, N.A., Heberlein, T.A., Decker, D.J., & Allred, S.B. (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.

Towers, A-M, Nelson, K., Smith, N and Razik, K. (2019) "Using ASCOT in care planning conversations. *Australian Journal of Dementia Care.*" *Australian Journal of Dementia Care*, 7 (6). pp. 31-35.

Williams, S. and Betts, P. (2010), 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.

Annex A: Methodology for this research project

Advisory group

At the beginning of the project an advisory group was formed to shape the design, progress and recommendations from the research. The group includes:

- Staff from DHSC, NHS Digital, Office for National Statistics,
- Local authority staff involved with experience of administering the survey, which also included some with wider national experience of working with NHS Digital or academic teams,
- Academics with specialist experience of the adult social care surveys,
- A service user,
- Two carers.

The group met four times during the project:

- At the start to review the research objectives and approach (face-to-face),
- To comment on the initial findings from the methodology review and basic secondary analysis and the design of the materials for the primary research (face-to-face),
- Once the primary research with local authorities and stakeholders was complete to present findings and seek advice on the timing of and approach to carer and user interviews in the light of the COVID-19 pandemic (meeting held on Teams).
- Once the primary research and secondary analysis were complete and a draft report sent to DHSC. The project findings were presented to the group, and members were also given a chance to reflect on our dissemination plans.

After the second meeting a separate meeting was held with the service user and two carers to get their input on the materials for service users and carers with a particular focus on appropriate recruitment and the topics in the interview. The service user was not able to attend the third meeting (online) so instead, two separate telephone calls were held between the service user and the project director.

The advisory group, including the service users and carers, offered advice and input which influenced how the project was carried out. This included:

- Advice on the timing of fieldwork with service users and carers. Initially it was advised we should carry this out in March after they or the person they cared for had taken part in the 2020 ASCS. When this became impossible because of COVID-19, they advised on a delay.
- Advised on the need to apply to the NHS Digital DARS (Data Access Request Service) for more detailed data than is publicly available.
- Recommended literature to include in the methodology and literature reviews.
- Advised on questions to include in primary research.
- Highlighted the concerns service users and carers might need addressed before being willing to take part in the research.

We had originally wished to involve four lay advisors (two service users and two carers) but we were unable to recruit a second service user. We used our networks, drew on the experience and networks of Jill Manthorpe and also advertised on the Shaping Our Lives website. We had wished to include lay representatives from the SSUSG but it emerged that this group no longer includes lay representatives. Our experience highlighted the difficulty of identifying service users and carers able and willing to take part in these activities. Although we had one fewer advisor than we wished for, the three who we involved were highly engaged and made valuable contributions to the research.

Ethical approval

The research received ethical approval from the Social Care Research Ethics Committee (SCREC) in November 2019. This primarily focussed on the primary research involving contact with participants. Subsequently, details were sent to them to confirm our application for secondary data through the NHS Digital Data Access Request Service (DARS) application and confirmation was received that the ethical approval covered these activities. Approval was also sought to recommence primary research with service users and carers using telephone interviews, once the initial period of COVID-19 related lockdown ended.

Literature and methodology review

The initial stage in the research was a review of the methodological documentation for the ASCS and SACE to gain an understanding of how they are carried out and how the guidance and approach may impact on the representativeness of the surveys. A methodology review report was prepared containing the detailed findings. In this main report, only elements of the methodology which are key to addressing the research questions have been covered. The methodological review was used to inform the design of materials and content of the primary research.

A literature review of relevant previous research on engaging with groups which tend to be regarded as hard to reach as well as innovations in survey methodology relevant to the aims of this project was carried out to inform later stages of the research and the resulting recommendations.

Primary research

The following research activities were carried out during (December 2019 - July 2020):

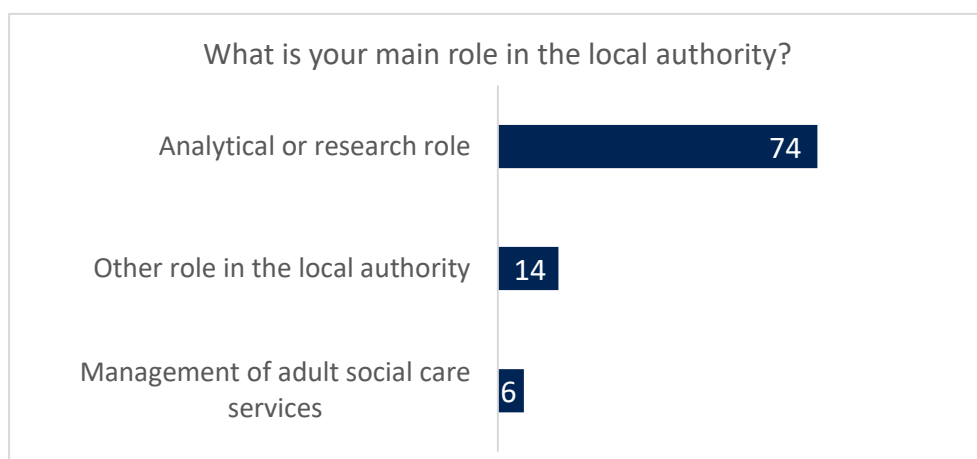
- A quantitative online survey which was sent to every local authority in England, conducted in December 2019 to January 2020;
- In-depth interviews with the online survey participants to explore their answers in more detail, conducted between January and March 2020;
- In-depth interviews with a range of stakeholders around the representativeness of the surveys and the suitability of the survey methodology, conducted between January and February 2020;
- In-depth interviews with service users and carers to explore their experiences receiving the ASCS or SACE, conducted in July 2020.

Online survey of local authorities

Ipsos MORI sent invitations to the Adult Social Care Director in every local authority in England to participate in the online survey. Additionally, NHS Digital sent invitations to their Adult Social Care Survey contact in every local authority. Invitations were sent out on 2nd December 2019 and the survey closed on 30th January 2020. One hundred and fifty-three local authorities were invited to take part, including two which do not administer the ASCS and SACE because of their small populations.

- We received valid responses from 94 people,¹⁰⁵ with 80 people completing the whole survey. Seventy-four of those who responded held an analytical role in their local authority.

Figure A.1 Role in local authority of survey participants



Base: 94 responses to the online survey

- Not all participants indicated which local authority they were from, but we had one or more responses from at least 73 different local authorities.
- Among those local authorities at least four local authorities in each region responded to the survey and the achieved sample included London Boroughs, County Councils and Unitary and Combined authorities.
- Responses were received from 9 individuals for whom local authority was unknown.
- We received two responses from 12 local authorities.

In this report, the results are based on the individuals responding to the survey. The maximum base size is 94 and it should be understood that these represent individuals, not local authorities. Despite the small sample size, we have chosen to present percentages rather than numbers as these are easier to interpret.

¹⁰⁵ Some duplicate responses were received and these were removed.

The data are unweighted. Although findings were analysed by subgroups such as type of local authority or views on how worthwhile the surveys are, small sample numbers mean it is only possible to present overall findings for all those responding to the survey. Although the sample covered all regions and types of authority and a range of experiences in relation to the ASCS and SACE, results should be regarded as indicative rather than representative of the views of all local authorities.

Interviews with local authorities

In-depth telephone interviews were conducted with 14 local authority staff, responsible for running the ASCS and SACE. These participants were selected from among those who responded to the online survey and agreed to a follow up interview. In the survey, 34 participants agreed to be followed up. From these a sub-sample were selected to reflect a range of different types of local authority in terms of:

- Ethnic diversity of the population,
- Region,
- Type of local authority (county council, London borough, unitary authority),
- Mix of urban and rural populations,
- Responses to the online survey indicating particular experiences, challenges, solutions or interesting viewpoints worth following up in an interview.

Interviews were carried out between 11th February and 27th March 2020. Each interview lasted 45 to 75 minutes and was audio-recorded with the permission of the participant.

The interviews explored their experiences of carrying out the ASCS and SACE and how they are done in practice, views on areas for improvement, knowledge and experience of the research questions such as under-representation of certain groups, and how to include short-term users in the research.

Findings were analysed by entering the transcribed data on a framework and conducting thematic analysis between cases and across topics within each case.

Interviews with stakeholders

We also conducted 14 in-depth interviews with a range of stakeholders around the representativeness of the surveys and the suitability of the survey methodology. The composition of stakeholders represented:

- Central or local government bodies or regulators,
- Voluntary/non-governmental organisations and unions,
- Think tanks/research institutes,
- Umbrella bodies,
- Academics with relevant specialisms.

We also spoke to one care home manager, though our original plan included talking to at least three care home managers.

Participants were identified based on their interest in improvements to the surveys, with expertise in seeking feedback from adult social care service users or carers, or which represent the views and interests of service users and carers.

These interviews were carried out between 20th January and 23rd April 2020. Each interview lasted 45 to 75 minutes and was audio-recorded with the permission of the participant.

The content of the interviews varied according to the experience of the participant. Interviews covered the use of the survey data, ASCOF and wider developments in social care statistics, challenges in including hard to reach groups in research and developments and innovations in approaches which could be used on the ASCS and SACE.

Findings were analysed by entering the transcribed data on a framework and conducting thematic analysis between cases and across topics within each case.

Interviews with service users and carers

At the end of the interview, local authority participants were asked about their willingness to be contacted to assist with recruiting for follow-up interviews with service users and carers. We received a positive response to this with at least seven agreeing to this. However, shortly after we contacted our selected three local authorities, the COVID-19 pandemic took hold in England. Two local authorities did not respond to our request and one contacted us explaining she needed to investigate it further. A decision was made at this point that it was not ethical or appropriate to pursue recruitment of service users and carers through local authorities at this time.

Due to COVID-19, fieldwork with service users and carers was carried out remotely rather than face-to-face. Fieldwork was delayed from March to June and was carried out after the NIHR announced that research could continue.

We conducted ten in-depth telephone interviews: six with service users and four with carers who recruited through a recruitment agency.

Recruitment

We set quotas for different types of participant and this was used by the agency in arranging the interviews through the use of screener documents. This ensured the recruitment agency selected service users and carers matching the specified sampling criteria

Once a participant agreed to take part, a number of documents were emailed or mailed to them, based on their preference, including:

- A copy of our privacy notice,
- A consent form,
- A participant information sheet,
- A copy of the relevant survey questionnaire (ASCS's questionnaire for service users and SACE's questionnaire for carers),
- A copy of the relevant invitation letter

Participants were asked to review all these documents prior to the interviews. Consent was sought again by the researcher on the day of the interview.

Fieldwork

Interviews lasted between 45 minutes and an hour and were carried out between 6th July 2020 and 24th July 2020. A thank you payment of £35 per participant was offered to each carer or user who took part. This payment was given as a thank you in recognition of the effort involved in taking part in such an interview.

Interviews with service users covered the type of care and support received, experiences of completing the Adult Social Care Survey, and barriers and facilitators to participation in the survey and in research more generally.

Interviews with carers covered the type and level care and support provided, experiences of completing the Survey of Adults Carers in England or the Adult Social Care Survey, and barriers and facilitators to participation in the surveys and in research more generally.

Participants' characteristics

We recruited service users who:

- Lived in their own home (rented or owned), and
- Required or used to require help or support because of a disability, health or memory problem and receive care and support services paid for or arranged by their local authority.

We spoke to service users with a mix of ethnicities and ages. Four service users had physical health illnesses or disabilities and two users had mental health or memory illnesses.

We recruited a mix of short-term and long-term service users. Those who lived in care homes were in the original sample design but owing to pressures on care homes in 2020 and the difficulty of carrying out telephone interviews with this group, it was agreed that they would be excluded from the sample.

We also recruited carers who provided care to a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness. Carers were a mix of ages and cared for users of different ages.

Within each group, we ensured to recruit a mix of age, ethnicity, gender and local authority.

Findings from the qualitative interviews have been included in the relevant section, integrated with findings from elements of the research.

The tables below show the characteristics of those who took part.

Table A.1 Characteristics of service users taking part in the in-depth interviews

Service users			
Gender	Ethnicity	Age	Support need
F	White British	62	Mental health
M	White British	67	Physical health
F	Mixed	44	Physical health
M	White British	45	Physical health, Mental health, Memory or cognition
M	White British	46	Physical health
F	Indian	69	Physical health

Table A.3 Characteristics of carers taking part in the in-depth interviews

Carers			
Gender	Ethnicity	Age	Support need of person cared for
M	White British	55	Physical health, Learning disability
F	White British	49	Physical health
F	Pakistani	35	Physical health, Mental health
M	Pakistani	36	Physical health

Reporting the findings

It is important to note that we have deliberately not used gender neutral language as the purpose of the review was to explore whether certain groups were under-represented, and gender was considered in this. As such, it was important to distinguish between male and female participants in our analysis.

Secondary analysis

Initial analysis was carried out using publicly available data from the ASCS and SACE to explore the issues of representativeness. However, there was insufficient detail about age, ethnicity and support reason to fully address the research questions. Therefore, an

application was made to the NHS Digital Data Access Request Service (DARS) in March 2020, once the data from the ASCS and SACE were onboarded to the service. Summary data about the eligible populations for the surveys was obtained for ASCS and SACE. For ASCS, this included care setting, primary support reason, age sex and local authority. For SACE, this included age, gender and local authority. Case level information was obtained for all those issued to the survey samples from 2014-15 onwards. The format of the data changed between 2014-15 and 2015-16 so only the data from 2015-16 onwards was analysed. For the ASCS data from 2015-16, 2016-17, 2017-18, 2018-19 was included in the analysis. For SACE data from 2016-17 and 2018-19 was included in the analysis.

Analysis was carried out to look at the proportion of the eligible population issued to the sample in individual subgroups and combinations of subgroups. This analysis was constrained by the need to keep analysis within sampling strata for ASCS and by the available variables and breaks for both surveys. For example, on the ASCS, age data on the eligible population is only available in two age groups. Analysis was then carried out to explore differing response rates between groups and combinations of groups. For this analysis more detailed information such as age in multiple categories or ethnicity was available. This analysis also included a split by local authority (for limited variables where numbers allow).

Once the bivariate analysis was completed, linear regression models were run to look at the factors determining under-representation at the issued sample and response stages once controlling for multiple factors.

Finally, weights were created for both surveys to correct for under-representation using variables available in both the responding sample and the eligible population. This was limited by the information available for the eligible population for each survey. These weights were used to compare weighted and unweighted analysis of key measures for each survey to look at the impact of under-representation on overall survey estimates.

The analysis outputs include several different age breaks:

- 18-64/65+ is used when this is the most detailed information available for the eligible population on ASCS,
- On SACE, the eligible population data includes age in eight categories, mainly ten-year bands but with 18-24 as youngest and 85+ as the eldest,
- For detailed analysis of age for response analysis on both surveys, age in nine categories which are mainly ten-year bands with 18-24 as youngest and 95+ as the eldest was used to allow greater understanding of patterns among the oldest old,
- For analysis of age by other characteristics, three age bands were used (18-44, 45-64, 65+) since this reflected the age patterns identified from the more detailed age analysis and allows patterns which are hidden by the two-band age split to be explored.

In reporting on the secondary analysis we were reliant on the categories available from the data. This included male and female but not others. It included the ethnic group categories which are recorded in the data.

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