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ASCS & SACE Discovery Report

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Summary

A discovery project was commissioned by DHSC to look at options for revising the Adult Social Care Survey (ASCS) and Personal Social Services Survey of Adult Carers in England (SACE), so that they are representative of the social care population (as defined in the Care Act 2014), and meaningfully reflect the experiences and outcomes of people who use care and support services and carers.

Content of the surveys

ASCS and SACE have two main purposes, which are to provide intelligence about the state of the social care provision and to provide data for the Adult Social Care Outcomes Framework (ASCOF). ASCOF is a set of social care outcome indicators designed to capture the social care system's performance nationally, as well as to guide and influence decision-making by local authorities in strategic planning, oversight and commissioning. The consistency of the surveys and the scope for benchmarking are particularly valued. The future of both the ASCS and SACE are, therefore, closely linked to the future of ASCOF. ASCOF is being reviewed in light of various feedback and as a result of reforms in ASC, including the introduction of the Care Act and CQC's new duty to assess local authorities' delivery of their ASC duties. Stakeholders felt that the surveys should align with and contribute to any new or adapted frameworks so that the surveys are measuring what matters in the current policy context, and are future focussed.

Among stakeholders, there was agreement that the content of the surveys should primarily be **driven by DHSC and LA needs but should also reflect lived experience**, being **co-designed or co-produced to ensure it reflects the experience and aspirations of those with care and support needs**. Agreeing the purposes of the surveys, and how they align with other sources of information, such as real-time feedback, is an essential first step prior to making decisions about how to redesign the surveys. Providing sufficient resource and access to enable the findings to be fully used is also important.

The Adult Social Care Outcomes Toolkit (ASCOT),[1] which is a measure of social care-related quality of life (SCRQoL) for adults who use social care services, is included in the ASCS, with an equivalent measure for carers in the SACE (Carer SCRQoL),[2] to contribute key measures to the ASCOF. In addition to the ASCOT and Carer SCRQoL, the ASCS and SACE include questions which are not part of ASCOT but which feed into ASCOF, as well as some general contextual questions which are needed to interpret what is contributing to service users' and carers' quality of life scores.

Among stakeholders, there was a consensus that the surveys are and should be used for measuring **outcomes** and **experience** rather than processes. Outcomes and experience were seen as distinct but equally important. **Outcomes** were seen as important because LAs have a responsibility to support and enable the whole person, not just deliver care, and this is related closely to views on the purpose of ASC. **Experience** was felt to be important because for people receiving care that is what matters most to them; they may find it hard to see beyond their current experience. Stakeholders also thought that the surveys should align with the Care Act, but expressed mixed views as to whether they do already.

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[1] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[2] Fox et al (2010) Personal Social Services Survey of Adult Carers in England – 2009-10: Survey Development Project. Technical Report.

Despite consistency in the aspiration to collect both experience and outcomes information there were **challenges and limitations** expressed. These related to the **balance between the need for consistency and asking about individual experiences and outcome preferences**. The population eligible for the ASCS varies hugely in terms of age, type of care needs, care received and ways of accessing social care, and this is likely to impact on their experience and the outcomes they value.

Any alternative survey questions implemented on the ASCS and SACE would need to be subject to rigorous testing to ensure they are measuring what is intended and are valid, robust and reliable measures. Significant developments such as these would require sufficient time and substantial funding. Research Practice Partnerships between LAs, providers and academics could provide a good approach to agree smaller changes to the questionnaires. Some stakeholders commented that the questionnaires were already long and burdensome and they thought that this led to respondent fatigue, so changes made to them should avoid increasing the length of their core content.

Representativeness

The **ASCS focuses on long-term users of adult care and support provided or funded by a local authority**. People who lack mental capacity to take part in the ASCS are removed from the sample before it is issued. The eligible population for **SACE is all carers aged 18 or over, caring for someone aged 18 or over in contact with their local authority in the previous 12 months**, directly or through a third party.

An important consideration is **whether the population eligible for the surveys should be extended to include groups not currently covered, in particular self-funders** (so it is aligned with the Care Act) and people **in receipt of short-term care**. There was agreement among stakeholders that that these two groups would be worth including, but a number of concerns were raised. These related to:

- Sourcing contact details of self-funders prior to the implementation of charging reforms. Digital social care records are being developed and will be maintained by registered care providers, and potentially used to support reporting of data from care providers to other bodies. However personal details would not be routinely shared outside organisations so there are legal and technical dependencies which would need to be resolved in order to enable this solution.
- The resource implications for LAs already struggling to administer the survey with the existing sample sizes, in terms of costs and administrative burden.
- The existing ASCS questionnaire not being appropriate for people in receipt of short-term care.

One approach would be to improve the surveys initially just for existing groups prior to expanding coverage once self-funders are in touch with local authorities in larger numbers for metering and client level datasets. There is the potential for digital social care records to be shared, and these could be used in a secure and regulated way to identify and then invite people to provide feedback via surveys. In the meantime engagement work with those developing client level data and national minimum datasets based on the digital social care records from regulated providers could be carried out to identify the content, format and permissions needed to facilitate potential future use of these resources for seeking feedback from those who use care services and carers.

Accessibility

Previous research has shown that differences in response rates between groups affect the representativeness of the ASCS and SACE. Improving the accessibility of the survey for particular groups, and improving engagement and motivation to take part, could **help improve participation, and the representativeness of the surveys more generally**. This could include better promotion of the translated questionnaires, a review of the cover letter and of the reminder strategy, and engagement with gatekeepers and with grass roots organisations representing people with care and support needs and carers. Extending the offer of face-to-face and/or telephone completion for people unable to use self-completion who would be otherwise excluded could also be considered. Finally, the revised and tested Easy Read version of ASCOT and the other questions on the main ASCS are ready to be adopted and address some of the issues raised with the current Easy Read version.

Ways of **capturing the views of people who lack capacity to complete a standard questionnaire** could also be further considered. In particular, the collection of **proxy responses** about people who lack capacity and whose experience would otherwise not be included in the ASCS is an option which has not been implemented on the main survey, but which has already been tested in terms of acceptability and feasibility, and developed (for ASCOT questions only). Stakeholders considered that proxy responses were acceptable when the other measures to enable participation were not successful, and described proxy responses as better than having no responses at all from people lacking capacity to consent for taking part. Additional steps required before ASCOT-Proxy can be implemented include seeking ethical approval under the Mental Capacity Act, adapting the cover letter and other ASCS questions to make them suitable for proxies, and establishing a method for identifying whether a proxy is needed and for identifying a suitable proxy.

Survey delivery organisation

The ASCS and SACE are **currently locally administered by LAs** with implications for efficiency and burden on LAs. An **alternative delivery model would be to administer the surveys centrally** with LAs providing samples to the organisation appointed by DHSC or NHS Digital. Overall, most stakeholders thought that a central delivery model would be preferable, because this would reduce the administrative burden on local authorities and provide more consistency. However, the importance of providing LA level findings, LA level data and outputs was emphasised. In addition, a central delivery model would not allow LAs to add their own questions at the end of the paper questionnaires and this led some stakeholders to ask if LAs could be given the choice between a central and a local delivery model. Finally, if a central delivery model is chosen some important information governance issues will need to be addressed so that LAs can share samples with the organisation appointed to conduct the surveys on their and DHSC's behalf. In the future, centralised client level data (anonymised) could be used to identify appropriate samples across LAs as a whole, but the contact details themselves would need to come directly from LAs to a secure location specifically for the purpose of the survey mailout, after further sample cleaning.

Survey delivery mode

ASCS and SACE are conducted using a **paper self-completion** approach and over the last few years many large-scale paper self-completion surveys have moved to mixed methods (online and paper), using a push-to-web approach. The decision to move the ASCS and SACE to a push-to-web approach will need to bear in mind the readiness of the survey populations (e.g. digital exclusion), the potential impact on response rate and representativeness, and the suitability of the survey for online self-completion.

There was an appetite for push-to-web among stakeholders, at least for SACE, providing paper remains an option. LAs, in particular, strongly supported the addition of an online mode, hoping this would reduce the administrative burden involved in conducting the surveys as well as the direct costs of printing and postage. At the time of the fieldwork, NHSD was running a pilot for SACE with ten LAs and the findings from those about the optimal approach for response and representativeness should inform how any online approach is rolled out. Any push-to-web questionnaire should be device agnostic so it can be completed on smartphones. The findings of the SACE online pilot should inform plans for the ASCS going forward. The previous mixed mode pilot on the ASCS led with paper and was not successful. We recommend that any future online option should be push-to-web to get the full financial benefits from going online and encourage online responses, and that this is piloted.

Online options also offer the potential for LA specific questions on a centrally run survey, as well as optional questions specific to respondents' circumstances and preferences.

Survey delivery frequency and timings

The **ASCS currently runs annually while the SACE runs every two years**. Stakeholders asked for parity between the surveys, arguing that both groups are equally important so **the two surveys should have the same frequency**. When deciding about the frequency of the surveys consideration needs to be given to the burden they generate for LAs and respondents, survey fatigue, the need for up-to-date data and feedback. Resource constraints, burden on LAs and participants and the difficulty of analysing data fully every year suggests that on balance the ASCS should become biennial (every other year) rather than SACE becoming annual.

The timing of the surveys within the year should ideally stay the same over time, for consistency and to avoid seasonal effects in comparison of data. However, stakeholders who were involved in the running of the surveys asked for the two surveys not to run at the same time as this was not manageable in terms of resources. If a central delivery model is adopted this may be less of a problem. Additional considerations about the timing included avoiding fieldwork in the winter, which tends to be a challenging period for health and social care providers.

Overall recommendations

A stepped approach to revising the surveys (outlined in section 6.4) is suggested in order to:

- benefit from improvements which have already been developed and could be adopted relatively easily, to address some issues with the surveys in a timely manner
- align with developments to the performance and outcomes framework for adult social care which are still in progress
- benefit from and inform developments such as client level data, digital social care records shared centrally, and charging reform once they are in place
- allow for full and meaningful engagement with the adult social care sector and the people it supports and their carers
- allow sufficient time for academically rigorous development and testing of any changes so that the final developments are fit for purpose.

1 Introduction and Background

1.1 The project

Over the last decade NHS Digital has co-ordinated two surveys which are carried out in local authorities on behalf of DHSC. These gather information on the outcomes of social care services and support. There are two surveys:

- Adult Social Care Survey (SACE) for people receiving long-term adult social care services from local authorities,
- Personal Social Services Survey of Adult Carers in England (SACE) for unpaid carers in touch with their local authority.

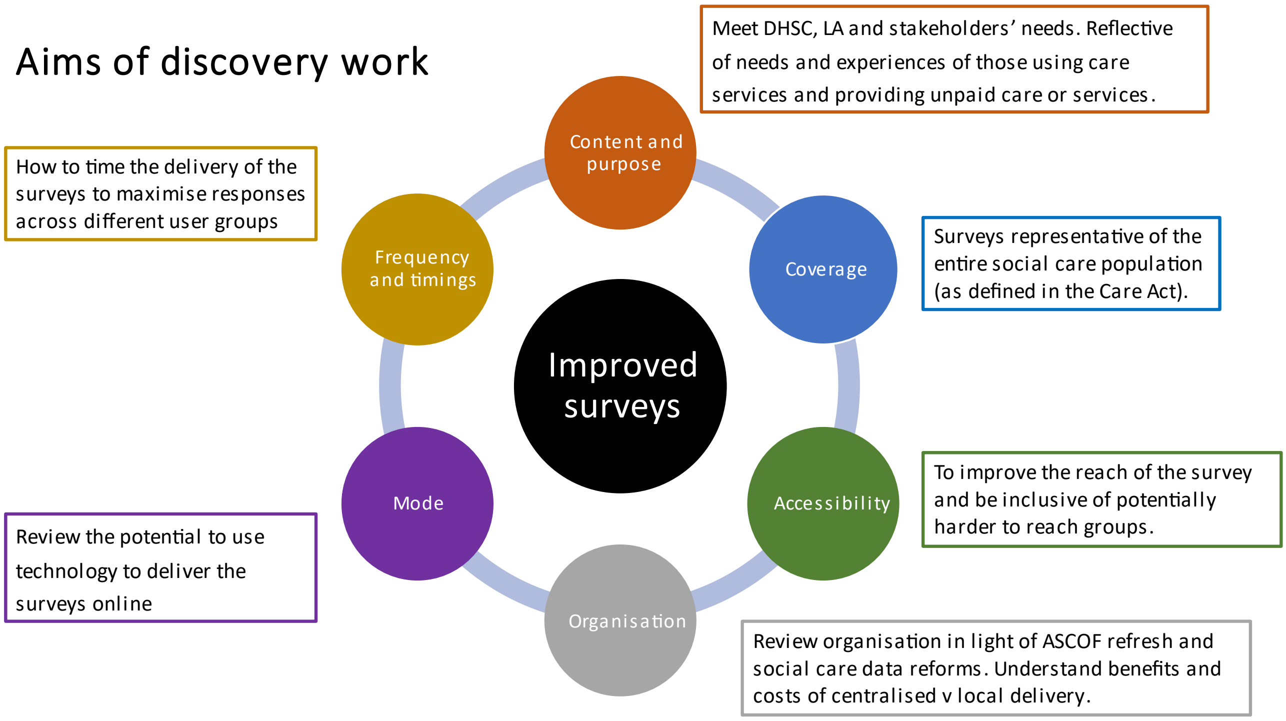
DHSC commissioned Ipsos to conduct a broad-based discovery exercise to explore and understand viable options for revising the ASCS and SACE. Ipsos worked with advisory partners University of Kent (PSSRU (Personal Social Services Research Unit) /CHSS (Centre for Health Services Studies)), CPEC (Care Policy and Evaluation Centre) and IPC (Institute of Public Care) on the research, which was carried out between February and April 2022.

This discovery work is part of a broader programme of work being carried out within DHSC to review Adult Social Care data and data collections more generally.

1.2 Project aims

The overall aim was to identify options to redesign these surveys to be representative of the social care population (as defined in the Care Act 2014), and meaningfully reflect the experiences and outcomes of people who use care and support services and carers.

The diagram which follows shows that the discovery work is intended to explore developments in six aspects of the surveys. These aspects and aims have been used to guide the research and structure the report. These aspects are interlinked and need to be considered together as well as individually. For example, the mode of the survey delivery (paper or online) may have implications for the accessibility of the survey. It has been clear throughout the research, that agreeing the purpose of the surveys is critical to making decisions about the content and other aspects of the survey design and approach.



Aims of discovery work

Meet DHSC, LA and stakeholders' needs. Reflective of needs and experiences of those using care services and providing unpaid care or services.

Surveys representative of the entire social care population (as defined in the Care Act).

To improve the reach of the survey and be inclusive of potentially harder to reach groups.

Review organisation in light of ASCOF refresh and social care data reforms. Understand benefits and costs of centralised v local delivery.

Review the potential to use technology to deliver the surveys online

How to time the delivery of the surveys to maximise responses across different user groups

DHSC set out that any resulting options need to ensure the survey(s) are replicable each year, generate data that can be used at local and national levels, and minimise the burden on local authorities and on survey participants. The output of this research will be recommended options and plans for further work needed to develop them in collaboration with the adult social care sector.

1.3 Approach to the research

The research has taken place over a short time frame and so a pragmatic approach was taken. The research involved four phases:

1. **a rapid evidence review** drawing together existing evidence and building on previous reviews
2. **scoping of options**, for revisions to the survey within the parameters set out in the brief
3. **qualitative research with stakeholders**, to ensure that the experience of those who have been involved in running the surveys, using the data or who represent people with care and support needs and carers are reflected in the presented options
4. **an options appraisal and consideration of future work** needed to implement them, drawing on the findings from the three previous phases.

Ipsos has led this work, engaging with the partners at each stage and providing reports to DHSC in writing after each phase so that the findings from each phase informs the next. This report includes a chapter on each of the phases, structured according to the six aspects of the project aims. The report ends with a final chapter of conclusions and recommendations which includes proposed next steps.

2 Rapid Evidence Review

2.1 Objectives

The objective of the rapid evidence review is to build on previous reviews, drawing out the relevant points for this research and adding more recent evidence as appropriate. This is not intended to be a full literature review, but rather a rapid review of the most relevant evidence to inform later stages of this research.

Previous literature was included to inform the overall objective of understanding viable options for revising the Adult Social Care Survey (ASCS) and Survey of Adult Carers in England (SACE) in relation to content, delivery and timings so that they could provide a more representative and better differentiated picture of user and carer satisfaction with services.

2.2 Approach and Framework for Review

The review was carried out using a framework based on the aims of the research as set out by DHSC. This chapter of the report is set out under these headings to draw together relevant evidence in relation to the issues outlined below.

Content of surveys	To ensure that information collected is fit for purpose for the stakeholders' needs and truly reflective of the needs and experiences of those both using care services and providing them. DHSC want to ensure the right questions are asked to be able to evidence what we need internally and in LAs.
Representativeness: Survey coverage	Define the eligible population to better match the user groups covered by the Care Act. Options are required for how data could be collected from a much broader group of respondents so that the surveys are fully representative of the entire social care population (as defined in the Care Act).
Representativeness: Accessibility and participation	It is known from the Ipsos work that the existing surveys are not representative of the current cohort in terms of issues and response. It is important to understand what delivery mechanism options are available to improve the reach of the survey particularly to be inclusive of potentially harder to reach groups.
Survey Delivery: Organisation	Review survey delivery models in light of ASCOF refresh and other social care data reforms. Understand the benefits and costs of delivering the surveys in a centralised national way compared to local authorities having responsibility for delivering the surveys.
Survey Delivery: Mode	Review the potential to use technology solutions to deliver the surveys online.

Survey Delivery: Frequency and timings	Understand the best options for the timings of delivery of the surveys. As the survey needs to cover those in long-term, short-term, transient and integrated care as well as information and advice seekers who do not go on to receive any formal care, options should be presented for how to time the delivery of the surveys that will maximise responses across all the different kinds of user groups whilst also giving a true reflection of the experiences of those filling in the survey.

The literature was collated from references provided by DHSC, known to Ipsos and recommended by advisors from PSSRU/CHSS, CPEC and IPC. In addition, some targeted searches were carried out.

2.3 Content of Surveys

2.3.1 The surveys, ASCOF and ASCOT

Both surveys contribute data which feed into the Adult Social Care Outcomes Framework (ASCOF). "The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve the outcomes that matter most to people. The ASCOF is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability."".[3] Since it is not possible to measure all of the objectives of ASC, it emphasises some more than others. There is a particular focus in the Care Act on wellbeing. ASCOF includes questions about maintaining quality of life rather than asking about wellbeing, though these concepts are closely related. Individual wellbeing and QoL can be understood as some of the intended final outcomes of social care. Those people who use social care services value not just these final outcomes, but also the experience of social care, as measured by the satisfaction question. As well as meeting central needs, ASCOF is also conceived as a tool to enable local accountability[4] and sector-led improvement, rather than top-down performance management.[5]

ASCOF has four domains:[6]

1. Enhancing quality of life for people with care and support needs

2. Delaying and reducing the need for care and support

3. Ensuring people have a positive experience of care and support

4. Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm.

The Adult Social Care Outcomes Toolkit (ASCOT)[7] was developed as a 'multi-attribute preference-weighted measure' of social care outcomes.[8,9] It was already in development and was included in the ASCS and SACE to contribute key measures to the ASCOF. ASCOT measures the social care

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[3] https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof

[4] ASCOF Handbook of definitions https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/687208/Final_ASCOF_handbook_of_definitions_2018-19_2.pdf.

[5] Malley (2017) Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators.

[6] Malley (2017) Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators.

[7] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[8] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[9] Malley, J. & Netten, A. (2008), Measuring User Experience of Social Care Services: A Discussion of Three Approaches.

related quality of life of different aspects of service users' life (SCRQoL) in the ASCS and carer social care related quality of life (CarerSCRQoL) in SACE. The ASCS questionnaire includes the eight domains from ASCOT with four categories or levels of response for each.[10] The ASCOT has been adapted to include an optional follow up about the extent to which care and support services help them with each domain. The most up to date version of the carer quality of life measure, ASCOT Carer, includes four categories for each of seven domains, but an earlier version is used in SACE and feeds into ASCOF. The CarerSCRQoL measure has only six domains (excluding one about time and space to be themselves) and has three rather than four response categories for each question. The ASCOT Carer domain of 'Time and Space to be yourself' was not included in the SACE because at the time of development, stakeholders were concerned about survey length and it was felt to be beyond the remit of local authorities. However, there is evidence that the seventh domain which is not in the SACE adds to the ASCOT measure.[11,12,13] This difference means that the most current ASCOT Carer measure is not included in SACE or ASCOF.

In addition to ASCOT the ASCS and SACE include questions which are not part of ASCOT but which feed into domain 2 of ASCOF, as well as some general contextual questions.[14] ASCS includes questions on satisfaction with services, access to information and advice, direct questions on quality of life, health, ability to do activities of daily living, and support received from unpaid carers. Some of these questions are used to inform the adjusted ASCOT social care-related quality of life measure, which gives an estimate of the impact of social care on SCRQoL, excluding factors outside of the control of social care services, e.g. differences in age or disability of populations over time or between LAs).[15] These other important questions are needed to interpret what is contributing to service users' and carers' quality of life scores, given varying contexts. They allow fairer comparisons over time and between LAs using the adjusted SCRQoL score. The SACE includes questions about the person they care for and the care provided, support and advice received, impacts of caring, occupation and other responsibilities and demographics. Both surveys went through a rigorous development process. Appendix A outlines which ASCS and SACE questions are part of ASCOT and which are not.

Although there is wider content in the surveys, the future of both the ASCS and SACE are closely linked to the future of ASCOF. In 2020-21, a preliminary review of ASCOF was carried out on behalf of ADASS and DHSC (see below or more information about this). Work is ongoing within DHSC to further develop and revise the ASCOF metrics, with consultation on the revised framework expected to take place in spring/summer 2022. Any consideration of the future content of these surveys needs to be made with reference to the future of ASCOF, since a key purpose of the surveys is to provide data for ASCOF.

2.3.2 Underlying purpose and development of ASCOF

During the later years of the Labour government and the period of Coalition government, there was a move to regarding the overall goal of adult social care services as being "to promote and improve individuals' quality of life".[16] Following the National Indicator Set (NIS), ASCOF was developed. This included the measurement of individual quality of life outcomes; and the application of these

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[10] Malley et al (2012) Assessment of the Construct Validity of the ASCOT Measure; Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[11] Fox et al (2010) SACE Personal Social Services Survey of Adult Carers in England – 2009-10.

[12] Malley et al, (2010) Developing a Carers' Experience Performance Indicator.

[13] Rand et al (2015) Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer).

[14] A table in the appendix shows how the questions in the ASCS and SACE are related to ASCOF and ASCOT.

[15] Forder et al (2016). IIASC report: Interpreting outcomes data for use in the Adult Social Care Outcomes Framework (ASCOF).

[16] Department of Health (2005) Independence, Well-being and Choice, London: Department of Health. Department of Health (2006) Our Health, Our Care, Our Say, London: Department of Health. Department of Health (2008) Putting People First, London: Department of Health.

data to inform decision-making and provide accountability for public spending.[17] There was also a move away from process or output related outcomes such as units of care provided to outcome measures which were based on what matters to people with care needs and their carers.

With this focus on measuring quality of life outcomes, ASCS was developed to replace previous user experience surveys.[18] Measures which form part of this outcome-oriented approach include ASCOT (SCRQoL) as well as a general quality of life question. "The aim is to measure the effectiveness of services in terms of how services improve quality of life, especially by responding to individuals' support needs and personal preferences".[19] The carers survey (SACE) was developed to align with the objectives of the carers strategy and to capture the voice of carers. ASCOT was originally developed by focus groups with service users and carers to understand and reflect what matters to them.[20] A developmental version of the ASCOT-Carer with three levels of response (CarerSCRQol) was included in SACE[21] (later developments of ASCOT-Carer continued after SACE had started).[22]

The surveys were designed to capture outcomes in a consistent way regardless of the services received, in a context of increasing diversity in how services were funded and delivered (for both adults with care needs and unpaid carers).[23] Although a question about satisfaction (experience) is asked it is not related to the specific package of care received in the questionnaire. However, it was anticipated that local authorities would already hold this information on their systems which could be linked to the survey responses. However, in practice few local authorities have the time and resources to analyse their survey data in this way.[24]

2.3.3 The development of ASCOT

The ASCOT measures of social care related quality of life (SCRQoL) and an early developmental version of the ASCOT-Carer, the carer social care quality of life (CarerSCRQol) were developed by the PSSRU at The University of Kent.[25] They underwent rigorous feasibility stages, cognitive testing[26,27] and piloting before implementation in the ASCS and SACE (though noting that SACE does not include the most recent version of the carer quality of life measure). Subsequently there has been considerable ongoing evaluation and research on ASCOT. Focussing on those which are relevant to ASCS and SACE, this has included:

- Research into the construct validity of ASCOT exploring the expected relationship between ASCOT and other variables in a face-to-face survey for older adults[28] and also a diverse

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[17] Rand et al (2020) What Does an Outcomes-Based Perspective Bring to an Understanding of Care and Caring, p606.

[18] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[19] Rand et al (2020) What Does an Outcomes-Based Perspective Bring to an Understanding of Care and Caring, p606-607.

[20] Fox et al (2010) SACE Personal Social Services Survey of Adult Carers in England – 2009-10; Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[21] Fox et al (2010) SACE Personal Social Services Survey of Adult Carers in England – 2009-10.

[22] Rand et al (2015) Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer).

[23] IPC (2021) ASCOF Refresh Consultation Feedback, p33.

[24] Heath et al (2015) 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.

[25] https://www.pssru.ac.uk/ascot/

[26] The SACE questionnaire underwent three rounds of cognitive testing with 30 carers who supported people with a variety of needs. Fox et al (2010) SACE Personal Social Services Survey of Adult Carers in England – 2009-10; Malley et al (2012) Assessment of the Construct Validity of the ASCOT Measure. Subsequently here was another round of 31 interviews. Rand et al (2012), Measuring the Social Care Outcomes of Informal Carer.

[27] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure.

[28] Malley et al (2012) An Assessment of the Construct Validity of the ASCOT Measure of Social Care; Rand et al (2017) Validity and test-retest reliability of the ASCOT-SCT4

sample of service users aged 18 or over, with needs related to physical or sensory impairment and mental health conditions.[29]

- Research to create an adjusted version of social care quality of life taking account of factors outside local authority social services control such as health, housing, local environment and deprivation. The adjusted score gives a measure of the impact of services on QoL, to the exclusion of these other factors, which allows fairer comparisons over time and between local authorities. This is done using an algorithm based on questions in the ASCS, rather than additional questions.[30]
- Research to understand the link between experience and outcomes, which found that care experience and outcomes are related but distinctive and there is value in measuring both.[31]
- Research on the intensity of the support provided and quality of life.[32]
- Research on how ASCOT compares to other measures. This evidence shows that ASCOT/ ASCOT-Carer SCRQoL is a distinctive construct. It captures the effect of social care services on QoL vs other constructs, like health or wellbeing.[33,34,35]
- Research to understand what influences ASCOT scores.[36,37,38]
- Research to explore the links between quality of life and other assessments of ‘what good looks like’. One study of the relationship between CQC quality ratings and residents’ SCRQoL found that residents in good/outstanding homes have better SCRQoL than residents in homes requiring improvement.[39] Another study found that quality matters most to those with the biggest care needs (most dependent).[40]

Any alternative survey questions implemented on the ASCS and SACE would need to be subject to rigorous testing to ensure they are measuring what is intended and are valid, robust and reliable measures. Although it would be possible to draw on the decade of research and understanding built up about ASCOT, any new measures would lack a body of evidence. This risk would be mitigated if new questions were drawn from other existing validated tools or questionnaires. It should also be noted that since ASCS and SACE started, ASCOT has undergone several developments which have not been incorporated into the surveys and so they have not fully benefited from all the development work by the PSSRU which has taken place. Some of the developments, such as improved Easy Read and a new proxy-report measure, are discussed in the section on survey accessibility.

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[29] Rand et al (2017) Validity and test-retest reliability of the self-completion adult social care outcomes toolkit.

[30] Forder et al (2017) The Impact of Long-Term Care on Quality of Life.

[31] Malley et al (2019) Relationship between Outcomes and Experience of Care.

[32] Forder et al (2017) The Impact of Long-Term Care on Quality of Life.

[33] Engel et al (2020) Measuring Carer Outcomes in an Economic Evaluation.

[34] Forder and Caiels (2011) Measuring the outcomes of long-term care.

[35] Van Leeuwen et al (2015) Comparing Measurement Properties of the EQ-5D-3L, ICECAP-O, and ASCOT in Frail Older Adults.

[36] Malley (2017) Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators.

[37] Rand and Malley (2016) The factors associated with care-related quality of life of adults with intellectual disabilities in England: implications for policy and practice.

[38] Van Leeuwen et al (2014) What can local authorities do to improve the social care-related quality of life of older adults living at home? Evidence from the Adult Social Care Survey.

[39] Towers et al (2019). A Cross-sectional Study exploring the relationship between regulator quality ratings and care home residents’ quality of life in England.

[40] Towers et al. (2021) Care home residents' quality of life and its association with CQC ratings and workforce issues.

2.3.4 Scoping review for a refresh of ASCOF

A review of ASCOF was carried out in 2020-21 by the Institute for Public Care (commissioned by ADASS and DHSC) and identified several issues with the framework, several of which relate specifically to the surveys, and some of which show a tension between different perspectives, related to stakeholders' use of the data, their role in the ASC sector and capacity constraints:[41]

- There is limited information about the circumstances of those responding which make interpreting results challenging (both their characteristics and information about the services being received).
- There is limited information on the reason for answers, which can lead to difficulties in interpreting findings (e.g. where respondents report not feeling safe it is unclear whether this relates to safeguarding, crime, risks from falls or illness). These makes the findings open to interpretation, limiting how useful they are to local authorities in making service improvements. Findings about specific questions are described in the table in the appendix.
- It is perceived as being based on a 'gift' model rather than a 'rights-based approach' and may not be effective in capturing user voice and experience or understanding what matters to people.[42] It should be noted that ASCOT is based on the 'capability approach' which incorporates the idea that someone has the right to wellbeing and should be able to achieve that in the manner they wish to. This is why ASCOT is framed around 'I' statements designed to measure the impact of services on people's lives.[43]
- It was designed before the Care Act 2014 (though the domains of ASCOT can be mapped to the Care Act [44]) and some critics suggest it does not reflect new pathways for adult social care or the importance of concepts such as independence or wellbeing. However, ASCOT has been tested or applied to a range of types of service, both traditional and 'new' (e.g. personal budgets, home care, day centres, wellbeing interventions, equipment or adaptations, info & advice).
- There is a perception that although ASCOT is designed to measure outcomes, those outcomes are closely related to social care 'inputs' (support with particular aspects of daily life) rather than impacts on life. It should be noted that in fact ASCOT is a measure of quality of life and can be used to measure the impact of social care on QoL, not inputs, though designed to be sensitive to social care inputs. This is based on the premise that good quality, effective and person-centred care should be able to respond to a person's social care-related QoL needs.
- ASCOF is too reliant on user-reported measures in the measurement of outcomes.
- It does not cover the outcomes of developments such as digital engagement and assistive tech[45], although the general nature of questions, not tied to specific services, have made it more flexible to changes than it might have been.

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[41] IPC (2020) ASCOF Refresh Part 1.

[42] IPC (2020) ASCOF Refresh Part 1, p12.

[43] Netten et al (2012). Outcomes of social care for adults: Developing a preference-weighted measure; Van Loon et al (2017) Quality of life in a broader perspective; Sen, A. (1993). Capability and well-being.

[44] PSSRU has explored how Care Act outcomes can be linked to ASCOT, while the ASCOF refresh looked at how wider obligations under the Care Act can be linked to ASCOT. Appendix A contains a table showing how ASCOT maps to the Care Act.

[45] IPC (2021) ASCOF Refresh Consultation Feedback, p15.

Implications of the ADASS scoping review for a refresh of ASCOF

Following the scoping review for a refresh of ASCOF two options were presented for the future of the framework:

- amend the ASCOF
- replace ASCOF with a new framework called the Performance and Outcomes framework, based around the Care Act 2014.

The future of ASCOF is being considered by DHSC, following this scoping review. As discussed above, data from ASCS and SACE are also used independently of ASCOF by local authorities, and so should be considered in their own right as well in contributing to ASCOF. Any plans for revising ASCS and SACE need to consider the extent to which the current measures in the surveys (ASCOT or variants of ASCOT (SACE) and other questions) have ongoing value regardless of any change to ASCOF, or whether the surveys should change to capture the new measures needed for any amended ASCOF or the new Performance Framework being developed by CQC. Any decision to add questions for the new framework while retaining the existing measures should carefully consider survey length and burden on participants, since there was a feeling that existing surveys need to be shorter.[46]

2.3.5 Alternative measures of experience and outcomes

There are other existing or potential measures of experience or outcomes of social care, beyond those included in the ASCS.

1. **TLAP's Making it Real 'I' statements**[47] **(Think Local Act Personal)**:

- Wellbeing and Independence – living the life I want, keeping safe and well.
- Information and Advice – having the information I need when I need it.
- Active and Supportive Communities – keeping family, friend, and connections.
- Flexible and integrated care and support – my support, my own way.
- When things need to change – staying in control.
- Workforce – the people who support me.

However, these have the limitation that they are designed for people on long-term packages of care.[48] They have also not been turned into standardised survey questions or fully validated, except for face validity.

2. **Making Safeguarding Personal statements** which might be appropriate measuring the experience of short-term users. This includes six domains (protection, empowerment, proportionality, prevention, accountability and partnership). However it seems that they are designed as a flexible tool for discussion rather than a standard set of questionnaire models.[49]

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[46] IPC (2020) ASCOF Refresh Part 1, p51.

[47] IPC (2021) Revising the Service User Care Survey for OPF, p20.

[48] IPC (2020) ASCOF Refresh Part 1, p12.

[49] https://www.proceduresonline.com/jersey/adults/p_pract_guid_making_sg_pers_guid.html

3. **ICECAP-A and ICECAP-O**[50], is a validated tool developed by the University of Birmingham as a measure of capability focussing on wellbeing[51]:

- attachment (an ability to have love, friendship, and support)
- stability (an ability to feel settled and secure)
- achievement (an ability to achieve and progress in life)
- enjoyment (an ability to experience enjoyment and pleasure)
- Autonomy (an ability to be independent).

However, ICECAP was not developed as a measure of social care-related QoL, but as a measure of care-related QoL 'beyond health'. The development of the measures did not engage with social care service users or practitioners – it is a general population measure targeted mainly for economic evaluation of healthcare interventions, although it may also be applied to social care studies. Studies have found that compared with ASCOT / ASCOT-Carer, the ICECAP / CES capture higher order domains rather than outcomes which align with the needs and concerns of social care service users and their carers (e.g. food and drink, personal comfort and cleanliness).[52]

4. **Personal Outcomes Evaluation Tool (POET)** which is a Care Act compliant tool to measure impact and outcomes for people going through self-directed support.[53] It can be used to assess performance on process conditions and outcomes for personal budget recipients (and short-term users) by benchmarking with a national dataset but focussing strategic plans in areas attuned to local experience. It can also be used in conjunction with TLAP 'Making it Real' measures.

5. **CQC Quality Matters** which was launched with multiple partners in 2017 to set out six priorities for improving the quality of adult social care which includes seven steps including 'measuring and publishing quality'[54]. Future actions set out in 2017 included:

- review the collection and use of data (quantitative and qualitative) across the system to identify opportunities to streamline collection and improve transparency
- use data to better support improvement
- explore the creation of a simplified data set, tailored appropriately for individual services, which helps to collect data and share it with regulators, commissioners, providers and the public
- establish an improved mechanism to collect and disseminate these agreed datasets
- focus on identifying and then measuring what matters most to people.

Another review argues that the current measures of experience and outcome do not include elements of high quality social care as identified by NICE (e.g. rapport, consistency of care, home visits of sufficient length). However, it should be noted, that these questions were included in the User Experience Surveys which the ASCS replaced.[55] One reason for the move away from specific questions about user experience was the small sample sizes in all the groups apart from older people receiving home care. A suggestion was also made that questions from a Carer's UK

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[50] ICECAP-A is for younger adults (18-64 years). ICECAP-O is for older adults.

[51] https://www.birmingham.ac.uk/research/activity/mds/projects/haps/he/icecap/icecap-a/index.aspx

[52] Presentation by Florin Vadean at ILPN 2016: A comparison of three instruments (ASCOT, ICECAP, and EQ5D) for the evaluation of outcomes of long-term care services | International Long-term Care Policy Network ILPN (ilpnetwork.org); Rand et al. (2019) Measuring the outcomes of long-term care for unpaid carers: comparing the ASCOT-Carer, Carer Experience Scale and EQ-5D-3 L.

[53] IPC (2020) ASCOF refresh Part 2, p9; https://in-control.org.uk/resources/poet-personal-outcomes-evaluation-tool/

[54] IPC (2021) Revising the Service User Care Survey for OPF, p2; IPC (2020) ASCOF refresh Part 1; GOV.UK (2016) Quality Matters.

[55] https://kar.kent.ac.uk/2910/1/DP2417_2_2.pdf

survey administered with a small sample of carers (regardless of contact with LA) could be considered for use in the SACE.[56]

2.3.6 How the results are used already

The findings from the surveys can be used in their own right but also as part of ASCOF. ASCOF is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability.[57]

Previous research[58] suggests that the results are used in the following ways:

- Looking at change over time. This is facilitated by the consistency of the surveys and ASCOF as a whole, over a decade (with very limited changes to content) but the scope for this is limited by a perception that the figures change very little over time at a national level and within local authorities (as they are not good at discriminating differences).[59] Understanding the figures and changes may rely on analytical expertise which is not always available in local authorities.[60]
- ASCOF is used for regional benchmarking and this was something which stakeholders were positive about.[61]
- ASCOF is used for comparisons across local authorities. Individual local authorities do analysis of the results but also use LGA Inform which facilitates comparisons of key measures from ASCOF between an individual local authority and other similar authorities in numbers and visually.[62] According to the ASCOF refresh they found that "data supports sector led improvement; bringing councils together to understand and benchmark their performance. This, in turn, stimulates discussions between councils on priorities for improvement, and promotes the sharing of learning and best practice."[63] However, the scope for benchmarking is limited by the timeliness and concerns about the quality of the data.[64]
- To set priorities for improvements to local services.[65] However, the ASCOF measures are supplemented by local indicators because the standard measures are not always aligned with local priorities.
- To monitor the success of improvements to local services, though changes can be hard to link to specific interventions.[66]
- Although measures in the surveys are not used by the government to performance manage local authorities, some local authorities use it for performance improvement.[67] There were also concerns that any proposed performance and outcomes framework to replace ASCOF could be used for top down performance management even though comparison is difficult given the different models of care employed by councils and differences in local contexts and conditions.[68] Since then DHSC has confirmed that the revised ASCOF is intended to explicitly avoid performance management metrics.

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[56] Cory (2019), Better Evidence for Better Care, p9

[57] DHSC (2019) ASCOF Handbook of Definitions

[58] IPC (2020) ASCOF Refresh Part 1; Aznar et al (2021) ASCS Representativeness Main Report

[59] IPC (2020) ASCOF Refresh Part 1, p9, p23

[60] Heath et al (2015) 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; Rainey et al (2015). Research capacity, knowledge, skills and use in Councils with Adult Social Care Responsibilities

[61] IPC (2020) ASCOF Refresh Part 1, p10

[62] https://lginform.local.gov.uk/

[63] IPC (2020) ASCOF Refresh Part 1, p54

[64] IPC (2020) ASCOF Refresh Part 1, p21

[65] IPC (2020) ASCOF Refresh Part 1, p26.

[66] IPC (2020) ASCOF Refresh Part 1, p31.

[67] IPC (2021) ASCOF Refresh Consultation Feedback, p26.

[68] IPC (2021) ASCOF Refresh Consultation Feedback, p8.

- By researchers at organisations such as PSSRU or NatCen to explore particular aspects of social care experience or outcomes.[69]
- For ONS analysis on public sector productivity, deriving a measure of quality of social care from the ASCS to adjust their input and output productivity equation.[70]

2.3.7 Future purpose of surveys

The scoping review for a refresh of ASCOF conducted by IPC on behalf of ADASS and funded by DHSC suggested that ASCOF should measure these things:

- outcomes demonstrated by those with lived experience of care services or caring
- measures that demonstrate the outcomes for populations
- measures that demonstrate good use of resources.

The second and third could be measured from other data sources such as local authority and NHS process and operational data. The first would come from hearing from those with lived experience. In considering the aspects of any framework which involves user reports, the surveys could be regarded as having a number of potential purposes beyond those achieved through the current surveys and which are unlikely to be achievable in one survey:

- Showing people that the council is listening both through the process of asking people questions but also by enabling “local councils to report to their communities on what is happening”.[71]

- Hearing about what matters to people under a rights-based approach in which questions such as ‘did it improve the life experience of the person with support needs’?[72], ‘can you lead the life you want to lead?’[73] or ‘do you have a life, not just a service?’.[74] In order to achieve this approach co-production of any future content with people with lived experience would be needed.[75] However, challenges in the implementation of co-production should be acknowledged when taking this approach.[76]

- Understanding care as a relationship, reflecting the dyadic nature of care[77] and mixed roles individuals have as carer and cared for.[78]

- The design of both surveys could better understand the role of unpaid carers as ‘co-clients’ of the council as well as ‘co-providers’.[79]

- Enabling local people to hold their council to account ‘for the quality of the services that they provide, commission or arrange’[80] but in order to do this the outputs need to be easy to

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[69] Wittenberg and King (2015) Data on Adult Social Care, p13.

[70] https://www.ons.gov.uk/economy/economicoutputandproductivity/publicservicesproductivity/articles/publicserviceproductivityadultsocialcareengland/financialyearending2019#quality-and-methodology

[71] IPC (2020) ASCOF Refresh Part 1, p11.

[72] IPC (2020) ASCOF Refresh Part 1, p57.

[73] IPC (2020) ASCOF Refresh Part 1, p12.

[74] IPC (2021) Revising the Service User Care Survey for OPF, p18.

[75] IPC (2020) ASCOF refresh Part 2, p8.

[76] Osborne et al (2021) Beyond co-production: Value creation and public services.

[77] Rand (2020) What Does an Outcomes-Based Perspective Bring to an Understanding of Care and Caring, p608.

[78] IPC (2021) Revising the Service User Care Survey for OPF.

[79] Rand (2020) What Does an Outcomes-Based Perspective Bring to an Understanding of Care and Caring, p608.

[80] IPC (2020) ASCOF Refresh Part 1, p26.

understand by lay people (which the quality of life score, derived from 8 questions, may not be).[81]

- Measuring whether the care provided reflects 'what good looks like'[82] (at a local or national level) which has links to the Quality Matters approach discussed above.[83]
- Uncovering whether social care in different areas meets national quality standards.
- Informing and supporting national policy development.[84] In order to be effective for this the data from the survey needs to be brought together with other data in a way which tells a coherent story[85] and data from the survey needs to be accessible and useable for researchers who may support with this analysis, with the measures needed as context for interpretation of outcome and experience (e.g. level of need).

Different stakeholders may hold different views about the purpose of the surveys. There are trade-offs between them. For example, a questionnaire which is standardised may be useful for benchmarking and national use, but be less useful for understanding a person-centred approach to support local improvement.[86] Any future developments need to consider the primary purpose of the surveys as this will influence not only the content but other design issues, covered in the rest of this report. When the SACE was first set up the primary aim was to monitor the implementation of the 2008 Carers Strategy which included benchmarking between LAs. Use of data for local purposes was seen as a secondary aim.[87]

2.4 Representativeness: Coverage

2.4.1 Introduction

The ASCS sample includes long-term users of adult care and support provided or funded by a local authority. To be included, a service user must be in receipt of long-term support services funded or managed by the council, at the point the list is extracted, following a full assessment of need. Certain specific groups are excluded from the sample (e.g. those in hospital, known to lack mental capacity etc).[88]

The eligible population for SACE[89] is all carers who would be contained within the last four rows of the Long-term SALT[90] return:

- 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.

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[81] IPC (2020) ASCOF Refresh Part 1, p54; Rodrigues et al (2014) also describe the reliance on measures of quality in choice of providers. Rodriguesa et al (2014) The public gets what the public wants: experiences of public reporting in long-term care in Europe; see Guardian article for an example of a public facing explanation of the quality of life score: https://www.theguardian.com/social-care-network/2018/apr/23/are-social-care-services-improving-peoples-wellbeing

[82] IPC (2020) ASCOF Refresh Part 1, p15.

[83] GOV.UK (2016) Quality Matters; Towers et al. (2021) Care home residents' quality of life and its association with CQC ratings and workforce issues.

[84] IPC (2020) ASCOF Refresh Part 1, p15.

[85] IPC (2020) ASCOF Refresh Part 1, p32.

[86] IPC (2021) Revising the Service User Care Survey for OPF, p17.

[87] Correspondence from PSSRU.

[88] Aznar et al (2021) ASCS Representativeness Methodology Review p11.

[89] Aznar et al (2021) ASCS Representativeness Methodology Review p41.

[90] Short and Long-Term support. Information on this is held by LAs and provided to NHS Digital.

Even among the eligible sample for each survey coverage is limited for a variety of reasons.

The current ASCS survey design completely excludes from the eligible sample several groups of people who come into contact with the local authority for care and support. The exclusions relate to the availability of sample information in the local authority and the suitability of the questionnaire.[91] These groups include short-term service users (e.g. reablement), those receiving equipment only and those receiving signposting (information, advice and guidance). Those receiving free care under Continuing Health Care funded by the NHS are also excluded.

Those who fund their own care are also not included, though it is less clear whether they should be. A view expressed in the scoping review for a refresh of ASCOF conducted by IPC on behalf of ADASS with funding from DHSC was that the survey should focus on those provided for by the council rather than the wider system.[92] However, DHSC's perspective is that measuring outcomes for people receiving ASC regardless of funding status would be valuable. This links to questions of whether the purpose of the surveys is to provide local authority level data or national level data and research, and the extent to which local authorities are concerned with measuring the experience of all those covered by the Care Act rather than those to whom they provide services, for which the inclusion of self-funders would be valuable.

2.4.2 Eligible long-term users of social care (ASCS)

The main reasons for under-representation among eligible groups social care users are.[93]

- not having survey issued (because inadequate information is currently held about them, or they are deliberately excluded according to the survey guidance)
- non-response (because they did not receive survey, refused to respond or were unable to take part)

A previous review identified how different sub-groups varied in terms of the main cause of their under-representation:[94]

- Groups underrepresented **at point of issuing sample** and **responding to the survey** include people with memory and cognition support needs (but with mental capacity) 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 response**.
- Groups under-represented in **survey responses but not issued sample** were those with mental health as their primary support reason, the youngest and the oldest users and all ethnic minority groups.

However data quality and completeness vary across LAs for some of these under-represented groups. For example the level of detail around ethnicity is not consistent[95] and data can be lacking for mental health users as details often held by third parties and LAs may struggle to access this information.[96] At a local authority level an additional concern for ethnic minority groups is the small sample size which limits analysis. Little consideration is given to oversampling ethnic minority

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[91] Though it should be noted that development work for ASCOT showed that the tool was suitable for people receiving equipment and people with mental health needs.

[92] IPC (2020) ASCOF Refresh Part 1, p15.

[93] Aznar et al (2021) ASCS Representativeness Main Report, p7.

[94] Aznar et al (2021) ASCS Representativeness Main Report, p28.

[95] Aznar et al (2021) ASCS Representativeness Main Report, p31.

[96] Malley (2017) Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators; Aznar et al (2021) ASCS Representativeness Main Report, p32.

users by LAs.[97]

A small proportion of LAs have issues with defining the eligible population because of discrepancies compared with the SALT records.[98] The accuracy or completeness of the sample extract was deemed to be poor for some LAs when compared to SALT. Some local authorities report not being able to have all eligible users in sample because they only update this information once per year.[99] However, for the ASCS these issues are limited and not the major cause of under-representation.

Those who lack mental capacity are excluded from the survey for practical and ethical reasons. For care homes, local authorities rely on providers reporting to them that someone lacks capacity before the survey invitations are sent. For people with care needs who live in the community, local authorities rely on other sources of intelligence. However there are ongoing issues around determining mental capacity of people with care and support needs and the consistency of practice around this. This results in questionnaires being sent to those who lack capacity, who are then unable to respond, or have someone else respond on their behalf without a formalised proxy procedure.[100]

Given the finite eligible sample in each local authority, the division of the ASCS sample into stratum and the annual timing of ASCS, the same people may be sampled every year. This results in survey fatigue. This has an impact on response, but there is also evidence of local authorities removing people from the sample for this reason (though this is not permitted by the guidance). Local authorities also run their own surveys and it is permitted to remove those who have taken part in other surveys from the sample. LAs have to discuss this with NHS Digital[101] but there is evidence that they are not applying this and other exclusions consistently.[102]

As a result of the issues described above certain groups are under-represented in the ASCS data compared with their prevalence in the eligible population:

- those with mental health problems, working age
- nursing home residents
- ethnic minority (compounded by issues with how this is recorded across LAs and lack of necessary detail)
- severe disabilities
- people from more deprived areas.

At the time of a previous review there was no guidance on how to encourage better response.[103] A much earlier review identified that ensuring a range of client groups are represented in the final sample and running the survey are challenging and time-consuming.[104] Information for understanding different response among particular groups (especially ethnic minorities) is not readily available to local authorities. This makes addressing the issues challenging but the

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[97] Aznar et al (2021) Representativeness Main Report p8, p48.

[98] Aznar et al (2021) Representativeness Main Report, p24.

[99] Aznar et al (2021) ASCS Representativeness Methodology Review, p14,15.

[100] Aznar et al (2021) ASCS Representativeness Methodology Review, p17, 34; Aznar et al (2021) ASCS Representativeness Main Report, p3; IPC (2021) Revising the Service User Care Survey for OPF, p3; IPC (2021) ASCOF Refresh Consultation Feedback, p44.

[101] Aznar et al (2021) ASCS Representativeness Methodology Review, p18.

[102] Aznar et al (2021) ASCS Representativeness Methodology Review, p3; ASCOF refresh consultation feedback; Aznar et al (2021) ASCS Representativeness Main Report, p37,38.

[103] Aznar et al (2021) ASCS Representativeness Methodology Review, p20.

[104] Heath et al (2015) 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, p18; Aznar et al (2021) ASCS Representativeness Main Report, p23, p69.

engagement of stakeholders, especially end users of data, can help shape local sampling requirements.[105]

People in care homes

Those living in care homes present particular challenges for inclusion in the survey, which was explored in the initial development work for the ASCS.[106] There are issues related to mental capacity to take part which are covered in a later section but there are wider issues about aspects of the survey organisation which need care provider support. Previous reviews have identified these challenges:

- care homes do not see ASCS as a priority and don't facilitate the process[107]
- liaising with care homes is perceived to be a resource intensive exercise by LA staff[108]
- local good practice identified pre-warning administrators (front-line and back-office staff) about the survey[109]
- staff in care homes act as gatekeepers, beyond their role of carrying out of mental capacity checks.[110] There was previous evidence of them intercepting mail[111]
- those in care homes may need support to take part in the survey which presents challenges in the comparability of results

2.4.3 Eligible carers (SACE)

For carers there is less data on the eligible population from which to draw the sample in comparison with service users, because carer contact details are sometimes held in service user records and lack detail, or their contact details are held by third parties. Data held by third parties may not be consistent or complete and there are also issues around data sharing related to GDPR.[112] Little is known about the demographic characteristics of carers, so stratification of the sample is not possible.[113] A previous review recommended more accurate and standardised record keeping on the part of LAs and third parties (e.g. recording the same demographic characteristics in the same way) to facilitate assessment of sample representativeness.[114]

The definition of carers for the survey is very wide and inclusive. However, in practice the definition of carer is not always clear cut, though NHS Digital provide detailed guidance and examples on this, and eligible carers can be excluded for allowed reasons.[115] Issues include:

- complexity about who should be included in SALT[116]

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[105] Heath et al (2015) 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, p14.

[106] Malley et al (2010) A report on the developmental studies for the National Adult Social Care User Experience Survey. Note that in the early stages of development the survey was called the Putting People First (PPF) Survey rather than the ASCS.

[107] Aznar et al (2021) ASCS Representativeness Main Report, p36.

[108] Heath et al (2015) 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, p14, Aznar et al (2021) ASCS Representativeness Main Report, p69).

[109] Heath et al (2015) 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, p15.

[110] Aznar et al (2021) ASCS Representativeness Main Report, p69.

[111] Smith/Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p14.

[112] Aznar et al (2021) ASCS Representativeness Main Report, p32.

[113] Aznar et al (2021) ASCS Representativeness Methodology Review, p4; IPC (2020) ASCOF Refresh Part 1, p47.

[114] Aznar et al (2021) ASCS Representativeness Main Report, p15.

[115] Aznar et al (2021) ASCS Representativeness Methodology Review, p43; Aznar et al (2021) ASCS Representativeness Main Report, p8.

[116] Aznar et al (2021) ASCS Representativeness Methodology Review, p44.

- complexity of defining who a carer is[117] and how definition has changed. This is not just a sampling issue but also leads to lower response as some eligible and invited carers don't realise they are using LA services and some do not self-identify as a carer.[118]
- inconsistency between LAs in whether or not short-term carers are included.[119]

A previous review identified how different sub-groups varied in terms of the main cause of their under-representation:[120]

- women in the oldest age group were **under-represented in the issued sample** compared with men but not in response.
- the oldest and youngest carers were **under-represented in the issued sample and in response**
- **older carers from ethnic minority backgrounds were under-represented in response**. Younger carers from ethnic minority backgrounds were not under-represented.

As with users of social care, sample sizes were small for ethnic minority groups, limiting the analysis which can be done.[121] Little consideration was given to oversampling ethnic minority carers,[122] though there is anecdotal evidence from the SSUSG[123] of over-sampling in some local authorities. In the carers survey there is a wider issue in some areas of small samples more generally, not just from specific subgroups.[124]

In the final data these groups are under-represented:[125]

- those aged 18-64
- non-white carers (but this affects particular ethnic groups and age groups and the information about this is not readily available to local authorities).

Survey fatigue is less of an issue when compared to the ASCS because it is carried out every two years and the carer population changes over time.[126] However survey length is an issue, particularly for this group who face a heavy burden of form filling.

As with the ASCS ensuring a range of client groups are represented in the final sample and running the survey is challenging and time-consuming for local authorities.[127] There are also concerns that non-response bias may affect results.[128]

2.4.4 Short-term users

For this group, which is largely excluded from the current ASCS, the issue is not sample availability, but rather the appropriate methodology for capturing information from people who may have received a six week service, which means that an annual survey design may not be appropriate because of issues with recall.[129] Timing is also an issue which may vary between

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[117] Aznar et al (2021) ASCS Representativeness Methodology Review, p45.
[118] Aznar et al (2021) ASCS Representativeness Main Report, p25.
[119] Aznar et al (2021) ASCS Representativeness Methodology Review, p55.
[120] Aznar et al (2021) ASCS Representativeness Main Report, p29.
[121] Aznar et al (2021) ASCS Representativeness Main Report, p8.
[122] Aznar et al (2021) ASCS Representativeness Main Report, p48.
[123] SSUSG: Social Services User Survey Group: advisory group for the ASCS and SACE, chaired by NHS Digital.
[124] Aznar et al (2021) ASCS Representativeness Methodology Review, p53.
[125] Aznar et al (2021) ASCS Representativeness Methodology Review, p48, 54.
[126] Aznar et al (2021) ASCS Representativeness Methodology Review, p49.
[127] Heath et al (2015) 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, p18; Aznar et al (2021) ASCS Representativeness Main Report, p69.
[128] Wittenberg and King (2015) Data on Adult Social Care, p51.
[129] IPC (2021) Revising the Service User Care Survey for OPF, p18.

individuals as, depending on the timing of fieldwork, they may still feel too ill (if too soon), or too recovered (if too late) for the survey to seem relevant.[130] The ASCOF refresh suggested that more use could be made of real time surveys for people receiving short-term care.[131] This implies a rolling programme of survey fieldwork with samples drawn every 3 months or so to capture recent experience.[132] An alternative would be to adopt the approach of the annual CQC patient experience surveys, which use a sample of people who received care in the previous three months. However, this might not generate a large enough sample (as only a quarter of short-term users would be invited to take part) and there could be seasonal impacts of only measuring experience at one point in the year.

An added complication for this group is that some short-term users may go on to become recipients of a long-term packages of care or may receive multiple episodes of short-term care and so may be invited to take part in the same survey twice (if ASCS and short-term users surveys treated as one survey) or may be asked to take part in two or more surveys with impacts on survey fatigue.[133] It also means that it may be difficult to understand whether outcomes are the result of the short-term care, the subsequent long-term package of care,[134] or NHS services (e.g. nursing or GPs), community based provision or accessible universal services.

Another challenge for this group is that the current content of the ASCS survey is less suitable for this group as it was designed with long-term care in mind. The ASCOF refresh suggested Making Safeguarding Personal statements for this group,[135] though as noted above, these seem to be points for conversation rather than an existing set of questions and focus on safeguarding rather than short-term care outcomes. A short-term users questionnaire was created in 2017 and cognitive testing was carried out by NatCen looking at some experience questions as well as outcomes among people who had recently received short-term care.[136] The questions tested were quite different from the ASCS - only the safety question was the same which limits comparability. Even the satisfaction question had a different answer scale (5 point instead of 7 point), though the Easy Read version of the ASCS also has a 5 point scale for satisfaction. If ASCS is changed then the short-term service users questions may need to be reconsidered and an important question arises of whether the ASCS and short-term users surveys should be aligned so there are some points of comparison.

The short-term user survey is likely to need a different of questions and method compared to one for long-term users hence the survey would need to run separately from the main ASCS. This has implications for burden on LAs which find the current annual ASCS and biennial (every two years) SACE demanding. In the ASCOF refresh research a proposal to run four surveys raised concerns in local authorities[137] and similar issues were identified in the Ipsos review of representativeness.[138] An alternative approach is to build feedback into reviews or contact with the person, rather than running a survey but this raises concerns about anonymity.[139]

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[130] Aznar et al (2021) ASCS Representativeness Main Report, p11.

[131] IPC (2020) ASCOF Refresh Part 1, p15.

[132] Aznar et al (2021) ASCS Representativeness Methodology Review p3,19; IPC (2021) the Service User Care Survey for OPF; Aznar et al (2021) ASCS Representativeness Main Report, p38,39.

[133] Aznar et al (2021) ASCS Representativeness Methodology Review, p19, 20.

[134] Rand et al (2017) Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT), p1.

[135] IPC (2021) Revising the Service User Care Survey for OPF, p14.

[136] Rand et al (2017) Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT), p4; Pilley et al (2017) Question testing for the Adult Short-Term Care Users Survey.

[137] IPC (2020) ASCOF refresh Part 1.

[138] Aznar et al (2021) ASCS Representativeness Methodology Review, p19.

[139] IPC (2021) Revising the Service User Care Survey for OPF, p18.

2.4.5 Recipients of information, advice and guidance

A key element of care provision involves receiving sign posting (information, advice and guidance) after contacting the local authority. This is an important aspect of a strength-based approach to social care which emphasises independence and prevention. To understand social care provision by local authorities this group should be included. However, there are practical issues with their inclusion as although some councils collect details and phone people back to check whether the information was helpful many do not. Some councils may be able to trace people through online systems, others cannot.[140] One possibility to overcome this could be more use of real time surveys for people diverted away from councils.[141] However, even here contact details and permission to re-contact would be needed, as ethical approval may not be given for data collection as part of information seeking calls.[142]

Once people who have received sign posting are successfully contacted, there may be challenges in asking about their outcomes or experience. They may be confused about the service they are being asked to comment on, and their experience may include experience of contact with the voluntary sector.[143] There is a wider issue about whether they would recognise their support as having come from the local authority, when it may have come from another organisation. They may also have chosen not to follow up the signposting.[144]

2.4.6 Extra care housing and supported living

The ASCS has versions for people living in the community and people living in residential and nursing care. It is unclear which questionnaire is most appropriate for those living in extra care housing and supported living schemes (whether the community service or residential care version). The survey guidance[145] lays out that mental capacity checks are needed for those settings and shared lives but there is no other guidance on carrying out the survey in those settings. Although some people in those settings may also be receiving long-term packages of care, others may not, and may be receiving day rather than residential care from shared lives.

2.4.7 Continuing Health Care

People receiving adult social care funded by the NHS through continuing health care (CHC) are not included in the current study design.[146]

2.4.8 Self-funders

At present local authorities do not hold contact information for most people who fund their own care. This means that the only ways to access an appropriate sample are limited and would not cover the whole population:

- through providers (whether residential or home care); a consultation with local authorities during the ASCOF refresh raised questions about whether providers would be willing to share this information.[147]
- through carers known to the local authority who are flagged as caring for someone not known to the local authority.[148]

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[140] IPC (2021) ASCOF Refresh Consultation Feedback, p20.

[141] IPC (2020) ASCOF refresh Part 1, p15.

[142] Experience of authors on another study.

[143] IPC (2021) ASCOF Refresh Consultation Feedback, p10.

[144] Windle et al (2010) Measuring the outcomes of information and advice services: Final report.

[145] NHS Digital (2021) Adult Social Care Survey Guidance 2021-22.

[146] Wittenberg and King (2015) Data on Adult Social Care, p13.

[147] IPC (2021) ASCOF Refresh Consultation Feedback, p18.

[148] Aznar et al (2021) ASCS Representativeness Methodology Review, p41.

With the advent of Charging Reform it is likely that local authorities will hold significantly more detail about many self-funders. As data development continues in this area it is likely further possibilities for developing a sample of self-funders may arise.

2.4.9 Carers who are not in touch with the local authority or outside scope of SACE

There are unpaid carers who do not make contact with their LA and so are not part of SACE at present.[149] The inclusion criteria for SACE changed in 2016-17 to include carers who have not had an assessment in the last 12 months – and there was feeling among LAs that the inclusion criteria are as wide as they can be with this survey design based on contact with the LA.[150] Previous research using census data and the 2010 Survey of Carers in Households describes the characteristics of carers in the general population (including those caring for self-funders) so that we can understand which types of carers are less likely to sampled in the SACE.[151]

Local authorities need to use vehicles other than SACE to capture views of other 'hidden' carers, for example through resident surveys and working with third party organisations to gather relevant information.[152]

Carers under 18 years are not eligible for SACE as they are under the remit of Dept for Education, though SALT does now have a record of the number of carers under 18 known to the local authority. Although it would be useful for LAs to have information about their experiences research among those under 18 (or potentially under 16) would need a different approach from SACE because of issues of consent and the nature of questionnaire.[153]

2.5 Representativeness: Accessibility

2.5.1 Introduction

Differences in response rates affect the representativeness of the survey (as outlined in summary in the previous section). Some of these differences relate to the accessibility of the survey instruments for particular groups such as those with a learning disability, sight impairment and cognitive impairments and in this section we review some tools which are used or have been developed to address this. However, there are wider factors affecting overall response to the surveys, which have differential impacts on different groups, thus affecting representativeness.

2.5.2 Engagement and understanding of the surveys

Previous research has identified the following issues and recommendations in relation to improving response on the surveys by improving engagement and motivation to take part:

- The involvement of and building relationships with well-established community groups or grassroots organisations could assist in promote survey participation by building trust and understanding,[154] because trust in the institution sending the survey can affect response,[155]

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[149] Aznar et al (2021) ASCS Representativeness Methodology Review, p45.

[150] Aznar et al (2021) ASCS Representativeness Methodology Review, p53.

[151] Pickard et al (2015) The 'visibility' of unpaid care in England.

[152] Aznar et al (2021) ASCS Representativeness Methodology Review, p53; Aznar et al (2021) ASCS Representativeness Main Report, p40.

[153] Aznar et al (2021) ASCS Representativeness Methodology Review, p53; Aznar et al (2021) ASCS Representativeness Main Report, p40.

[154] Rand et al (2020) What Does an Outcomes-Based Perspective Bring to an Understanding of Care and Caring, p1, 14; Aznar er al (2021) ASCS Representativeness Summary.

[155] Smith/Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users; IPC (2021) ASCOF Refresh Consultation Feedback, p80.

particularly in ethnic minority communities[156] or among particular user groups (e.g. mental health[157]).

- Building trust could also help address fears that taking part will negatively impact on services received.[158]
- Gatekeepers such as unpaid carers can be enablers for participation if engaged in survey[159] but can also act as a barrier by intercepting and censoring mail, particularly if the survey is considered to be too long or burdensome[160] or the purpose is not understood.[161]
- Improved, more accessible letters[162] and an improved reminder strategy. More reminders are costly but could make a difference to response especially the use of different messages and formats (e.g. postcards) in invitation letter and reminders. There is also potential for versioning of letters to acknowledge previous participation for those sampled in consecutive years. The content and design of invitation letters could be reviewed to be shorter and relevant to the respondent,[163] while ensuring all key information is included.[164] However, the added burden for LAs of any of these things need to be considered.[165]
- For carers avoiding the term ‘carer’ in the covering letter could improve response among those who don’t identify as carers.[166]
- Conveying the importance and purpose of the survey can assist for both the intended respondent for the survey and any gatekeepers and potentially mitigate a lack of interest,[167] survey fatigue[168] or the length of the survey impacting on response.[169]
- A lack of incentivisation for care homes and individuals to motivate participation also affects the willingness to take part in these surveys[170] though in earlier development work it was suggested that incentives can be seen as a subtle form of coercion[171]. Some LAs have used incentives in the past but the impact on response is not clear and incentives are no longer recommended.[172] Unconditional incentives are unlikely to be viable due to LA financial pressures and they would need NHS Digital funding.[173] More research is needed before implementation of incentives to understand their potential impacts.[174]
- A lack of understanding that services have been provided or funded by the LA can be an issue, especially among mental health service users.[175]
- Among a population in need of long-term care and support there are other barriers to participation such as the accessibility of materials.

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[156] Aznar et al (2021) ASCS Representativeness Main Report, p50.

[157] Aznar et al (2021) ASCS Representativeness Main Report, p5; IPC (2020) ASCOF Refresh Part 1, p52.

[158] Aznar et al (2021) ASCS Representativeness Summary, p9; Aznar et al (2021) ASCS Representativeness Main Report, p42.

[159] Aznar et al (2021) ASCS Representativeness Summary, p21.

[160] Aznar et al (2021) ASCS Representativeness Main Report, p44.

[161] Aznar et al (2021) ASCS Representativeness Main Report p4,8,9,41; IPC (2020) ASCOF refresh Part 2, p51.

[162] Aznar et al (2021) ASCS Representativeness Main Report, p44.

[163] Smith/Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p6.

[164] Aznar et al (2021) ASCS Representativeness Methodology Review, p26, 27.

[165] Aznar et al (2021) ASCS Representativeness Methodology Review, p57, 58.

[166] Aznar et al (2021) ASCS Representativeness Methodology Review, p46.

[167] Smith/Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p15.

[168] Aznar et al (2021) ASCS Representativeness Methodology Review, p21, 22; Aznar et al (2021) ASCS Representativeness Main Report, p67,68.

[169] Heath et al (2015) 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, p18.

[170] Aznar er al (2021) ASCS Representativeness Summary p14; Aznar et al (2021) ASCS Representativeness Main Report, p43.

[171] Smith/Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p6.

[172] Smith and Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p21; Aznar et al (2021) ASCS Representativeness Main Report, p43.

[173] Aznar et al (2021) ASCS Representativeness Methodology Review, p23.

[174] Aznar et al (2021) ASCS Representativeness Main Report, p11.

[175] Aznar et al (2021) ASCS Representativeness Main Report.

2.5.3 Easy Read

From the beginning the ASCS has included an Easy Read version of the questionnaire, based on recommendations from the development work (focus groups and pilot interviews with people with a learning disability) and established principles.[176] Time constraints around the work meant that the scale of this development work was limited. This version is intended primarily for those with a learning disability (sent to all those in that stratum) but are also available to others (including those with another cognitive impairment) on request.

Easy Read is characterised by plain language, simple layout and format, and the use of images to illustrate key messages in the text. This includes images of the activity or topic being discussed, and symbols next to answer categories including smiley faces, thumbs up/down and ticks and crosses. Despite high response among those in the learning disability stratum, feedback suggested that these tools could be improved and were not suitable for some sub-groups such as those with autism. It was felt that the questions could be further improved to promote inclusion, engagement and increase response rates. Specific issues affecting Easy Read materials include:[177]

- the lack of robust, empirical research to support the use of Easy Read
- the evidence on the effectiveness of different modes and formats is limited and inconclusive
- Easy Read still favours more able individuals and it is inaccessible to large groups of people with more severe intellectual disabilities
- there being no Easy Read version of the SACE questionnaire [178] although the extent of the demand for this has not been established.

Therefore work was carried out to address these issues. Cognitive testing of the revised Easy Read ASCOT questionnaire showed that despite improvements made to it, some participants still struggled with 4-point scales, abstract questions such as control over one's life and dignity, and found it hard to answer using codes provided. Some also said they would still ask a carer for help to respond. Nonetheless, face validity was established for the revised measure, which was co-produced by, and cognitively tested with, people with intellectual and developmental disabilities and people with autism.[179] This work highlighted the clear benefits of involving people with intellectual disabilities and/ or autism in the design and testing of data collection instruments. In the case of ASCOT, feedback from people with intellectual disabilities and/ or autism highlighted difficulties in the interpretation of words and images, and helped to improve the questionnaire using revised iterations in a systematic way.[180] A later study of ASCOT-ER investigated the instrument's feasibility, construct validity and factor structure in a survey of people with intellectual disabilities. It concluded that there was preliminary evidence of the ASCOT-ER's feasibility, uni-dimensionality, and construct validity. This means that a well-designed ASCOT Easy Read questionnaire can be used to generate reliable and useful data.[181]

Another issue for the group using the Easy Read questionnaire is that the ASCOF refresh recommended that a revised ASCOF would need more questions specifically about the experience of those with a learning disability. The ASCOF refresh consultation found that for this group a

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[176] Malley et al (2010) A report on the developmental studies for the National Adult Social Care User Experience Survey.

[177] Turnpenny et al (2016) Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT).

[178] Aznar et al (2021) ASCS Representativeness Methodology Review, p42.

[179] Turnpenny et al (2016) Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT).

[180] Turnpenny et al (2016) Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT).

[181] Rand et al (2019) Feasibility, factor structure and construct validity of the easy-read Adult Social Care Outcomes Toolkit (ASCOT-ER).

whole life approach is needed, recognising that support may be needed throughout life, rather than being something which develops in old age.[182] This has implications for questionnaire content and survey fatigue.

2.5.4 Seeking the views of people who lack capacity

In England non CTIMP[183] research with adults lacking capacity to consent (LCC) is subject to approval from a Research Ethics Committee flagged as approved to review research conducted under the Mental Capacity Act (MCA).

Informed consent for participation in a research exercise is provided when a person has:[184]

- understood the research
- understood the consequences of taking part or refusing
- retained, weighed up and used the information about the project
- communicated their decision to take part or not.

Before concluding that someone lacks capacity to consent, researchers must make ‘every attempt’ to enable participation,[185] for example by:

- using simple language
- taking one decision at a time
- finding the time and the setting that is most likely to help the person feel safe and comfortable
- ensuring that communication uses language/other means familiar to the person and considers cultural factors
- considering use of non-verbal language such as pictures, prompts, gestures
- if the person is agreeable, involving others who know best how the person prefers to communicate
- making sure the person has any support aids they require (hearing aids, glasses etc.)
- building rapport and embedding consent within relationships between researcher and participant where possible.

Having established whether someone lacks capacity to consent, if the project has received REC approval under the MCA, researchers need to seek advice from a personal or nominated consultee about the feeling and wishes of the person who lacks capacity. Researchers then make a decision about the person's involvement in the research based on the advice received from the consultee. Research projects that do not have REC approval under the MCA cannot include adults LCC.

ASCS and SACE used to seek and receive ethical approval from a REC at the HRA each time they were conducted, but the approval did not cover adults LCC. The surveys are now classified as service evaluation and no longer require ethical approval before each iteration, unless changes are made to them.

In practice, it is not possible for adults LCC to actually complete a questionnaire or take part in a conventional, structured survey interview. The inclusion of adults LCC in ASCS would therefore need to be done through proxies or though adapted methods such as Talking Mats, semi-structured interviews or Easy Read (some of which could lead to standard information and some

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[182] IPC (2021) ASCOF Refresh Consultation Feedback, p14.

[183] CTIMP is Clinical Trials of Investigational Medicinal Products.

[184] Dobson and Hamilton (2020) Conducting Research with People Who Don’t Have Capacity to Consent.

[185] UREC (2019) Specialist Research Ethics Guidance Paper, Research involving adults who don’t have the capacity to Consent.

which could not). Later work stages will need to further explore the ethical implications of collecting data from proxies and in particular whether this would require REC approval under the MCA.

For the research to be approved under the MCA the researchers must answer these questions:

- Can the project be as effectively undertaken with participants who have the capacity to consent?
- Is the research about an impairing condition that affects the person?
- Does the research concern treatment or care of that condition?
- Is the research of potential benefit to the participant and is the risk proportionate? OR does the research potentially benefit others with the same or similar condition and involve negligible risk?

When the surveys were developed those who lacked mental capacity were deliberately excluded from the design. They are not included in the sample frame (if identified) but are included in the eligible population to which the results are weighted.[186] Although the development reports suggested that a priority should be developing methods for including the experiences of those who lack capacity to take part,[187] this group has continued to be excluded from the design, though in practice if care homes do not provide information on capacity they may be included, as evidenced by the 10% who have help with completing the questionnaire (26% among those with memory of cognition problems).[188] The development work for the main survey suggested consideration should be given to the inclusion of the DEMQOL instrument[189] which is a patient reported outcome measure design to enable the assessment of health-related quality of life for people with dementia. This includes a 28 item questionnaire for the person with dementia or a 31 item versions for a caregiver. Both are interviewer administered rather than self-completion. The length of the scale and the need for a self-completion approach on the ASCS and SACE meant it was not suitable for the survey.

Although the scoping review for a refresh of ASCOF recommended advocates as a way to support those lacking capacity in taking part in the ASCS[190], the original development work for the ASCS did not recommend advocates except where the person with care needs already had a relationship with them and there were also concerns about capacity and resources for this.[191]

2.5.5 Proxy responses

When the surveys were designed, the use of formal proxy respondents was not included in the design. However, it was recognised that support may be needed from others in order to be inclusive and so there were instructions about this together with information to remind people of the carers survey, make it clear that care and support workers should only help when there were no alternatives and to emphasise it is about quality of life, not a judgement on care homes. The ASCS includes questions on who helped with completion of the survey and what their role was.[192]

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[186] Wittenberg and King (2015) Data on Adult Social Care, p13.

[187] Malley et al (2010) A report on the developmental studies for the National Adult Social Care User Experience Survey.

[188] Aznar et al (2021) ASCS Representativeness Main Report, p9.

[189] https://www.bsms.ac.uk/research/neuroscience/cds/research/demqol.aspx

[190] IPC (2020) ASCOF refresh Part 2, p9.

[191] Malley et al (2010) A report on the developmental studies for the National Adult Social Care User Experience Survey.; Rand & Caiels, 2015 Using Proxies to assess Quality of Life: A Review of the Issues and Challenges.

[192] Malley et al (2010) A report on the developmental studies for the National Adult Social Care User Experience Survey.

However support is not always available and type of support can bias response.[193] Nonetheless many respondents have support in completing the ASCS.[194]

Subsequent studies have explored the feasibility and challenges involved in collecting social care outcomes data from proxies in a more formalised manner[195,196] about the feelings, opinions and attitudes of adults lacking capacity to consent. Challenges included:

- care workers' resistance to the idea of acting as a proxy respondent. By contrast, unpaid carers appeared comfortable with adopting the proxy role[197]
- the perceived difficulty of judging care recipients' internal subjective state (i.e. how they 'think' and 'feel'). Carers wanted a way to elaborate and justify answers
- proxy respondents' wanting to express that their own response (as a proxy) differed from how they thought the care recipient would respond
- paid carers' concern that answering negatively to questions on ASCOT could reflect badly on them, especially if there is no box available for open ended comments to explain why they provided a negative response
- the satisfaction reported by those helped to complete by care and support workers was higher than those who completed it themselves, raising questions about the potential reliability of proxy reports given by care and support workers, which may relate to bias in responses or the nature of support received by those who are helped to complete the survey.[198]

Resulting from the above, the resulting proxy version of the ASCOT questionnaire (ASCOT-proxy) has the following features[199]:

- providing two sets of response options for each proxy perspective (one for the proxy's own view and one from the proxy's view of what they think the care recipient would answer if they were able to);
- adding comments boxes to give proxies the opportunity to explain why they have selected a given response option (especially where these indicate unmet need);
- clearly identifying the role of the proxy respondent (unpaid carer or paid care and support worker), including their relationship with the care recipient; and
- providing clear guidance setting out exactly what is expected of the proxy respondent and how they should complete the questionnaire. Both unpaid carers and paid care and support workers 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.

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[193] Smith & Malley (2012) Understanding and Addressing Underrepresentation in a Postal Survey of Social Care Users, p7; IPC (2021) ASCOF Refresh Consultation Feedback; Aznar et al (2021) ASCS Representativeness Main Report, p8, 47.

[194] Aznar et al (2021) ASCS Representativeness Methodology Review, p25.

[195] Caiels et al (2019) Exploring Views of Being a Proxy from the Perspective of Unpaid and Paid Carers.

[196] Rand et al (2017) Developing a Proxy Version of the Adult Social Care Toolkit (ASCOT).

[197] Caiels et al (2019) Exploring Views of Being a Proxy from the Perspective of Unpaid and Paid Carers.

[198] Aznar et al (2021) ASCS Representativeness Main Report; IPC (2020) ASCOF refresh Part 1, p47.

[199] Rand et al (2017) Validity and test-retest reliability of the self-completion adult social care outcomes toolkit.

> The ASCOT-Proxy questionnaire has recently been piloted in a survey of carers and people with dementia, who live at home. It was found to be a feasible method of data collection, along with the ASCOT-Carer, and the measure is valid and reliable.[200]

2.5.6 Translated questionnaires

The surveys offer translations in 17 languages.[201] There is limited uptake of the existing translations perhaps related to lack of awareness[202] of their availability among the surveys' audiences. Local authorities send a translation request sheet with the English questionnaire when they are aware that the recipient may not speak English, but information on preferred language is not consistently held by local authorities. Lower response among minority groups may relate less to translation than wider issues of trust and understanding (outlined above) as well as literacy, cultural issues, a lack of confidence and the use of dialects which are not available in a written form (e.g. Sylheti).[203] A previous review recommended ways in which the translated versions could be made more accessible.[204]

The translated questionnaires would benefit from further reviews as they have not undergone full validation testing or cultural reviews, except in a very limited way as part of the review of the satisfaction with social care surveys among ethnic minority groups.[205] PSSRU have developed guidance based on the development of culturally adapted and validated translations of ASCOT (Dutch, Finnish, German, Japanese, Norwegian) and ASCOT-Carer (Japanese, German, Finnish), following the best practice guidelines by ISPOR.[206] A validated approved translation should involve forward & back translation, cognitive testing, then a check on psychometrics (including at least, structural validity), if possible.

2.5.7 Large print and other options

All the questionnaires are offered in large print and local authorities are allowed to offer face-to-face or telephone interviews (using a standard provided script) when participants could not otherwise respond for reasons of accessibility.[207] The questionnaires can also be sent electronically if requested (not online survey).[208] However, people may not be aware of these options, the resource for these is limited and the use of telephone and face-to-face is limited to a small number of local authorities.

2.6 Survey Delivery Organisation

2.6.1 Adult Social Care data context

A review in 2020 by the Office for Statistics Regulation (OSR) found that the adult social care sector is very poorly served by data compared with the education and health sectors despite a public expenditure on the sector of nearly £25 billion. Potential reasons for this include responsibility for social care being de-centralised (to local authorities) involving private providers, and being partly self-funded and provided by unpaid carers.[209] Data are needed for the sector to

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[200] Unpublished report.
[201] Aznar et al (2021) ASCS Representativeness Methodology Review, p31.
[202] Aznar et al (2021) ASCS Representativeness Main Report p49, 50.
[203] Aznar et al (2021) ASCS Representativeness Main Report, p49.
[204] Aznar et al (2021) ASCS Representativeness Main Report.
[205] Gray et al (2014) Exploring Satisfaction with social care services.
206 https://www.pssru.ac.uk/ascot/translations/; Wild et al (2005); Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation.
[207] Aznar et al (2021) ASCS Representativeness Methodology Review, p12.
[208] Aznar et al (2021) ASCS Representativeness Methodology Review, p51.
[209] Wittenberg and King (2015) Data on Adult Social Care, p1.

solve problems, support efficiency and maximise outcomes and for individuals and families to make decisions about care.[210] This means that policy is being developed without adequate statistics and there are unanswered questions.[211] Another review suggested that the outcomes measured at the moment are process outcomes rather than outcomes for the individual, family or community which means we cannot see the whole person and tackle the root causes of problems, taking account of the skills, capacity and resilience of the wider community.[212]

Three areas were identified by the OSR for improving statistics about social care:[213]

- **Leadership and collaboration** across government departments (DHSC, DWP, BEIS), local authorities, private sector providers, the health sector, NHS Digital, NHSX, CQC and ONS.
    - "There needs to be a strong voice to champion statistics that meet a range of user needs and strong leadership to implement the required changes."[214]
    - In addition, as part of the development of technology in social care, infrastructure should be developed to support integration of health and social care data, innovative approaches to analysis and data linkage.
    - National Information Board's framework for action to be operationalised by NHS Digital and the client-level dataset proposed by DHSC form part of this leadership.[215]
    - There are pilot examples such as the development of a health and social care record in Greater Manchester. However, there are issues that not all Clinical Commissioning Groups (CCGs) and LAs map onto each other completely, making integration of health and care statistics challenging.[216] In addition, there are ongoing changes in the organisation of this and it is not yet known whether CCGs or Integrated Care Systems (ICSs) will be responsible for data sharing agreements and integration of the care records.
- **Addressing data gaps** because statistics have not kept pace with changes to service delivery:
    - Care outside statutory control (traditional route of relying on data from local authorities is not enough because they estimate a third of social care is self-funded)[217]
    - Unpaid care (there is limited evidence, but estimates suggest the value is 4-5 times that of publicly funded care)[218]
    - Experience: pathways in health and social care and understanding the quality of care (ASCS, SACE, LGA complaints data and CQC reports are only sources) and outcomes for those who experience social care (linking data on spending on care, needs being met and individual outcomes). Another review suggested person level links between health and social care data to understand movements through the systems.[219]

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[210] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p3.
[211] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p10.
[212] Cory (2019), Better Evidence for Better Care, p2.
[213] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p3-4.
[214] Office for Statistics Regulation (2020), Adult Social Care Statistics in England.
[215] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p10.
[216] Cory (2019), Better Evidence for Better Care, p4.
[217] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p8; Cory (2019), Better Evidence for Better Care, p8.
[218] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p8.
[219] Cory (2019), Better Evidence for Better Care, p19.

- **Improving existing official statistics**
    - areas to address include accessibility, coherence, quality, timeliness and granularity of data
    - improving access via a proposed ONS[220] Portal to signpost users to existing statistics.[221]

The Office for Statistics Regulation (OSR) sets out three pillars in a code of practice for statistics:

- trustworthiness (confidence in people and organisations that produce statistics)
- quality (based on data and methods)
- value (support society's need for information, including wider use by charities, community groups and individuals)

The purpose of statistics should be to:

- provide a robust evidence base for national and local policy development and decision making
- allow individuals and organisations to reach informed decisions, answer important questions, make the case for change or hold government to account.

A review in 2021 of the impact of the COVID-19 pandemic highlighted how the pandemic has demonstrated the need for statistics, the impact of well-communicated statistics on society (for government and citizens) with unprecedented engagement with statistics, and rapid developments to meet emerging needs. The importance of investment in data sharing and linking, data infrastructure and analytical resource was also flagged.[222]

The OSR assessed existing official statistics about social care (including ASCS and SACE) against these criteria:

- accessibility
- insight and coherence
- quality: the impact of care workers assisting with the ASCS was cited as a quality issue[223]
- timeliness
- granularity: more granular data is needed on characteristics of the person, their needs and the setting of care (e.g. SACE doesn't always include ethnicity in a consistent way as LAs can choose to include the question or use their own data, so this information is not available for all LAs, and religion is not included for any LAs)[224]

The published report contains only examples, not the full review but this should be obtained as part of the process of revising the surveys and any developments should be in line with the purposes and pillars set out by the OSR.

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[220] Office for National Statistics

[221] NHS Digital has made some ASCS and SACE data from 2016-17onwards available in a more interactive form using Power BI. Microsoft Power BI

[222] OSR (2021) Improving health and social care statistics, p4-5.

[223] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p17.

[224] Office for Statistics Regulation (2020), Adult Social Care Statistics in England, p18.

Subsequently, the OSR identified lessons from the pandemic which inform a strong statistical system (and which could also be seen as relevant for individual collections such as the ASCS and SACE)[225]. Data should be:

- transparent and trustworthy
- responsive and proactive – horizon scanning and sharing plans between statistics producers is needed and resource and data infrastructures need to be flexible to adapt to new demands[226]
- collaborative to meet gaps in the data from the perspective of data users, provide analytical leadership and co-ordination of statistics, and realise the potential from data linkage
- clear and insightful
- timely with consideration given to the trade-offs between timeliness and accuracy

The ASCS and SACE cover England only. An OSR review of adult social care statistics for Great Britain highlighted the differences in data collections between the nations.[227] Any new developments to ASCS and SACE should consider whether this improves or reduces the comparability with data from Wales and Scotland.

The review of ASCOF suggested that the introduction of client-level returns is relevant and may fit with proposed indicators under the new framework, suggesting that new returns should not be added but instead should fit with client-level data returns.[228] The DHSC 'Data saves lives' policy paper also suggests that client-level data returns will improve the way local authorities and central government can understand interactions of clients with social care.[229] Any revision to the ASCS and SACE should consider how client-level returns may offer opportunities or approaches for the surveys in the future. Other relevant developments which should be considered in revising the ASCS and SACE include:[230]

- a programme to adopt digital social care records which link with the NHS record and allow capture of real-time information (at registered care provider level)
- a data framework for adult care setting out what will be collected, and standards used
- DHSC and NHSE provider data project to develop a minimum dataset for long-term data capture from CQC registered care providers (care homes and domiciliary care)
- research on a national minimum data set for care homes for older adults, exploring the feasibility of implementation with providers using digital care records (DACHA study[231]).

The ASCS and SACE are not the only sources of information on outcomes and experience of care. The CQC annual report "State of Care", provides an annual assessment of health and social care in England, looking at trends, highlighting examples of good and outstanding care, and identifying factors that maintain high-quality care.[232] This is based on analysis of their inspection data, feedback from their 'Give Feedback on Care' service, phone calls and social media, qualitative interviews, analysis of other available data (e.g. Carer's UK survey) and expert input. It is notable

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[225] OSR (2021), Improving health and social care statistics, p5.

[226] OSR (2021), Improving health and social care statistics, p10.

[227] OSR (2020) ASC Statistics: a way forward for Great Britain, p3.

[228] IPC (2020), ASCOF refresh Part 1.

[229] DHSC (2022) **Error! Hyperlink reference not valid.**

[230] DHSC (2022) Data saves lives: reshaping health and social care with data (draft) - GOV.UK (www.gov.uk)

[231] DACHA Study

[232] IPC (2020), ASCOF refresh Part 1, p9.

that most experience evidence in that report concerns health, rather than social care and that it relies on information from other sources.[233]

2.6.2 Organisation of the surveys

Currently the survey guidance and materials are provided centrally by NHS Digital but the fieldwork is administered locally in local authorities (some administering surveys themselves and some sub-contracting to a survey provider). In a review of adult social care statistics more generally, the OSR commented that data quality is variable between local authorities and differences in interpretation affect the reliability of data and users' trust in it.[234] They suggest that local authorities should be upskilled about data capture and analysis to improve the quality of data submitted and enable them to monitor their own performance. Statistical resource for social care also needs to be improved for parity with health.[235]

Two previous reviews have sought the views of local authorities on continuing with the current local delivery or moving to a more central approach, or a more local approach. Both showed that there were differing views and no clear consensus.[236] The review of the representativeness of the surveys found that 40% of responding local authorities felt responsibility should stay with local authorities and 42% felt the organisation should be centralised, with 18% being uncertain.[237]

Arguments for retaining local control include:[238]

- the value of local intelligence (e.g., checking deaths in sample) and the design which means sample needs to be provided locally
- greater opportunities to promote the survey locally
- greater engagement from participants if the survey is 'owned' locally
- feedback from the survey on safeguarding flags are actioned locally (in some LAs)
- concern about the loss of funding for LAs associated with running the surveys
- the ability to include local variation in the questionnaire.

Arguments for centralised survey administration include:[239]

- improved consistency (e.g. in definitions, assumptions and procedures)
- improved efficiency (e.g. in scanning questionnaires rather than local manual data entry)
- increased local capacity to analyse data (if resource was not reduced).

Other developments may affect the balance of arguments in favour of central or local. For example with an online survey, it would be feasible to have local variation even with a survey being run centrally. Currently the sample is drawn by each local authority because only they hold the sample frame of eligible people. If a move was made to a client-level return to NHS Digital it is possible that the sample could also be managed centrally.

There are examples of other surveys which rely on local completion but where the fieldwork is administered centrally. The Active Lives Children and Young People survey has a questionnaire hosted by Ipsos but with the survey promoted locally by Active Partnerships and schools.[240] The

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[233] CQC (2021) The state of health care and adult social care in England.

[234] OSR (2020) ASC Statistics: a way forward for Great Britain, p3.

[235] OSR (2020) ASC Statistics: a way forward for Great Britain, p5.

[236] IPC (2020), ASCOF Refresh Part 1, p54.

[237] Aznar et al (2021) Representativeness of adult social care surveys Main Report, p70.

[238] Aznar et al (2021) Representativeness of adult social care surveys Main Report, p70.

[239] Aznar et al (2021) Representativeness of adult social care surveys Main Report.

[240] Ipsos (2022) Active Lives Children and Young People Technical Report.

National Student Survey involves a survey run by Ipsos, but individual universities promote its completion locally. The independence of the survey from the universities is one of the points used to encourage participation by students (making it clear their responses, including open ended, will be anonymous).[241]

2.7 Survey Delivery Mode

2.7.1 Decision to transition to a Push-to-web approach

ASCS and SACE are conducted using a paper self-completion approach and over the last few years many large scale paper self-completion surveys have moved to mixed methods (online and paper), using a push-to-web approach. Examples include the patient experience surveys Ipsos conducts for CQC (maternity, adult inpatient, children and young people), and the GP Patient Survey we conduct on behalf NHS England. The CQC adult inpatient survey is a good example to learn from as it covers an older population with 65% of the sample aged over 65. The last iteration of Your Care Rating (two syndicated surveys we conducted on behalf of care home providers until 2019) also used a Push-to-web approach for the survey of family and friends of care home residents.

Ipsos' scoping report for CQC listed the criteria that would be used to decide about the transition to a push-to-web approach.[242] They included:

1) Readiness of survey population (to complete the survey online)

2) Ability to deliver an online survey i.e. availability of telephone number and/or email addresses in the samples. The survey invitation with log in details can be sent by post if no email addresses are available but mobile number are important to send targeted SMS reminders.

3) Suitability of survey for an online method:

- the questionnaires need to be appropriate for online data collection, and 'device-agnostic' so that they can be completed on any device;
- response rates using a 'push-to-web' methodology tend to be lower than those using traditional methods, and so it is important to consider existing response rates for the survey to understand the likely impact of a new approach.

4) Other quality issues e.g. would online exacerbate existing non-response biases or reduce them?

5) other issues such as complexity of survey process and sampling. In the case of ASCS and SACE, this would include exploring and addressing any concerns stakeholders may have about the push-to-web approach, whether SMS reminders could be sent out and by whom, whether just SACE or both surveys should transition, and associated timings.

Pilots were carried out on both ASCS and SACE in 2018-19 in two local authorities. SACE had a push-to-web pilot with 29% of responses received online. On ASCS the initial invitation included both online and paper and 1.4% of responses were received online.[243] Those responding online had a younger age profile (and younger people tend to be under-represented in both surveys). A further online pilot was planned for SACE in 2020-21 but that year the survey was postponed until

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[241] https://www.thestudentsurvey.com/about-the-nss/

[242] CQC Patient Survey Programme (2019) Mixed Methods Scoping Report.

[243] Aznar et al (2021) ASCS Representativeness Main Report; IPC (2020) ASCOF Refresh Part 1, p59.

2021-22 with a plan for ten local authorities to participate[244] and so there are no published findings yet. It will be essential for findings from this to feed into recommendations for developments on SACE and ASCS.

2.7.2 Potential impact on response rate and representativeness

A push-to-web approach sometimes reduces the response rate so it will be important to consider the impacts of this in a context of generally declining response rates on the ASCS and SACE[245] when making the decision to transition to a push-to-web approach.

That being said, the drop in response rate could be partly mitigated by SMS reminders (if mobile numbers are available) – these have good impact on response rate overall but the impact differs between demographic groups. In CQC adult inpatient survey pilot, the response rate increased when the survey was transitioned to a push-to-web approach with 4 mailings and SMS reminders. It was 45.1% instead of 42.8% in the control group.[246] However, anecdotal evidence from local authorities indicates that currently their recording of mobile numbers for people with care and support needs and carers is patchy and some of the target population for the surveys do not have mobile phones. The consistency of recording is something which could be addressed in future through guidance to LAs and providers.

In addition, a push-to-web approach can affect response rates amongst different demographic groups in different ways. For example, it may bring people into the sample that would not otherwise respond, and it tends to increase the percentage of certain groups taking part e.g. young people. The maternity experience survey we conduct on behalf of CQC saw its response rate increase by 15 percentage points when the survey was transitioned to a push-to-web approach, from 37% in 2019 to 51% in 2021. Since response is lowest among younger carers in SACE a move to online may improve response among that group.[247]

2.7.3 Digital exclusion issues

Digital exclusion will be a major consideration for the audiences of ASCS and SACE: research by Age UK in 2021 highlighted that the older population are still less likely to be digitally included; among those aged 75+, more than 40% do not use the internet.[248] This situation has been the main argument for the surveys remaining paper based up to now. Office for National Statistics data from 2021 also shows that 14.9% people with a disability have never used the internet, compared to 6.3% of the UK population.[249] However, there is qualitative evidence that use of tablets and mobile phones may have increased among people with care needs and unpaid carers as a result of the pandemic.[250] In addition, in the recent social care white paper (People at the heart of care) the government made a commitment to boost the adoption of technology in ASC and use the full potential of technology to support people's lives and aspirations, which could lead to more people with care and support needs adopting digital technology over the coming years.

The Ipsos 'Tech tracker'[251] from 2018 showed that internet access tailed off significantly after the age of 65, and particularly amongst those in lower social grades. Further, while smartphone usage

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[244] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-carers-survey-2021-22; NHS Digital (2021) Personal Social Service: Survey of Adult Carers in England, Information and Guidance.

[245] Aznar et al (2021) ASCS Representativeness Main Report, p202; IPC (2020) ASCOF Refresh Part 1, p14.

[246] Ipsos (2019) NHS Adult Inpatient Survey.

[247] Aznar et al (2021) ASCS Representativeness Summary p25,50; Aznar et al (2021) ASCS Representativeness Methodology Review, p54.

[248] DHSC (2021) People at the Heart of Care, page 29.

[249] DHSC (2021) People at the Heart of Care, page 29.

[250] NHSX (2021) Reviews on Digital technology and Digital skills in ASC.

[251] Ipsos (2018) Tech Tracker Q3 2018 Report.

was increasing, the tracker found that older smartphone owners used their phone for a more limited range of activities.

2.7.4 Benefits and disadvantages for the content of ASCS and SACE questionnaires

When transitioning to mixed paper and online approaches, questionnaires need to be reviewed to ensure they are device agnostic. Ipsos device-agnostic design principles focus on harmonising visual appearance, removing or reducing non-essential content, and standardising question text and response options across devices and modes. Our mobile-first questionnaire design principles include:

- avoiding exceeding 140 characters in the question's stem (including spaces)
- limiting the number of response options to 7 per question
- avoiding the use of sliders
- using five point scales
- removing conversational phrases and unnecessary wording
- ensuring the question stem, instructions and response categories are distinctly formatted.[252]

If revisions are made to the content of the ASCS and SACE questionnaires in light of changes to ASCOF then changes or tweaks to ensure the questionnaires are device agnostic could be made simultaneously.

2.7.5 Scheduling of postal mailings and survey invitations

With a push-to-web survey a secondary data collection mode, typically paper-based, is currently essential to increase response rates and reduce the forms of non-coverage and non-response bias typically observed in online surveys (which produce samples that are younger and less socially deprived than the population at large). However, in order to persuade a reasonably large proportion of the sample to respond online rather than by post, the mail questionnaire option has to be withheld during early mailings. To maximise the effectiveness of the SMS reminders they would need to be carefully integrated with the postal reminders: in the CQC patient experience surveys SMS reminders are usually timed to arrive a day or so after the postal invitation. Ideally they should make explicit reference to the latter and include a direct link to the survey questionnaire, thereby bypassing the need for recipients to type in URLs.

2.7.6 Other considerations

Experience from other surveys that have transitioned to a push-to-web approach show that:

- For surveys as important as ASCS and SACE a consultation process with local authorities, organisations representing people with care and support needs and unpaid carers, and other stakeholders, would be valuable. This could be held following the findings from the SACE pilot to inform whether to roll this out on the survey and to consider a mixed-mode approach on the ASCS.

- A pilot with some local authorities would be important to assess the feasibility of a push-to-web approach, explore the availability of contact details (mobile, email) and practicalities re. mailouts and SMS reminders, and assess the impact of a push-to-web approach on response rate and analysis. NHSD has designed and conducted an online pilot for SACE and the results are expected over the coming months.

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[252] CQC Patient Survey Programme (2019) Mixed Methods Scoping Report.

- The feasibility of transitioning the Easy Read version of ASCS to a mixed method approach would need to be explored in more detail. Adapting ASCOT ER to an online approach has been tried and tested with limited success.[253]

- The transition to a push-to-web approach could make use of translated questionnaires easier (though noting that these would also need to be offered on paper).

2.8 Survey Delivery Timings

2.8.1 Frequency

The current frequencies for the surveys are annually for ASCS and every two years for SACE. They have run this way since 2010-11 for ASCS and 2012-13 for SACE (after a voluntary SACE in 2009-10).[254] In 2020-21 because of the pandemic the SACE due to take place was postponed until 2021-22 and the ASCS was made voluntary. Of the potential 151 local authorities with responsibility for adult social care only 18 took part in the ASCS in 2020-21.

Previous research about the surveys has shown that opinions among local authorities and stakeholders are divided on changing the frequency of the surveys with the following (sometimes conflicting) views being held.[255]

- SACE should become annual
- ASCS should become less frequent:
  - so it alternates with SACE (each happening every other year), or
  - to happen the same year as SACE to have a year between surveys

- ASCS should become more frequent
- The current timings should be maintained.

Various considerations feed into these views:

- **Burden on local authorities:**

  - Local authorities are limited in the analytical use they can make of the data because of the cycle of constant surveys so reducing frequency could help

  - Reducing frequency could free up resource to introduce a short-term users survey in alternate years[256]

  - Although data might be felt to be needed more frequently, it is not realistic to get this from survey-based measures.[257]

- **Burden on participants:**

  - In the context of declining response rates (from 40.5 per cent in 2010-11 to 29.3 per cent in 2019-20[258], and from 40.1 per cent in 2009-10 to 32.5 per cent in 2021-22 for SACE)

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[253] Razik et al (2019) Easy Read: usability Evaluation of an Electronic Adaptation.

[254] Aznar et al (2021) ASCS Representativeness Main Report, p23; Wittenberg and King (2015) Data on Adult Social Care, p13.

[255] Aznar et al (2021) ASCS Representativeness Main Report, p71.

[256] Aznar et al (2021) ASCS Representativeness Methodology Review, p35.

[257] IPC (2020) ASCOF Refresh Part 1, p53.

[258] Fieldwork for 2020-2021 survey took place while a national lockdown was in place and as such the survey was made voluntary for this wave. For this reason, response rates for 2020-21 survey are not included as only 18 local authorities took part, meaning figures would not be comparable.

and repeated sampling of some survey strata reducing the frequency of the ASCS would reduce burden on participants and might help address these issues.[259]

- **Need for up-to-date data**
  - A government review of health and social care data commented that with annual data collections, information is often not up to date which prevents the government from identifying problems and responding in real time.[260]
- **The need for people receiving services and carers to be able to provide more frequent feedback**
  - There is appetite for users to be given more chances to feedback as needs can change quickly but not via ASCS.[261]
  - There is also appetite for carers to be given more chances to feedback as responsibilities can change quickly, but the best way for more frequent feedback may not be via SACE.[262]
  - One suggestion for allowing more regular feedback without increasing the frequency of the surveys is that the information should be part of annual or end of service reviews or other points of contact not just as a standalone survey.[263] However this could result in a loss of anonymity.[264]

2.8.2 Timing of survey administration and fieldwork

For ASCS the current survey timings involve sampling from September to December, fieldwork from January to March and data submission to NHS Digital from April to June. These timings were chosen to minimise burden on LAs by sampling at a similar time to the extraction of information for other returns such as SALT and to avoid interfering with end of year reporting by LAs.[265] The data are published in October of the fieldwork year. This means that fieldwork is carried out during times of winter pressures and greater ill-health, however changing the timing could affect comparability with previous years.

For SACE the current survey timings involve sampling from June to October, fieldwork is October to November.[266] Findings are published in June of the year following fieldwork.

There is some concern that ASCOF data are not provided in a timely enough fashion to be as useful as they could be.[267]

2.8.3 Other issues related to timing

The timing of fieldwork can be an issue at individual respondent level - individuals can consider themselves too ill or too recovered to participate, particularly if their care was short-term.[268] If the

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[259] Aznar et al (2021) ASCS Representativeness Methodology Review, p35.

[260] Data saves lives: reshaping health and social care with data (draft) - GOV.UK (www.gov.uk)

[261] Aznar et al (2021) ASCS Representativeness Main Report, p71.

[262] Aznar et al (2021) ASCS Representativeness Main Report, p71.

[263] IPC (2021) ASCOF Refresh Consultation Feedback, p15.

[264] IPC (2021) Revising the Service User Care Survey for OPF, p18.

[265] Aznar et al (2021) ASCS Representativeness Methodology Review, p11-13.

[266] Aznar et al, (2021) ASCS Representativeness Methodology Review, p4; IPC (2020) ASCOF Refresh Part 2, p43.

[267] IPC (2020) ASCOF Refresh Part 1, p27.

[268] Aznar et al (2021) ASCS Representativeness Main Report, p11.

surveys are extended to include people who have received signposting or information, then a questionnaire up to year after that information was received may results in problems of recall.[269] A view was expressed by a contributor to the ASCOF refresh that "we need a mechanism that asks the current ASC Survey questions whilst someone is having, or has completed, their experience of ASC".[270]

Because of ill-health and the need for support among respondents a long enough fieldwork period is needed to enable people to participate.

Other developments in social care statistics may involve more frequent client level data returns from local authorities and any changes to the surveys should reflect this with any change to the timings and frequencies being suitable for the next 5-10 years to avoid future changes.[271]

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[269] IPC (2021) Revising the Service User Care Survey for OPF, p18.

[270] IPC (2021) Revising the Service User Care Survey for OPF, p17.

[271] IPC (2020) ASCOF Refresh Part 1, p4.

3 Scoping Options

3.1 Introduction

The intention of considering options for the surveys is to outline some of the trade-offs for changes to the surveys under the different elements which may be changed. A series of options for the different aspects of the surveys were set out and agreed with DHSC and partners before the stakeholder interviews and informed the topic guide. During the stakeholder interviews we had an open discussion on these topics and also presented some different options and trade-offs under each topic in order to understand the range and strength of views about them. The options presented during each interview depended on the interests and expertise of the stakeholders and what had already been covered in the more open discussion.

3.2 Content and purpose of surveys

Aim: To ensure that information collected is fit for purpose for the stakeholders' needs and truly reflective of the needs and experiences of those both using care services and providing them. The Authority want to ensure the right questions are asked to be able to evidence what we need internally and in LAs.

3.2.1 Purpose for stakeholders

In order to ensure that information collected in the surveys is 'fit for purpose for stakeholders' needs', it is essential to understand what the purposes of the surveys are and which stakeholders are relevant. During the stakeholder interviews we spoke to a range of stakeholders to understand their views on the current surveys and their needs from them now and in the future. In terms of purpose there are several options to be considered here. We explored the extent to which the surveys do or should fulfil the following purposes, some of which may be compatible within a single survey (ASCS or SACE) and some of which may not be. The surveys are used to inform local authorities of the experiences of some of their services' users and carers. It should also be noted that an important purpose of the surveys is to feed into the Adult Social Care Outcomes Framework. ASCOF relies on the surveys alongside other health and social care system data. Some of the potential options below would also rely on other data (not just the surveys).

3.2.2 Content

Only once the purpose is understood can there be a proper development of content options. However, based on existing knowledge of the surveys and the potential purposes various content options were considered, some of which are alternatives and others which could be combined.

3.3 Representativeness: Survey coverage

Aim: Define the eligible population to better match the user groups covered by the Care Act. Options are required for how data could be collected from a much broader group of respondents so that the surveys are fully representative of the entire social care population (as defined in the Care Act).

When the ASCS and SACE were designed it was recognised that some important groups were excluded because local authorities did not hold appropriate sample information about them or they were not able to take part. Therefore the focus has been on adults with a long-term package of care and adult carers in contact with the local authority. Since then alternative ways of meeting care and support needs have become more important and so the focus on long-term care to the exclusion of short-term care, signposting and equipment, and NHS funded continuing health care (CHC) has become more problematic. The Care Act also gives local authorities responsibility for prevention and supporting the wellbeing of a wider group of people with needs.

Care Act: Preventing needs for care and support[272]

(1) A local authority must provide or arrange for the provision of services, facilities or resources, or take other steps, which it considers will:

(a) contribute towards preventing or delaying the development by adults in its area of needs for care and support;

(b) contribute towards preventing or delaying the development by carers in its area of needs for support;

(c) reduce the needs for care and support of adults in its area;

(d) reduce the needs for support of carers in its area

(2) In performing that duty, a local authority must have regard to:

(a) the importance of identifying services, facilities and resources already available in the authority's area and the extent to which the authority could involve or make use of them in performing that duty;

(b) the importance of identifying adults in the authority's area with needs for care and support which are not being met (by the authority or otherwise);

(c) the importance of identifying carers in the authority's area with needs for support which are not being met (by the authority or otherwise).

The increasing role of the voluntary sector and the recognition of unmet needs means that those who are not in any kind of contact with the local authority might also be relevant for the surveys. In addition, with increasing levels of dementia among older people, the implications of excluding those who lack mental capacity to take part has become greater. The options considered were about the eligible population to the covered and whether to include those who lack capacity to respond for themselves.

3.4 Representativeness: Accessibility and participation

Aim: It is known from the Ipsos work that the existing surveys are not representative of the current cohort in terms of issue and response. It is important to understand what delivery mechanism options are available to improve the reach of the survey particularly to be inclusive of potentially harder to reach groups.

Differences in response rates affect the representativeness of SACE and ASCS. Improving the accessibility of the survey instruments for particular groups, and improving engagement and motivation to take part, could help improve participation, and the representativeness of the surveys more generally. In terms of accessibility, ways of capturing the views of people who lack capacity

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[272] https://www.legislation.gov.uk/ukpga/2014/23/section/2/enacted

to complete a questionnaire on paper could be further developed. In particular, the acceptability and feasibility of collecting proxy responses about people who lack capacity and whose experience would otherwise not be included in ASCS is an option which has not been implemented on the main survey, but which has been developed. In this section we have listed separately options for improving participation and options for improving accessibility. Some of these were explored when the surveys were first designed and are worth re-considering now, though issues such as capacity may still remain. The options considered included increasing participation, particularly from minority or seldom heard groups, and increasing accessibility more generally. Some of the options have already been developed but not implemented on the surveys and others are new options or represent an increased focus on accessibility procedures already suggested for the surveys.

3.5 Survey Delivery: Organisation

Aim: Review survey delivery models in light of ASCOF refresh and other social care data reforms. Understand the benefits and costs of delivering the surveys in a centralised national way compared to local authorities having responsibility for delivering the surveys.

NHS Digital centrally organises the surveys, providing the questionnaires (multiple versions), invitation letters, guidance and support on running them. They are administered locally in each local authority using the administrative records from which they also extract data for the SALT returns. Some local authorities run the survey themselves and others commission a survey organisation to administer the data collection. The ASCOF refresh and the implications of the Care Act suggest a wider group of people should be included in the surveys, not all of whom are in contact with the local authority (see coverage section). Social care reforms will potentially involve a wider range of people being in contact with local authorities, including self-funders metering to the care cap or asking their LA to arrange their care under the 'fair cost of care'. Moves to a client level data return to NHS Digital offers the potential for standardised information being shared by local authorities at an individual level. Although the current plans for the client level dataset would not include contact details, the move to individual level returns to NHS Digital might make this more feasible (with additional information governance in place). All of these have implications for the benefits and costs of the surveys being centrally or locally administered.

3.6 Survey Delivery: Mode

Aim: Review the potential to use technology solutions to deliver the surveys online.

Over the last few years many large-scale paper self-completion surveys conducted on behalf of the UK government have moved to mixed mode (online and paper), using a push-to-web approach. This means that survey invitations are sent out by post or email (depending on the contact details available) with log in details to complete the survey online. Reminders sent out by post will then include a paper version of the questionnaire so that people who do not use the internet or do not have access can still take part. Paper questionnaires are not sent out with the initial survey invitation.

Online self-completion of surveys has many advantages over paper, regarding the quality of the data collected, the speed of the data collection and processing, the costs and environmental impact (no printing and postage required). However, the transition to a push-to-web approach needs to be carefully considered, taking into account the survey audience, and their likelihood of using digital technology.

Small pilots of a push-to-web approach have taken place on SACE and ASCS and findings from the most recent pilot on SACE will provide important learning points.

3.7 Survey Delivery: Frequency and timings

Aim: Understand the best options for the timings of delivery of the surveys. As the survey needs to cover those in long-term, short-term, transient and integrated care as well as information and advice seekers who do not go on to receive any formal care, options should be presented for how to time the delivery of the surveys that will maximise responses across all the different kinds of user groups.

Currently the ASCS takes place annually and the SACE every two years (though with a break in 2020-21 because of the pandemic). It includes those receiving a long-term package of care or carers who have been in touch with the local authority or their partners at the time of sampling. The inclusion of wider groups in the sample has implications for the appropriate frequency. The burden on local authorities also needs to be considered.

3.8 Combined options

As well as exploring trade-offs and the multiple options for each aspect of the survey, consideration was given to some combined options, looking at how changes in different aspects of the survey would work together. These and other combinations which emerged and a timeframe for implementation are considered in the option appraisals chapter.

4 Findings from stakeholder interviews

4.1 Background and methodology

For this discovery project, a qualitative approach to seeking the input of stakeholders was used to obtain an in-depth and well-rounded view of the viable options for revising the Adult Social Care Survey (ASCS) and the Survey of Adult Carers in England (SACE).

In total,14 depth stakeholder interviews were conducted with 19 participants. Some interviews were paired or group interviews within or across organisations according to the preference of the participants. Each interview lasted up to 80 minutes and took place via Microsoft Teams between 9th and 25th March 2022. Interviews were carried out with a variety of stakeholders including central and other government bodies, local authorities and organisations representing people with care needs. This included people with these types of experience:

- running or coordinating the surveys,
- responsibility for collating evidence about social care in their organisations or research projects and using it to provide insight or contribute to performance frameworks,
- responsibility for digitising records,
- conducting research with people with care needs and disability, including those lacking capacity
- representing the experiences of those with care and support needs.

All participants were aware of the surveys and many had a good understanding of them because of their involvement in running them or using the data.

The aim of the interviews was to better understand their views on both the current ASCS & SACE, their purpose and uses, and how these surveys could best be revised in the future. Consideration of revisions in the future included discussions around content, coverage, accessibility, survey organisation, frequency, and mode.

All stakeholders were purposively selected by Ipsos and DHSC based on who would likely be able to offer useful insight into both surveys, and the overall purpose of ASC and the surveys. The stakeholders were then recruited by Ipsos. Quotas were set to include a range of experience and knowledge from across ASC.

Table 4.1 outlines the number of interviews completed across the four key groups.

Table 4.1: In-depth interviews

Type	Number of interviews
Central government	3
Local government	6
Organisations representing people with care and support needs	2
Other (academic, organisations focusing on user voice or providing advice to social care professionals)	3
Total	**14**

4.1.2 Notes about the interpretation of findings

The stakeholder interviews were qualitative with a purposive sample. Unlike quantitative surveys, this approach is not designed to provide statistically representative data, but rather it is designed to be illustrative and exploratory, with findings presented thematically rather than quantified throughout this report.

Verbatim comments from the interviews have been included in this report. These should not be interpreted as defining the views of all participants but have been selected to provide insight into a particular issue or topic expressed at a particular point in time. All quotes used throughout this report are taken from the qualitative interviews. Where there is a risk that a comment might identify an individual the inclusion of their quote has been checked with them.

4.2 Content

4.2.1 Purpose of ASC and frameworks for assessing whether it meets those

Describing the purpose of adult social care can be challenging as it is individual to each person. There was also felt to be a tension between rhetoric and reality. There is an aspiration for it to “enable people to live the life they want to lead" but the reality may be that is it about "supporting vulnerable people with social care needs". It was suggested that historically social care has been something which is done to people but there is an increasing move to co-production and putting the person in control. Nonetheless there was **broad consistency** among stakeholders in the purposes of ASC:

- Adult Social Care was felt to be part of a **public duty** to support people who are vulnerable or cannot meet their own needs to ensure they have the **same rights and equality** with those who are able, and receive support as and when they need it.

“To help and support people who may have short, medium or long-term vulnerabilities which mean they need support to live as well as they can.” **Central government**

- There was an emphasis on **independence**, perhaps involving community resources so that it was not just about LAs providing support.

“To achieve better independence and improved quality of life for people who might not be able to undertake everything for themselves” **Other**

- The focus was not just on support with practical things like washing and dressing but also on ability to take part in the wider community and on their **own wellbeing** with the Care Act promoting a very broad definition of wellbeing.

- Safeguarding was also mentioned with **support and resources to enable people to keep safe** being important.

4.2.2 Purpose of ASCS and SACE now and in the future

There was a consensus that the surveys are and should be used for measuring **outcomes** and **experience** rather than processes. Outcomes and experience were seen as distinct but equally important. Although one organisation said process measures were historically what they relied on, it was pointed out by others that process data is collected by other means within LAs so does not need to be collected in these surveys.

Outcomes were seen as important because LAs have a responsibility to support and enable the whole person, not just deliver care, and this is related closely to views on the purpose of ASC. What matters is not just the quality of the care and support but whether the people receiving it are "achieving the things they would like to achieve."

''Outcomes are important because that is why we are giving people care and support. It should be to enable them to have better health and wellbeing outcomes.'' **Other**

Experience was felt to be important because for people receiving care and support that is what is most important to them; they may find it hard to see beyond their current experience. The current surveys ask about the experience of services received but it was suggested that experience should extend to the experience of accessing services.

"The experience that somebody has of accessing and then being provided with adult social care is a really important thing that we need to capture and that should be captured across the board." **Central government**

There was general agreement that the surveys should **align with the ethos and principles of the Care Act** but there were mixed views about the extent to which they already do.[273]

"I think what's good about the current surveys is that they do cover...all of the domains in the Care Act, so it's much more about wellbeing…it's very much about getting the views, the experience and the self-assessed perspective of people, rather than us assuming that because we've delivered X, Y and Z service and we did it within a reasonable time that everything's OK." **Local government**

"[There is a] Risk that [you] end up collecting more and more data about the existing array of familiar services that have been there for many decades and it's not consistent with the aspirations, ambitions, duties, and spirit of the Care Act in terms of people being able to direct their own support." **Organisation representing people with care and support needs**

Despite the consistency in the aspiration to collect both experience and outcomes information there were **challenges and limitations** expressed. This related to the **balance between the need for consistency and asking about individual experiences and preferences for outcomes**. The point of the Adult Social Care Outcomes Framework (ASCOF) into which ASCS and SACE feed is to provide an overarching picture of ASC outcomes. But one of the challenges for the survey is that there is a huge variety in those who are eligible for the ASCS, from people in their early 20s

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[273] Appendix A contains a table showing how ASCOT maps to the Care Act.

with mental health problems to people in their late 90s with dementia or frailty. It was felt to be important not to be prescriptive about the outcomes people should experience. Examples were given such as younger people valuing independence while older people may value feeling safe or supported or not all people feeling employment is relevant to them.[274]

"It's actually a huge group, and so they all will have different needs and preferences.'' **Other**

It was felt that the advantage of the Adult Social Care Outcomes Toolkit (ASCOT),[275] which is included in the ASCS and SACE, is that despite these differences you can compare outcomes across these different groups, including in relation to quality of life. However, people also need an opportunity to raise things about their experience which may be more specific.

"It probably is more important to focus upon outcomes but to make sure that people do have an opportunity to raise concerns about … the standards that aren't very good, … like reliability or the extent to which support workers will want to maintain a relationship with you.'' **Other**

However, although questions which reflect individual experience were felt to be valuable, there was also a view that questions should be as general as possible to avoid stereotyping people in what was asked. An example was including questions which do not prescribe how people should be living but reflect how they want to live e.g. "Are they enabled to do what they want to do?".

From the perspective of a national organisation with responsibility for ensuring people who use health and care services can share their experience to improve standards of care, the ASCS and SACE were felt to look at satisfaction (experience) too broadly. They contrasted this with the data they collect themselves which is far more focussed on user experience.

It was recognised that the content should be **driven by DHSC and LA needs but should also reflect lived experience**, being **co-produced to ensure it reflects the experience and aspirations of those with care and support needs**. An organisation representing those with care and support needs felt that the ASCS should be measuring how ASC contributes to "a meaningful and equal life or good lives". The Making it Real, framework and statement of what good, personalised care and support looks like was suggested as a model for this co-produced person-centred approach. However, there was felt to be a tension in these aspirations.

''The voice of lived experience needs to be a central part of the assurance process.'' **Local government**

The content of the surveys matters not just to provide the most useful data about what is happening now but because it could itself **shape what happens in ASC**. An example was that, given the emphasis on prevention, the impacts of ASC on reducing admissions to hospital should be measured rather than whether those coming out of hospital can go into ASC. Both organisations with an overview of LA activities and an organisation representing lived experience expressed this.

Data collection should reflect: "where you want to go, not just where you are at the moment." **Organisation representing people with care and support needs**

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[274] The ASCOT questions were designed with this objective in mind. They should be answered from the person's own preferences, values and attitudes. The questions were also designed to have broad relevance across age groups and different support needs.
[275] ASCOT was developed as a measure' of social care outcomes. ASCOT measures the social care related quality of life of different aspects of service users' life (SCRQoL) in the ASCS and carer social care related quality of life (CarerSCRQoL) in SACE.

Any assurance framework should be: ‘‘driving the right behaviours by measuring the right things.’’ **Local government**

4.2.3 Use of ASCS and SACE

There was a general sense that more use could be made of the data from the surveys because of the potential value they offered. For example the national consistency of the surveys was felt to be important and there was potential for local use.

‘‘That’s the value of having something that’s nationally collected and is standardised.’’ **Other**

Even at a local level the consistency was valued, alongside the flexibility to identify local issues. **Local authorities use the results**:

- to monitor their LA performance
- to benchmark against other similar LAs
- as an external sense check against the national picture
- to prompt further research locally
- as ‘pat on the back’ if they are doing well
- as a ‘temperature gauge’.

In practice, however, this local use was variable and results were not always shared in a way which was accessible and could lead to changes in services. The surveys were valued locally, however, there was limited evidence of results shaping services locally and one LA member of staff said she was not aware of any radical changes driven by the survey results in her ten years in the LA. However, there was evidence of local use for improvement in some areas.

‘‘We’re using it locally, that was the whole thing around sector led improvement, that we’ve tried to bring into our use of the surveys. So it doesn’t matter, in a way, what’s happening nationally, if this survey continues to be useful locally.” **Local government**

‘‘It’s written into the documents that there’s an expectation that local authorities will use this for improving services locally, but there’s no national framework, there’s no national challenge around that.’’ **Local government**

There was a strong theme that LAs lack research capacity to make use of the findings.[276] This was reported by those in LAs, as well stakeholders from other organisations. This did not reflect a lack of skills but rather a lack of ‘manpower’ meaning only essential reports were produced rather than detailed research such as looking at how the data map to the social care journey. Because of the pandemic and pressures on capacity in LA ASC statistics research teams, the extent to which the surveys were actually used in LAs varied with activities ranging from quite complex analysis to no recent use (not since the 2018-19 surveys).

"If I'm honest with you, we don't have enough time to analyse into details.” **Local government**

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[276] This is in line with findings from the MAX project, See Heath, C., Malley, J., Razik, K., Jones, K., Forder, J., Fox, D., Caiels, J., and Beecham, J. (2015) How can MAX help local authorities to use social care data to inform local policy?

LAs felt as though they were in a cycle without enough time between surveys to use the results before the next survey has to be run. Furthermore, managers expect analysis on the latest results and there is always another survey about to be published with no time to analyse it once it is.

“It's a cycle repeating and every time I present this to a senior manager, they always say, 'It's really great. We need to do more analysis on this. We need to link this with this. Link this with that,' and by the time I come to linking various things, the new survey comes out.’’ **Local government**

Suggested approaches to overcoming this pressure on local authorities included:

- reducing the frequency of the surveys (see section 4.7)
- centralising the surveys (see section 4.5)
- working with and paying for the time of user groups who might be interested in using and interpreting the results e.g. mental health service users.

LAs add questions and text boxes to the surveys so that they can gain important local information and understand why people feel the way they do. This is sometimes supplemented by people calling the council for support with completing the survey. Through this they are able to hear what people actually think about the services they receive and LAs are able to “listen to people about local issues”.

National government use of the data was also limited. As a result of wide confidence intervals in the data, even at a national level some measures such as satisfaction were relatively static despite reductions in budgets and support and so there was concern in some quarters about how the evidence from the surveys could be used, for example to withhold money from the sector.

It was felt to be unclear how DHSC use the results, though at least some participants expressed the view that DHSC should be the primary user of the data.[277] NHS Digital’s role is to lead on data collection and analysis but they do not use it for policy inferences as that is beyond their remit. As a result there was a perception outside NHSD and DHSC that the findings have not been pushed out or become part of the conversation about ASC.

‘‘NHS Digital have got limited resources, they do the statistical work on it and they put it out. It's mainly data files as opposed to findings. Maybe there's nothing in there but then if there's nothing in there, then that should lead to a revision.…We can't just keep doing it just because it's on the timetable.’’ **Local government**

Other organisations which took part in the research saw the potential in the data but made limited use of it. The reasons for this included:

- It not being possible from the publicly available data set to identify people with specific impairments (e.g. sight loss), which would make the data useful to organisations representing people with particular support needs. Instead they use national general population surveys such as the English Longitudinal Study of Ageing (ELSA) and Understanding Society (UKHLS).
- It was felt the surveys collected ‘what the system wants’ rather than being for the people and ‘asking the right questions’ to reflect their experience and outcomes. The surveys may lack

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[277] There have been a number of (mostly NIHR-funded) projects to analyse ASCS and SACE, so data are being used by academics in projects funded by DHSC but there was a lack of awareness of this among some of the stakeholders we spoke to.

credibility among some groups as they are not seen as ‘service user led’ and there might be more confidence among these groups in a survey led by an organisation such as Healthwatch.

- Awareness of the surveys and what they could offer was perceived to be low among people with care and support needs and carers.
- Awareness was also low among organisations which might use the results for assurance or assessing how their guidance is used.
- The complexity of the measures, for example, the quality of life measure was not felt to be easy for the public to understand in the way it is presented.
- Difficulty accessing the data, beyond the summary reports published.

“The ambition should be to be able to make the surveys understood at many levels, whether it's an individual level, a local authority level, regional level, national level and it's a difficult trick to do but … if we can at least move it in that direction whereby more people understand it, that will produce better outcomes for people in itself.” **Local government**

4.2.4 Content

There is a tension between:

- a feeling that the questionnaires are too long and burdensome, leading to participant fatigue and satisficing[278] in how participants respond which suggests they need to be shortened, and
- a sense that there needs to be more scope to ask about what matters to the LA or people using care services, which suggests a longer questionnaire.

Furthermore, the consistency of questions from year to year was felt to be important for the production of trend data. One way of addressing these conflicting needs could be having a core content which is asked every year for consistency and then questions which are not asked every year but which come up from time to time under a particular theme.

It was noted that LAs most frequently add questions about dignity and respect among their optional questions and it was suggested that this should be added to the core questionnaire.[279] Another suggestion was that people could be asked about their ideal care service. Access to additional demographics which could identify particular user or carer groups such as those with a vision impairment would widen the use of the data.

Among existing content, questions on safety and whether services make them feel safe, experience of services and whether information is easy to use and accessible were felt to be particularly valuable.

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[278] Participants choosing the middle option rather than really considering their answers.

[279] Although the questions in the ASCS 10: ‘Which of these statements best describes how having help to do things makes you think and feel about yourself?’ and 11 ‘Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?’ are intended to capture information about dignity.

4.2.5 Other sources of evidence

Although LAs did conduct other surveys a view was expressed that the ASCS and SACE were the most comprehensive source of information. There was felt to be a paucity of data on processes and outcomes in adult social care. There was also a perception from outside that LAs do not do much at a local level outside the statutory surveys, perhaps related to capacity. However, LAs provided examples of other evidence they gather:

- Qualitative evidence using a ‘three conversations’ approach soon after contact – which was appropriate for longer term users of care and shorter interactions e.g. for advice. It was conducted by telephone, taking about 10 minutes, while the interaction was fresh in their mind. There was little formal recording of findings but it was felt to be valuable for identifying the impact of the interaction with the LA using a strength based, relationship based approach which enables people to report on what they didn’t like or what went well outside the Care Act domains.

- Short surveys at reviews or following provision of occupational therapy or reablement, which may be run by the service areas and contain less than ten questions. The LA can include the questions they need and change them over time.

- Short-term service users survey.

- 'Direct feedback in the moment' when interacting with people with care needs and carers.

Other organisations used:

- qualitative data from ‘Experts by Experience’, involving the public in inspections
- ‘Give Feedback on Care’ online questionnaires
- national surveys such as ELSA, Labour Force Survey, Understanding Society, Active Lives Survey and Millennium Cohort Study.

4.2.6 Implications of other ASC changes for purpose and content

There was a recognition that a variety of changes are taking place in the ASC sector at the same time, which have long-term implications. This affects how the surveys might be changed as they are closely related to other aspects of social care statistics and evidence. It was suggested that there could be an interim version of the surveys followed by an ideal version once other changes were in place.

‘‘There's also the massive context of a huge programme of reform, right across adult social care, whether it's the Build Back Better plan with the charging reforms or the white paper [on wider system reform, including] … all the work around assurance. …The government describes that as a 10-year vision.” **Local government**

The integration of health and social care also has implications for the surveys as people may not be aware of where their care is coming from and there is a need to avoid asking the same thing twice to avoid burden on participants, something which is highlighted in the LGA response to the Health and Social Care integration white Paper.[280]

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[280] LGA response to Health and social care integration: joining up care for people, places and populations | Local Government Association

Participants were aware that CQC are developing a framework for inspecting LA's delivery of adult social care. It was suggested that CQC would have a framework for this assurance and that ASCOF would need to change to reflect this and the surveys would then feed into that revised framework. The CQC assurance framework has six evidence categories that they would use to make judgements:

- people's experience,
- processes,
- outcomes,
- observation of care and care environment,
- feedback from staff and leaders, and
- feedback from partner organisations.

"ASCS and SACE will feed into the category 'people's experience." **Central government**

"That's what they [LAs] would want the surveys to function as, to be able to provide the evidence that they need in order to fulfil that inspection requirement from the CQC.'' **Local government**

The CQC approach was described as taking a human rights approach and the surveys would ideally provide evidence in line with this approach.

"I think we would probably go to the human rights as core of all of this. So, any information that allows us to understand how the rights of the individual are being protected or not or supported or not, especially when it comes to things like privacy and dignity and a family life, that's probably the core of what we would ideally like. Especially if we could have it in a categorical form." **Central government**

Another priority area from CQC's perspective is research which is able to uncover issues such as bullying or abuse in 'closed cultures'. It was pointed out that people with reduced capacity are most likely to be vulnerable and families and carers need to be involved in identifying these situations. As well as affecting the content of the surveys this would have implications for frequency since information would be needed much more regularly to uncover these issues.

It was felt that the development of the CQC assurance framework should and would come first (before the re-development of the surveys), however there were some concerns about the timescale for developing and implementing the new assurance framework and whether it was too challenging.

''Assurance would be ahead of the surveys, as the timelines currently stand, because it's due to go live from the 1st April 2023.'' **Local government**

DHSC are currently in the process of implementing a Client Level Data collection, which will replace SALT to track provision and the process journey of the individual. There was a suggestion from a central LA organisation that in the future Client Level Data from LAs and routine data might provide for some information needs and that there should not be too much emphasis on the user surveys. An LA also described how this Client Level Data could be helpful to track journeys through the system and how people experience it (though this is not part of the current plans for this development). The Client Level Data would be anonymised and so provision of identifiable information from LAs for a survey sample would raise information governance issues which would need to be overcome (potentially through provision of identifiable information separately for the specific purpose of issuing survey invitations).

There are also plans for a national Minimum Data Set (MDS) using registered provider digital social care records being developed by NHSE and DHSC and one for care homes being developed by the DACHA project.[281] However, there was considerable work to be done in the digitisation of social care records and technicalities of data sharing to make the most use of a Minimum Data Set (MDS) from registered care providers.

4.3 Coverage and representativeness

4.3.1 Challenges in reaching current eligible respondents for ASCS

Currently the ASCS focuses on long-term users of local authority funded care and it was agreed they are an important group.

Participants mentioned various challenges in reaching the current eligible population for ASCS, in relation to sample quality, capacity from local authorities and care home providers to support the survey, and survey fatigue.

The success of the survey partly relies on the accuracy of the contact details used to send out the questionnaire and the importance of issuing the survey to the right people. In practice, preparing the sample takes time and LAs do not necessarily have the resources required to remove people who lack capacity, are ineligible, or have died, and to check that contact details are complete and accurate.

Similarly, once questionnaires are sent out some groups of respondents are likely to need support to complete them, for example people in residential homes. Care homes do not necessarily have the capacity to support residents, and their ability to do so may vary from one year to another. This leads to a low number of responses from care home residents.

Survey fatigue and falling response rates were issues of significant concern. The number of responses required means that in some LAs the same people are invited every year, which leads to survey fatigue. Falling response rates were reported to impact on margin of error and therefore analysis. In some local authorities every eligible person is issued to the survey; there is no sampling.

“Our worry is... reducing response rates...and that’s threatening to become serious enough that we’re losing the ability to do some of the analysis that we’d like to do. The margin of error is creeping up and that means we’re less able to detect differences and, so that’s a worry.” **Local government**

Considering the achieved samples, participants expressed concerns over the representativeness of ASCS in terms of ethnicity (the only available breakdown in the publicly available data set is white vs non-white) and level of deprivation, for which there is currently no data. Concerns were also expressed about the representation of seldom heard groups.

4.3.2 Other groups to include in ASCS and challenges in including them

Views on whether to expand the survey to cover other groups were mixed. Those in favour of expanding it argued that the current ASCS did not represent the whole population of people using care and support services, that it did not provide an accurate picture of satisfaction with ASC, and that by excluding short-term users and people in receipt of equipment (and not long-term care) it

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[281] Work package 4 – DACHA Study

did not align with the Care Act which puts a lot of emphasis on prevention and avoiding escalation of care needs.

“There is a large focus in the Care Act on maintaining people within their own homes and trying to prevent people from needing services as much in providing the services that they need and currently, the surveys don’t cover that.” **Local government**

Other participants thought that while expanding the eligibility for the survey would be useful, it would also raise a number of challenges related to identifying people, reaching them in a timely manner, and the added burden for local authorities (which already found administering the current ASCS resource intensive). One participant from an LA concluded that they would prefer to focus their resources on getting the current ASCS right.

Another participant pointed out that the national Minimum Data Set (MDS) generated by registered care providers centrally sharing a consistent limited set of data from digital social care records could eventually provide information about many of the new groups being considered. At the very least this would provide demographic information about the characteristics of those receiving registered care services, but longer term it could provide regular updates on the experience of care. Within providers digital social care records may contain ‘real-time’ information but any central sharing would likely be based on regular submissions (monthly or quarterly) to retain control over what is shared. Potentially in the longer term, if the legal and technical dependencies associated with sharing data could be overcome, the CLD and digital social care records could be interoperable, using unique identifiers:

"So that the data transfers between the two seamlessly without having clients and carers having to tell their story again and again to each social care provider". **Central Government**

Short-term users

There was agreement that adding short-term users to ASCS would be worthwhile, and that their exclusion generated a gap in LAs’ understanding of how well they supported these people and prevented an escalation of their care needs through reablement services. This is a group which local authorities have reliable contact details for and so could be included in a survey. However, others pointed out this had already been tried and was very burdensome for councils to administer.

“We were trying to develop a short-term services survey, got so far with it but it’s very difficult, and administratively it was very difficult because the timing, you have to get in there quickly after the service has ended, and the administrative burden on councils can be quite high.” **Local government**

Taking this into account, one organisation asked whether feedback could be collected in real-time – something which the national MDS being developed by NHSE and drawn from digital social care records could make easier to implement in the coming years, once it is developed beyond demographics and if it can be used for research purposes. It is likely central submissions would be regular rather than completely ‘real-time’ so that care providers could control which data are shared externally (e.g. restricting safe-guarding related information). Other much longer-term options included people with care and support needs using digital social care records themselves in a way which could enable pop-up questions or surveys to be offered to them.

‘‘The way to go is to collect more data in real-time across a greater piece. Because there is burden on local authorities, …we do need to get smarter at collecting data and making sure that we use the data we collect, and that we don't place different [demands] on citizens or any other organisations that are essentially asking for similar data.'' **Organisation representing people with care and support needs**

Self-funders

Self-funders were thought to be worth including in ASCS, and some pointed out that their experience and outcomes could be very different from those of other groups. Identifying self-funders was considered a barrier to their inclusion, until they come forward to their LA to be metered for the care cap. The national minimum dataset (MDS) from regulated care providers being developed by NHSE and DHSC and the national minimum dataset of care homes being developed as a small-scale pilot as part of the DACHA study[282] would potentially provide information about self-funders using CQC regulated care services such as care homes and domiciliary care in the future. Day care and other non-CQC regulated services would not be captured.

"In an ideal world, I would absolutely love to be able to have data that showed the difference in reported outcomes across self-funding and local authority funded recipients of care. That would be the gold standard for me. It would allow me and our organisation to better interrogate the difference between warranted and unwarranted variation." **Central government**

Information, Advice and Guidance (IAG), equipment only, and CHC

The inclusion of people asking for IAG was thought to be complicated because some of them may not end up receiving paid care so the existing questionnaire would not necessarily be appropriate. Similarly, people in receipt of equipment only would need different questions. Participants did not have strong views on the inclusion of people in receipt of Continuing Health Care, except that LAs would not have their contact details. They might need to be contacted by a different route such as people being discharged from hospital.

4.3.3 Challenges in reaching current eligible respondents for SACE

Challenges in reaching current eligible respondents for SACE include the availability of carers' contact details at LA level, and consistency in how carers are identified and recorded between different LAs.

Some LAs contract third-sector organisations to support carers and are therefore only in touch with a small minority of carers to whom they provide services directly such as short breaks. The data held by partner organisations cannot necessarily be accessed by LAs to send out invitations to take part in the SACE, or the data bases need to be deduped against the LA one which is not always straightforward in the absence of a unique ID.

In addition, there is no consistency between LAs in how carers are identified. For example, a family member present at a care assessment may or may not be recorded as a carer. While waiting for the 2021 census data on prevalence of carers at LA level to get a precise view of the gap between the number of carers known to LAs vs those in the local population, the perception was that the carers known to LAs are those with the most significant and intense caring responsibilities.

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[282] Work package 4 – DACHA Study. These national MDS should not be confused with the existing workforce National minimum dataset collated by Skills for Care (https://data.gov.uk/dataset/9cd42409-1a44-4e6c-9696-29d6a760e746/adult-social-care-workforce-data-set-asc-wds).

"Particularly for the carers, the service delivery mode differs so much in each local authority that … it would be hard to get the same kind of data from each local authority about carers.'' **Local government**

Other issues mentioned included survey fatigue (which could partly be mitigated by better communication about the impact of the survey), and the perception that the achieved sample for SACE was not representative of the current eligible population in terms of ethnicity.

4.3.4 Other groups to include in SACE and challenges in reaching them

In line with the views expressed about ASCS, participants had mixed views about expanding the eligibility criteria for SACE. Finding hidden carers was considered to be a challenge, partly because they do not identify as carers. Options suggested included going to GP surgeries, looking at the recording of carer status on GP records (assuming these could be shared), and using the Minimum Data Set (MDS) being developed by NHSE and DHSC if and when it is created from DSCRs, with the caveat that it is not expected to record carers in their own right but could record carers' details as part of service users' information.

Even if additional groups of carers could be included in the sample, some practical considerations would need to be addressed: the current questionnaire would not be relevant for carers not currently supported by LAs, and LAs would not necessarily be able to administer a much larger survey as some were still stuffing envelopes manually on the ASCS and SACE.

"It's difficult for the local authority to take on more and more, isn't it? Because it will become more and more costly to include all those extra groups and especially, how on earth would we find out about them? The carers that use the website and then went off and did their own thing, … how are we ever going to include them in a carer's survey? We don't know who they are...you would change the purpose of the survey if you were then rolling it out to lots of carers that hadn't really had much interaction or any interaction with the council.'' **Local government**

4.3.5 Sample available from local authorities now and in the future

Sample currently available from LAs primarily includes people in receipt of paid care that is fully or partly local authority funded, and carers who receive support from LAs. This includes people on long-term packages of care (in current survey sample), people on short-term packages of care (not in the current survey sample), people receiving LA equipment (not in the current survey sample). Going forward, many developments were mentioned that will affect the sample available.

The implementation of the charging reform, expected to be around October 2023, means that self-funders are expected to come forward to their LA to start metering their care costs towards the cap. However until this happens there is a degree of uncertainty regarding the number of people who will come forward, and how quickly they will come forward. Still, this could make it easier to include self-funders in ASCS and could also increase the number of carers covered by SACE.

Next, digital social care records (DSCRs) are being developed. These will be maintained by care providers and will provide information about the paid care services a person is receiving. Once set up, data are expected to be available to care providers almost in real-time. A Minimum Data Set (MDS) is being developed by NHSE to gather data from DSCRs centrally through regular submissions. Initially this is in the form of a Minimum Viable Product (MPV) focusing on some basic variables such as demographics, carers, and services received. This would need to be confirmed and the data architecture built but if it goes ahead this would cover all users of CQC regulated paid care services regardless of funding status. However, currently this is being developed at an aggregate level and therefore would not include information such as contact details and there would be further work to do to in order to develop this dataset for sampling purposes. Longer term this information might be shared centrally and linked with client level data held by LAs. However, the possibility of using this approach for analysis or sampling would depend on complex legal, technical and information governance issues being resolved and a sharing of data across organisations. These records could potentially also be used to supplement the data collected in the survey, if respondents give permission for data linking and providing safeguards are put in place to avoid data being analysed at provider level without permission. In the future, digital social care records could also make it possible to seek views from service users in real-time, if permission was available for this purpose, through pop-up surveys or recording feedback during the delivery of services.

“The vision for the minimum data set is that if by 2024 we have 80%-plus care providers on digital social care records, then that's a hugely transformative source of up-to-date, almost real-time data that we can gather.” **Central government**

Finally, Client Level Data (CLD) returns are being developed which LAs would be expected to return regularly to NHSD, rather than summary tabular returns. Currently 41 LAs are taking part in a voluntary pilot with quarterly returns to NHSD. If it is anonymised then it will not be possible to use it for sampling. However, the demographics available in CLD could be used to inform the sampling or weighting approach for ASCS, or LAs could link survey data with CLD information, with respondents’ permission (which is not part of the current surveys and would need to be added). The implications of this would need to be discussed with local authorities to ensure that it does not include information which would identify individual care providers

4.4 Accessibility

4.4.1 Encouraging people with care and support needs and carers to take part

To encourage people to take part in ASCS and SACE, participants thought that the surveys needed some clear messaging about their purpose and impact. Knowing what difference their participation would make could help engage people.

“I think it's really down to the purpose for them. If there's a really clear purpose, I often found that was the best way to motivate people to be involved and engaged.” **Central government**

“Simple and transparent. Just telling people why you are receiving this survey, what is going to happen with your responses, and why should you respond.” **Other**

The language used in the two surveys would also benefit from being reconsidered. It was described as ‘inaccessible’, ‘very formal’ or ‘too academic’. While formality could reassure respondents that the survey invitation was genuine, it could also be off putting. Resulting from this, a participant advocated for plain English and shorter response scale.

“The other feedback we get about surveys in English, …[is that] the questions are a bit academic. They come across as quite long winded. I know there are reasons for this but why are there seven responses to this aspect of the question? Do we really need so many? Does it have to be so long? …A plainer reading version for everyone might be better.” **Local government**

For people with a learning disability or autism, one participant advocated the use of Talking Mats, while another thought that the Easy Read version of ASCS needed to be improved, on the grounds that it was not cognitively tested, and that it was out of date with illustrations not fit for purpose.[283]

"I've got to espouse the work that we've been doing with Talking Mats, and it's very expensive because it does need people to be out there and doing it, but we always used to say that all of this stuff should needs-led, not funds-led. … If you considered that as the abiding principle, then having those sort of accessibility options like Talking Mats and having people to help interpret is very obvious. It's a no-brainer, really, you've just got to do it." **Central government**

4.4.2 Securing buy-in from gatekeepers

Securing buy-in from gatekeepers was considered a challenge. Some LA participants reported frustration with care homes, feeling they were sometimes too protective of residents and quick to make decision about their lack of capacity. Some LAs wanted to be able to send questionnaires to care home residents regardless of capacity with the hope that a family member could help them complete it. Gentle promotion of the survey, providing information about it and how the findings would and would not be used, could perhaps help alleviate concerns from gatekeepers.

4.4.3 Practical issues affecting participation and how to overcome them

Practical issues affecting participation included concerns over the length of the questionnaire, and it being repetitive and monotonous. Ways of reducing the length included using data linking to append demographics already held by LAs to SACE data, and reducing the number of points on the scales. In terms of accessibility, it was suggested that LAs should print the questionnaire at the recommended font size of Arial 14[284] or bigger, as eyesight problems are common in old age, and that a face-to-face mode should be offered to residents in care homes, with the caveat that this would be very expensive.

4.4.4 Involvement of people who lack mental capacity in ASCS

To include people who lack mental capacity in ASCS, suggestions were made to maximise the accessibility of the survey by offering Talking Mats, PECS (picture enabled communication systems), a face-to-face completion mode,[285] and a shorter questionnaire. It was acknowledged that these changes would impact on trends.

Proxy responses were considered acceptable when the measures suggested above were not enough to enable participation. Proxy responses were described as better than having no responses at all from people lacking capacity to consent for taking part.

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[283] It should be noted that a revised easy read version of the ASCS has been developed and tested by PSSRU which may address some of these concerns if implemented. (Turnpenny, A., Caiels, J., Whelton, B., Richardson, L., Beadle-Brown, J., Crowther, T. Forder, J., Apps, J., and Rand, S., (2016) Developing an Easy Read version of the Adult Social Care Outcomes Toolkit. Journal of Applied Research in Intellectual Disabilities, Kent: University of Kent).

[284] It is not clear the extent to which LAs adhere to this recommendation when printing materials due to concerns about paper costs and perceived survey length.

[285] In the NHS Digital guidance, LAs are encouraged to offer the option of face to face completion (see p.27 https://digital.nhs.uk/binaries/content/assets/website-assets/data-and-information/data-collections/social-care-user-surveys/ascs-guidance_2020-21_v4.pdf).

"So, this is about weighing up whether it's more important to get a view of this experience of this individual, or whether it's important to really make sure that it is that person in complete control of what they are providing. I think I'd actually be okay with a proxy. Given the situation that we're currently in, given the change that's going on with the legislation that's coming in, I think on balance, it's more important to just get those experiences." **Central government**

"[Use proxy] otherwise you get nothing on the voice and views. And whilst it's a very significant chunk of people who draw on care and support, so again a trade-off, but if you don't trade it off there's a huge segment whose voices and experiences will be left out. Wouldn't want that, for sure.'' **Organisation representing people with care and support needs**

It was suggested that while proxy responses to ASCS are currently accepted and stand at about 9%, a more proactive approach to include people who lack capacity via proxy would need to be tested and piloted. Proxy responses would need careful testing, and it may be worth designing a proxy questionnaire in which the question wording remind the respondent that they are answering on behalf of the person with care needs.[286] One challenge this would pose is how to identify people who require a proxy version rather than the standard version of the questionnaire.

"You want to ensure you can identify that cohort of people that you would be targeted to do that, then identify the proxies that would be reporting on their behalf. Having volunteers from that cohort of people for the cognitive testing to make sure that the questions are being understood in the way that you would expect. Doing some trial runs of the responses to see if …what you are intending to ask is what's being interpreted and therefore what's being responded to. And building that evidence base." **Central government**

While supporting the wider inclusion of proxy to represent the views of people who lack capacity, participants still mentioned a number of disadvantages in relation to the accuracy or strength of the feelings reported, proxies potentially skewing the findings if they make up a large proportion of the results e.g. for working-age adults with learning disability and autism. One participant also wondered if this could make it harder to identify closed cultures.[287]

In light of that, participants flagged up that responses from proxies were not a substitute for the views of people who lack capacity, but supplemented them or complemented them. This is in line with NHSD approach to the analysis of existing proxy responses (these can be compared with responses provided by people in receipt of care and analysed separately, though the main report combines them). However, it went further than this with the suggestion that means should be developed to enable the active participation of those who lacked capacity to complete a survey like the ASCS but who could respond to a more qualitative or flexible approach to reporting their own views.[288]

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[286] It should be noted that a proxy version of the ASCS along these lines with a distinction between the views of the proxy and the person with care needs has been developed and if implemented could address some of these concerns. (Caiels, J., Rand, S., Crowther, T., Collins, G. and Forder, Julien 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 Service Research, Kent: University of Kent).

[287] Defined by CQC as 'a poor culture that can lead to harm, including human rights breaches such as abuse'. In services with a closed culture, people are more likely to be at risk of deliberate or unintentional harm.

[288] ASCOT-CH4 already does this. It uses a mixed methods (observation, staff and family interviews, semi-structured interview) approach. To use it in the ASCS would need considerable resource to implement.

4.5 Administration of the surveys

4.5.1 Preference for a central versus local delivery model

Overall, most participants thought that a central delivery model would be preferable, because this would reduce the administrative burden in local authorities and provide more consistency. However, the importance of providing LA level findings and outputs was emphasised, and this was not something that could be compromised. Any approach would need LAs to receive their own data back.

‘‘I'm sure if there was some huge system designed whereby local authorities would…submit a data return at the start of the process which has the details of…the people who are receiving the services and what services they get, then just sitting back for three months and getting a nice, shiny report with the results on at the end, then I'm pretty sure most people would go for that.’’ **Local government**

‘‘For a reduction in burden on local authorities and to streamline processes and to speed up the turnaround, I would say centrally. But I would want to be very clear that actually local authorities would have access to their own portion of the data because I think that feedback loop to the local authority is really, really important in this process. (…) They use that data once they get it to … target their local actions.’’ **Central government**

A small number of participants asked for a mixed model, with LAs having the choice between a locally vs a centrally administered survey. They thought that retaining the possibility of local delivery model was important because it allowed LAs to add their own questions at the end of the paper questionnaires, which was very important to LAs, and they thought it could make respondents more willing to take part.

‘‘I know that the consideration's been given to centralising the whole process. We'll tell someone in the centre who it is that they need to contact and then things would happen from there, but then we would lose all local knowledge or local ability to, the fact that we can have free text boxes and we can get comments back which we don't submit centrally works for both of us. They, DOH get the numerical responses and we get our local insights, so centralising it and losing that would not be a good option for us.’’ **Local government**

Related to this, an organisation representing people with care and support needs argued that a central delivery model would still require local engagement with people with care and support needs and carers, and local promotion of the survey to reassure people it is genuine.

4.5.2 Challenges with a local delivery model and ways to reduce them

The local delivery model currently in place was described as very resource intensive for LAs, with many of them still stuffing envelopes manually. Some LA participants asked for more staff and resources to administer the surveys. Ways of reducing the burden related to the scheduling of the surveys and SALT return: ideally these should not be required all at similar time as the resourcing implications for LAs and NHSD are very significant.

4.5.3 Implications of a central delivery model

Even participants who supported a central delivery model were aware that this would not be straightforward to implement, because information governance issues would need to be resolved with all LAs before they could share samples with NHSD or the organisation appointed to conduct the surveys.

‘‘I think the logistics of organising that [a central delivery model] and doing that would be so hugely complicated (…) Trying to sort out 151 data sharing agreements with local authorities would be an absolute nightmare.’’ **Local government**

CQC uses a central delivery model to run all their patient experience surveys (which rely on NHS trust providing samples), a participant from that organisation thought that IG issues could be overcome:

“Speaking as a central organisation, I always think that the central way is the best way, for consistency and ease. It costs a little more to begin with, but actually in the long run, it's probably more efficient as well. (…) I think using a third-party organisation, generally speaking, tends to be the right thing to do in terms of those IG considerations. It makes it a lot easier then, because there are so many existing contracts, protocols, that can just be amended.” **Central government**

The other important implication if a central delivery model was chosen was that LAs would not be able to add their own questions if the surveys still involved a paper mode, as this would require printing different questionnaires for each LA which would offset the economies of scale and would not be practical. LAs would therefore need to find other ways to collect feedback or data on local issues or initiatives.

‘‘I don’t have full visibility of what they [LAs] do, but they always have some sort of initiative going on and I’m sure that they’ll then want to measure the impact of that … in the social care space. …I think local surveying would still need to continue for them to measure those initiatives.’’ **Central government**

The online pilot for SACE, partly administered by NHSD on behalf of 5 LAs, did not require LAs to sign a data sharing agreement with NHSD. NHSD provided an online script and LAs sent out the survey invitations to eligible carers with the URL provided by NHSD, then LAs downloaded their results and sent them to NHSD. While this meant there were no IG considerations to resolve, the survey still required significant involvement from LAs and from NHSD. As the pilot was only administered online, LAs could add their own questions if they wanted to, which NHSD checked and scripted. A further five LAs ran their online surveys locally.

4.6 Mode

4.6.1 Adding an online self-completion mode

There was strong support for the addition of an online self-completion mode: LAs were reported to be asking for it year after year, this was expected to be faster and cheaper to administer than paper-self-completion, with a lower impact on the environment and reduced printing and mailing costs (in the face of rising postal charges). The NHSD online pilot analysis will involve a high-level cost-benefit analysis of participation in the online survey for SACE. One LA reported that carers requested an online version. It was also expected to make it easier for people to take part as they would not need to go out to post their response. That being said, organisations representing people with care and support needs highlighted the importance of getting this right in terms of accessibility, making the online survey accessible to screen reading software and device agnostic.

“It's easy with this sort of group to fall into the stereotype of saying, 'Oh, they're not going to be digitally able,' which is not true, a lot of them are. A lot of even people in their 70s are often more than capable of filling out a digital form. And I can imagine, they'll certainly be a cohort of people who would feel that that is a slightly less intrusive ask of them than being given the sheet of paper and having to fill it out and then give it back to someone else to be taken off somewhere.” **Other**

The online pilot for SACE was designed to enable researchers to measure the impact of adding an online mode on the survey results and response rates. Only local authorities which were large enough to run two simultaneous surveys (standard paper approach and an experimental approach) were included so that the effects of local area could be controlled for in comparisons. Results are expected over the coming months.

4.6.2 Push-to-web approach

In line with the above there was support for a push-to-web approach, at least for SACE as participants assumed carers would be more likely to be online than people with care and support needs. However, there was agreement that a paper questionnaire should always be sent out to non-respondents after the first mail out with URL only (so people do not have to request a paper version).

Some participants mentioned experiments that had been or were being conducted, whose findings should be used to inform decisions about a push-to-web approach for each survey: the online pilot for SACE, whose results should be available soon, had a split sample with some participants getting both a URL and a paper copy and other participants getting a URL only and having to request a paper questionnaire if they needed it. Prior to that in 2018-19, two LAs tested a push-to-web approach for both surveys, which was described as successful for SACE but not for ASCS. Decisions regarding a push-to-web approach for SACE will obviously depend on the results of the above experiment and pilot. If successful, a push-to-web approach for ASCS could also be considered but would need to be well thought through and piloted with due consideration given to the accessibility needs of the audience.

> ‘‘A couple of years ago two local authorities tried doing online with ASCS as well as with carers, …. And their uptake for carers was really promising, they had about 30% uptake on the online. But … for ASCS, between the two of them only 13 individuals responded.…. So I think that needs more work and consideration, again, relating to the strata and the needs of the individual. But I don’t think we should rule it out completely because there are plenty of people with care needs who are more than able to use online services. So, it’s just something that would need more consideration than the carers one would.’’ **Central government**

4.7 Frequency of the surveys

4.7.1 Frequency of ASCS and SACE

Views on the frequency of the two surveys were mixed. Some wanted more regular feedback on the grounds that there was very little data available from users and carers about their experience and outcomes and that more data was needed for inspection and performance monitoring. Others thought the surveys should run less frequently because of administrative burden and survey fatigue. There was however agreement that:

- there should be parity between the two surveys: their frequency should be the same whether it is every year or every other year. While they appreciated that the ASCOF time series would be impacted, they thought that this parity would be more aligned with the Care Act. If the surveys are conducted every other year, other sources of feedback could be used locally between each iteration.

- the two surveys should not be conducted at the same time, because this is not manageable in terms of resources for LAs and NHSD.

‘‘[If ASCS was conducted every two years like SACE] it would potentially reduce the burden on most teams that are shrinking, not growing in size in the data world in councils, if we kept the model of local admin.’’ **Local government**

‘‘I think the internal capacity to service some of [the wider reform agenda]… is definitely lower than it was a few years back.’’ **Local government**

- If short-term users of care and people only receiving equipment and adaptations are included in ASCS, they will need to be surveyed shortly after receipt of the service, so the frequency of their survey would need to be looked at separately.

Some participants suggested that real-time feedback should be considered instead of surveys, with light touch feedback captured more frequently at ad-hoc points. They thought that developments such as digital social care records could make this possible in the future.

4.7.2 Timings of the surveys in the year

Participants who had a view on the timings of the surveys agreed that it should be consistent over time and avoid the winter period which tends to be challenging for health and social care providers. For ASCS the timings may have to be different for short-term users of care and people in receipt of equipment only (if included), compared with long-term users of care and support: for example, they could be sampled on a given month based on all those who had received short-term support or equipment that month.

Requests were also made to ensure to ensure that survey timings do not coincide with SALT returns as in some LAs the same members of staff deal with both. Tensions were expressed with regard to the amount of time taken to process and publish the data, and the lack of resources available within LAs to administer the surveys and prepare the data for NHSD, with some LAs asking for timings to be extended. Overall, the survey process was described as spanning across four months for LAs.

4.8 Other emerging issues

4.7.3 Most important concerns raised by stakeholders

Asked what their biggest concern was, stakeholders mentioned the following points, most of which were already detailed earlier in the report:

- the need for clarity regarding the purpose of the two surveys, and for a coherent approach to data collection in ASC;

‘‘Whatever happens, it's just being absolutely clear what the purpose of the survey is and how it will be used and then you design it, and what it is and what it isn't, rather than just assumptions that aren't necessarily played out. It's just that clear purpose.’’ **Local government**

- the usefulness and impact ASCS and SACE. A few participants from national organisations commented that the two surveys were not very useful to them in their current form. Ways to make the surveys more useful to them involved including self-funders, adopting a human rights approach, and making it easier to access individual data at LA-level so organisations could do their own analysis;

- value for money: related to the above, a participant wondered if the surveys delivered value for money as they could not see much impact locally. Given the strain and burden on LA resources, they wanted ASCS and SACE to generate data useful to LAs, but some LAs reported that they did not have time to fully analyse the data collected;

- the representativeness of the surveys, with large groups of people not being included in them at all and other groups under-represented;
- survey fatigue among the target groups;
- the administrative burden for local authorities;

‘‘I talk about burden a lot … I know they [local authorities] use the data, I know they use the results, but it’s painful for them to get to that point because of the printing and the envelopes and various other things. (…) But we know the survey does add value.’’ **Central government**

- the accessibility of the surveys, in particular to people with sight loss.[289] One organisation representing people with care and support needs was willing to user test the questionnaire, in particular the online version, to ensure it would be suitable for people with sight loss.

4.7.4 Co-production and local involvement

Although ASCS and SACE were originally developed and tested with people with care and support needs and carers, it was pointed out that the meaning of co-production had developed since then, and that co-production would now involve people with care and support needs and carers having a bigger say. This could be in the delivery of services or in the content, purpose, approach and design of the two surveys. The language used by stakeholders was co-production rather than co-design.[290]

‘‘I think there's been a recognition that social care historically has [sometimes] been something ‘done to’ people and now there's much more of a move … to co-production and working ‘with’ people and not being so directive; putting the person in control.’’ **Local government**

“The questions have to be designed with, co-produced with people with lived experience ultimately and actually asking the right things to try and get a sense of actually their experiences and… their aspirations" **Local government**

Involvement of local independent organisations such as Healthwatch to promote the surveys and support people to complete it was considered key to the success of the surveys, but it was noted out that this would need to be funded. Guidance from NHS Digital already encourages LAs to involve local independent organisations to promote the surveys, but it is unclear how much this is happening in practice.

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[289] Please note that NHS Digital guidance already encourages LAs to offer telephone completion mode if appropriate.

[290] Ladder-of-coproduction.pdf (thinklocalactpersonal.org.uk)

5 Options Appraisal

5.1 Introduction

In this chapter we review the options for the surveys in the light of feedback from the stakeholder interviews and discussion of the project during an SSUSG meeting in March as well as further reflection on the rapid evidence review. We show which options have clear advantages or are preferred and discuss the trade-offs between them.

5.2 Content and purpose of surveys

Aim: To ensure that information collected is fit for purpose for the stakeholders' needs and truly reflective of the needs and experiences of those both using care services and providing them. The Authority want to ensure the right questions are asked to be able to evidence what we need internally and in LAs.

5.2.1 Purpose of surveys

The **main priority** for the surveys for stakeholders we spoke to is to explore both the **outcomes** and **experience** of receiving support with care needs, or supporting someone with care needs. **Process data is of lower priority** because it can be collected by other means.

Stakeholders suggested that the outcomes measured should relate to **Care Act outcomes**, align with the new **CQC assurance framework** and should reflect a **forward-looking** view of what social care is trying to achieve as what is measured affects what is prioritised. In line with this approach, any revisions to the current ASCOF should align with the CQC framework and the surveys should then feed into that as one of many other sources of evidence.

The surveys are particularly valued by **local authorities** for **benchmarking** against other local authorities and nationally and **comparing trends** over time. Therefore having measures which are **consistent** is important.

To have value for groups who **use services or carers** or organisations which represent them, work is needed to ensure that any **changes are co-produced, the purposes agreed** on and the **data made more accessible and understandable**.

There was limited understanding of how **DHSC use the data** but it was acknowledged that their needs should determine the purpose, alongside the needs of LAs.

Deciding on the purpose of the surveys, how they will be used and their link to assurance or outcomes frameworks are key to the revisions as it will determine what changes to content, coverage and approach are appropriate. The future success of the surveys relies on engagement and support from LAs, care providers, organisations in the ASC, people with care needs and carers. This is more likely to be forthcoming if the purposes and benefits for those with care needs, carers and the organisations which support them are clear. There is limited support for continuing to collect data from surveys 'because it is on the timetable'.

Potential purpose	**Conclusions**
For those receiving publicly funded care and their carers to express their experience and have their voice heard.	Experience is important and a priority. There is a tension between collecting standardised information for benchmarking and comparisons and enabling people to feedback as they wish.
For those receiving any type of paid for care and their carers to express their experience and have their voice heard.	Currently the surveys only cover LA funded care but self-funders are increasingly important to all users of the data.
For those with care needs, unpaid carers and organisations which represent them to hold local authorities, providers or the national care system to account.	The surveys are not currently used for this because of difficulty accessing and understanding the data. Even organisations representing these groups do not use the data much. Because of the public interest and value of the data a change to how the data are presented, shared and interpreted is needed and would be valued. Work is also needed so that these groups feel the surveys are credible and understandable.
For local authorities to identify areas for improvement or monitor the impacts of changes.	This is a stated aim of the surveys but not currently used as much for this as it could be – related to analysis capacity and lack of resource to do other research and no challenge on whether this is happening.
For local authorities to measure whether they are managing demand and using their resources effectively (performance management).	This was not mentioned as a priority.
For local authorities or central government to benchmark local authorities against each other or their region (in outcomes or experience).	This is one of main current and valued uses of the survey from the point of view of local authorities. NHS Digital has prepared a publicly available [Power BI data analysis tool] as part of the Adult Social Care Analytical Hub. This enables data users to compare

	findings from the ASCS and SACE from 2016-17 onwards between LAs and against all England figures. It is unclear how widely this tool is used.
For local authorities or central government to explore changes over time (in outcomes or experience).	This is one of main current and valued uses of the survey – by local authorities, but lack of significant change over time means it is more of a sense check.
For central government to understand which types of social care are most efficient in terms of use of resources (inputs) and achieving the intended outcomes of the Care Act (wellbeing related outcomes, independence, prevention) considering both publicly and self-funded care.	The data are not used centrally for in depth analysis of this type. And at present the data only cover publicly funded. In order to measure this other information would be needed beyond the surveys.
For central government to measure whether the intended outcomes of social care services (Care Act outcomes) are being achieved at a national level considering both publicly and self-funded care.	The data are not used centrally for in depth analysis of this type. In future, the surveys could be part of the CQC assurance framework examining this at an LA level. If CQC is holding LAs accountable under a framework then the CQC and LAs would like the surveys to measure things under this framework, though CQC would put this under ‘people’s experience’ rather than outcomes.
For academic or other researchers to carry out further in-depth research about social care outcomes or experience in England.	There is an interest in the data, however difficulty accessing the data in sufficient detail limits use for this purpose by DHSC and other organisations outside NHS Digital. There is also limited experience of using the findings in organisations outside LAs, DHSC, NHS Digital and academics with a specific interest in the surveys.
To provide data for outcomes frameworks (e.g. ASCOF) or other central data analysis or evidence (e.g. ONS productivity analysis).	The surveys are currently used to provide evidence for central government in combination with other sources of data.

These findings do not suggest that changes are needed to the underlying purposes of the surveys (experience and outcomes measured in a comparable way across LAs). However, to meet those purposes more effectively, align with new frameworks for assurance (as that is what the sector will be working towards and would like to measure) and fully reflect the needs and experiences of those who use services and carers, changes are needed.

5.2.2 Content

The surveys cover people with a **wide range of experience and need** and there are trade-offs between asking questions which are:

- **Specific** to particular needs and experience which people may want to give feedback on, but which may make assumptions about the outcomes expected for different people, and also may not be comparable between groups
- **General** enough to allow comparison, do not make assumptions but which may not enable people to give specific feedback about their experience.

These trade-offs may become more marked and challenging if a wider group of people are included in the surveys, including those receiving short-term services, equipment and information, advice and guidance.

There are also trade-offs in enabling people to give detailed feedback about experience which is relevant to them and not making the surveys any longer or more burdensome.

Option A	**Option B**	**Conclusions**
Surveys exist only to feed a wider framework (such as ASCOF) and so their content is dictated by that framework.	Surveys have value in themselves and gather data independent of a wider framework.	Since there are limited resources and what is measured affects priorities, the surveys should align with new frameworks as that is where the focus is. LAs and others could use the surveys more broadly, outside the framework but the data need to be made more accessible, and additional resource and more published interpretation and discussion are needed. The concept of core modules which are asked every time with periodic modules on other topics/ optional questions on other topics may fit with this and allow other purposes without increasing burden.

Surveys are designed to capture all that is needed regarding self-reported user experience of services.	Surveys are just one tool among many for LAs or the DHSC (e.g. reviews, consultation, in depth qualitative research).	There is a move within social care to 'real-time' data and CQC assurance will take an 'always on' approach. This means annual or biennial surveys can only be part of the evidence, particularly as digital social care records and client level data could potentially enable easier and regular access to meaningful data collected during the provision of social care, if the legislation permits. Given these changes, priority should be given to content which can best be measured in surveys like this, not duplicating data collected elsewhere. Attention also needs to be given to the associated information governance and technical issues.
Surveys are designed to have general questions which would apply whatever service has been received/ whether or not a service has been received to allow comparison across different forms of support (current surveys do this).	Surveys are specific to the service being received. E.g. those on long-term packages of care would be asked quite different questions from those on short-term packages, receiving equipment or advice or guidance (e.g. as the user surveys used to).	Since the value for LAs lies in being able to look at all long-term users together, there are minimum sample sizes, and routing is best avoided in paper questionnaires, the surveys focus on general questions which are applicable to all groups. To compare the impacts of different models of care this comparability needs to extend to new groups included in the surveys but the questions may not appear relevant to all groups and there may be issues with sample sizes for subgroups if the questions are very specific.
Surveys use academically validated measures developed and tested through research with people with care needs and their carers which	Surveys incorporate new or adapted co-produced measures which reflect the current context and ways in which needs are met and the increasing emphasis in the ASC sector and	To have respect among academics and in central government and produce robust statistics the questions need to be tested and validated. However, these measures can lack credibility among some of those who are being asked them and organisations which represent

have a long record of use (evidence about effectiveness and data for time trends).	research about the active involvement of the public in research.	them. To deliver measures which are ‘fit for purpose for the stakeholders’ needs and truly reflective of the needs and experiences of those both using care services and providing them’ any adaptations and new content should be developed in partnership between people who use care and support and carers, academics, survey methodologists, LAs which collect and use the data, and central organisations. Any approach to redeveloping the surveys should use the latest best practice in co-production or co-design and partnership, which has evolved and developed since the surveys were originally designed using the best practice at that time (focus groups, qualitative interviews). What is needed is a working out of the options and trade-offs in collaboration to develop measures which meet all parties’ needs or enable a consensus to be reached that the surveys cannot meet all needs and being transparent about their purpose and how other needs are being addressed through other research or sources of data. Approaches such as Delphi could potentially be used for consensus building but these may be considered too rigid or ‘academic’ for this purpose. A more flexible or deliberative approach may be effective, for example online groups and discussion.[291] Such an approach would need funding and time to develop, as well as clear principles and structure. But it could address issues of stakeholder buy-in and trying to build a consensus. Developments in open text analysis and coding could be used to make greater use of the evidence provided in

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[291] https://www.thiscovery.org/about/

		open text comments boxes, providing information governance issues can be addressed.
Surveys are about the experiences of all people with care needs or carers including those who have no services to report on.	Surveys are about services received and their impact.	Within the framework of LA based surveys, it is not practical to include people who receive no services. However, among those who have received services or support, asking about experience of accessing services or enabling linkage with other evidence about care journeys, following receipt of care would be of value.
Surveys are about outcomes (e.g. on quality of life or wellbeing).	Surveys are about experience of services (e.g. satisfaction).	Both these aspects which form part of the existing ASCS and SACE are important and should remain a focus. It was felt both should be a priority.
Surveys are about overall experience (including of accessing services)	Surveys are about the specifics of experience during the process of service receipt (e.g. length of visits, promptness, quality of food, laundry etc) in a social care equivalent of health patient experience surveys.[292]	To compare groups with divergent needs and services, overall and general questions are needed. However, to enable people to have their voice heard more specific questions may be needed. However, the dangers with more specific questions are their relevance, assumptions about what is important and burden on participants. In the section on mode we explore how a change to the mode might address these trade-offs. One reason for the move away from specific questions about user experience (as in the pre 2010 User Experience Surveys) was the small sample sizes in all the groups apart from older people receiving home care. Sample sizes would continue to be an issue even if the mode makes flexible routing more feasible.

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[292] Example of inpatient survey content is here: [Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries | International Journal for Quality in Health Care | Oxford Academic (oup.com)]

5.3 Representativeness: Survey coverage

Aim: Define the eligible population to better match the user groups covered by the Care Act. Options are required for how data could be collected from a much broader group of respondents so that the surveys are fully representative of the entire social care population (as defined in the Care Act).

There were mixed views on expanding the coverage of the surveys. It was recognised that, since the Care Act covers not just those eligible for long-term packages from an LA but also self-funders and those receiving support in other ways, data from a wider group would be valuable. However, from a pragmatic point of view, reaching existing eligible groups presents some challenges and at present it is not feasible to survey some of the groups of interest, and doing so would add to the cost and administrative burden of the surveys. One approach would be to improve the surveys for existing groups prior to expanding coverage once self-funders are in touch with local authorities in larger numbers for metering, and client level datasets and digital social care records are available.

Option A	Option B	Conclusions
Surveys should consider only those in contact with local authorities/or partner voluntary organisations.	Surveys should be about all those with care and support needs or with caring responsibilities in a geographical area (including self-funders and potentially those receiving no formal services), however they are met or not met.	Including all those in a geographical area was felt to be ideal but pragmatically, with the current sampling approach, surveys can only cover those in touch with the local authority. Over time the population in touch with LAs may expand. If the surveys are to expand beyond those in touch with the LA an alternative sample, e.g. through health records would be needed.
Surveys should consider only the existing sample groups (long-term care and carers in touch with the local authority).	Surveys should include in their samples all those receiving any kind of support from the local authority/ or their partner organisations (short-term, equipment, signposting).	Short-term users are a priority group for LAs because reablement is an important part of their provision and they do have records and contact details for this group. Including this group is desirable and feasible, but the frequency and content would need to be different from the current ASCS. Those using equipment and sign

		posting are of interest but sampling may be challenging and these groups may not recognise the relevance of a survey. Any changes should take into account the fact that carer/ service user roles may overlap – people may support each other and someone may receive and provide support. This overlap is likely to become more pronounced if the groups in scope for the research are extended.
Surveys should include only those with the capacity to respond for themselves.	Surveys should have a proxy approach, so that those who cannot take part still have their outcomes or experiences considered.	Identifying whether participants have capacity is a challenge for local authorities, as it relies on input from care homes which sometimes either do not respond (meaning those who lack capacity are still included) or exclude all residents (meaning those with capacity are excluded). Although capacity fluctuates, LAs should have some information about the capacity of people they support which could be used instead or as a sense check of the care home feedback. In addition the capacity check process only covers those in care homes, but some receiving home care also lack capacity. Proxy responses are considered of value, alongside other more flexible methods for hearing the views of those with limited capacity themselves but any approach needs to be flexible and allow for capacity not being known.

5.4 Representativeness: Accessibility and participation

Aim: It is known from the Ipsos work that the existing surveys are not representative of the current cohort in terms of issues and response. It is important to understand what delivery mechanism options are available to improve the reach of the survey particularly to be inclusive of potentially harder to reach groups.

5.4.1 Participation

Approach to increasing participation	Conclusions
Engage with gatekeepers (including care homes) and grass root organisations to promote the surveys locally and build trust, particularly among minority groups.	Experience of engaging with care homes on mental capacity checks shows this is challenging, particularly given the pressures in the sector.
Work with groups representing particular service user groups (e.g. those with mental health conditions) to show how the surveys are relevant to them.	It was suggested that some groups such as mental health service users could play an active part in analysing and interpreting the results of the surveys. Such an approach would require sufficient funding and resource to compensate people for their input and build capacity.
Review the cover letter for the survey invitation to acknowledge previous survey invitations, and convey the purpose and importance of the survey and what difference the surveys make nationally/ locally (though noting that the purpose of the surveys may not be local change).	Since the surveys are used as a sense check and general benchmark, many areas do not have evidence of change. There is limited evidence of how they are used centrally. If the surveys fed into a CQC assurance framework it is possible that people would understand the importance. Some LAs do share survey findings with participants but sometimes this may be a URL of a website and there is limited capacity to share findings on paper. It was felt that sending an infographic of findings might motivate people to take part in the future.

Consider removing the word ‘carer’ from SACE survey invitation so that it appeals to people who do not identify as carers.	Hidden carers are an issue. However, removing the word carers might not be enough, as this group might not recognise the relevance of the questionnaire if they do not recognise that they are a carer or have not received any services from the local authority. Furthermore, previous research has shown that carers in touch with LAs are those with the most intense caring responsibilities. To reach hidden carers, an alternative sampling approach would be needed, for example those listed as a carer with their GP.
Review the reminder strategy e.g. number, type and timings of postal reminders, add SMS reminders where mobile numbers are available. Combine this with gathering a wider range of contact details including mobile phone number and email address when people contact the council so there are more ways of making contact.	LAs were uncertain about how many people they have email addresses for, but there was evidence of a preference among some carers to be contacted by email. At present the printing and postage costs of the main invitation and reminder are a concern. Additional reminders which are not by post may be more realistic from a cost perspective. The online experiment in 10 LAs has involved different reminder regimes. Although the prime purpose of the pilot experiment was an assessment of the impact of an online approach compared with paper, it may be possible to learn something about the effectiveness of different reminder regimes as there were 5 different reminder approaches in the pilot.
Review and validate translated questionnaires then better promote them among minority groups and routinely collect information about language needs in a standard format so that translated versions can be better targeted.	Preferred language should be part of future client level data or digital social care records to support the distribution of the appropriate questionnaire. Preferred language rather than first language is what is needed here and should not present an additional burden to LAs and providers as this would be needed in the delivery of services anyway. The translations should be reviewed and tested for appropriateness using best practice approaches for this. Any revised or new questions in English should be written in plain English and accessible language. The existing questions were felt to be long winded or academic.

Offer incentives to boost participation e.g. prize draw for individuals or a compensation for care homes for managing capacity checks and coordinating participation in their setting.	This was not specifically discussed but the challenges of engaging with care homes were discussed and so a motivator or incentive may be of value to those organisations. Support is needed not just for the capacity checks but also for supporting people in participating in the survey. In the past individual participant incentives have been used in a few LAs but feedback suggests that they did not have much impact.

5.4.2 Accessibility

Approach to increasing accessibility	**Conclusions**
Establish a consistent and systematic way of allowing proxy responses for people who lack capacity to consent for taking part (because of profound or multiple learning difficulties or cognitive decline). An adapted and tested version of the ASCOT for proxy report (ASCOT-Proxy) has been developed and could be adopted into the survey. Additional required steps are to: (1) adapt the cover letter and other ASCS questions to also be in proxy-report format; (2) to establish a method for identifying whether a proxy is needed (by identifying in advance as now, or by hearing once the survey has been sent out); (3) to establish a method of identifying a suitable proxy respondent. It is recommended that the proxy knows the person well (e.g. close friend or family member).	Proxy responses were considered to be of value when self-report was not feasible. An adapted version has already been developed and tested. Before it is implemented, REC approval to include people lacking capacity under the Mental Capacity Act would be needed. The HRA Confidentiality Advisory Group (CAG) must also be consulted. Procedures would be needed for identifying consultees and proxies. This was not developed as part of the questionnaire development testing work for the proxy version of the ASCS. An approach for identifying proxies was developed for another study (Measuring the Outcomes of People with Dementia and their Carers (MOPED)). It was not used in practice because of the pandemic but could potentially be adapted for and piloted on the ASCS (which has a different recruitment procedure from the MOPED study). More challenging is identifying whether someone has capacity. Using future individual level records shared between health, social care and LAs in a more real-time way should support LAs in identifying those who lack capacity. If care homes and others know there is a proxy version, there could be a greater incentive to engage with the capacity check process. A further challenge is finding a suitable proxy once a lack of capacity has been identified. Improved

	carer records and links between carer and the person with care needs records would assist with this.
Consider offering more face-to-face and/or telephone options for people unable to use self-completion who would be otherwise excluded.	This is already built into the guidance. The challenge is resourcing – if resource was available this would be a valuable enhancement. Information on this is in the NHS Digital survey administration guidance and in some areas local organisations such as Healthwatch have helped with this. However, this is not a national approach or widespread because there is no additional funding for this. Consideration could be given to involving the NIHR Clinical Research Network (CRN) which supports patients, the public and health and care organisations across England to participate in high-quality research. They are able to support consent, recruitment and data collection and could take tablets to people who need support with a 'push-to-web' approach. They may also be able to support with issues surrounding consent and identifying consultees and proxies described above.
Extend the availability of support with self-completion for people who cannot complete the survey independently (e.g. through advocates, though further development is needed to understand whether an existing relationship is needed to be effective).	We have been unable to speak to an advocacy organisation as part of this research but would recommend this is explored further. Based on the ASCOT-Proxy development project literature review[293], we would not recommend advocates for proxy reports. However, advocates could play a valuable supporting role for those able to respond themselves, if sufficient resources are allowed for this.
Adopt the revised and tested Easy Read version of ASCOT and the other ASCS questions on the main ASCS (as it addresses some of the issues with the current version).	This would address concerns about the current Easy Read raised in the interviews.

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[293] Rand and Caiels (2015) Using Proxies to assess Quality of Life: A Review of the Issues and Challenges.

Consider whether an Easy Read version for older adults with cognitive decline rather than a learning disability could be developed to make the survey more accessible to that group (work to develop this is already underway).	This was not specifically discussed, however alternative approaches (e.g. Talking Mats or PECS) to enabling those with limited capacity to take part were discussed and so there is an appetite to findings ways to include people were possible. This should be done alongside a more formal proxy questionnaire. This would also need substantial development and testing as any version of the questionnaire in Talking Mats would be a challenge. Previous unpublished work related to this[294] learnt that people with moderate stage dementia found it challenging to use Talking Mats to discuss SCRQoL but there has been no systematic investigation of how this compares with unstructured interviews.
Develop an Easy Read version of SACE.	It was unclear the extent to which this would be a priority. Other work to ensure the surveys are in plain English and accessible might reduce the need for this.
Routinely collect information relevant to accessibility so that an appropriate version or support offer (Easy Read, large print, telephone option etc) can be sent to participants and those who need a proxy response can be identified (though being aware that capacity can fluctuate).	This is key and the requirements for ASCS, SACE and other surveys should be fed in as the Client Level Data, digital social care records and Minimum Data Set (MDS) are developed. Ideally they should contain information needed to identify people for research, to target appropriate materials and to maximise the use of information LAs hold which would be of value in analysis. The information governance and technical issues involved in doing this need to be addressed so that the systems are set up in a way which legally facilitates this and has the support of those involved (adult social care sector and the public).

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[294] https://www.talkingmats.com/gaining-views-on-social-care-outcomes/

5.5 Survey Delivery: Organisation

Aim: Review survey delivery models in light of ASCOF refresh and other social care data reforms. Understand the benefits and costs of delivering the surveys in a centralised national way compared to local authorities having responsibility for delivering the surveys.

Option A	Option B	Conclusions
Surveys should be administered locally based on local knowledge of the sample and context so that information such as disputes or deaths can be removed from the sample at the last moment.	Surveys should be administered centrally to take advantage of efficiencies and increase consistency – with samples provided securely by local authorities to an independent provider of survey services directly or via NHS Digital (after ineligible people have been removed at the point at sample provision)	Local access to the data and the ability to remove those who should not be contacted were of key importance. However, this does not preclude potential future central administration of the surveys. There are IG challenges which need to be overcome so that identifiable contact information can be shared outside organisations. While some stakeholders have expressed an appetite for identifiable digital social care records to be used for research purposes, projects to develop means for doing this are still underway. NHSE and DHSC are working on a National Minimum Dataset for records from registered providers. The DACHA project is working on a minimum dataset for data from registered care homes, which involves data linkage of admin data for a prototype MDS in three integrated care systems.[295] In the future, therefore, information from digital social care records could be centrally collated, allowing for analysis. Although the information shared centrally would be anonymous, this dataset could potentially be used to identify sample for surveys, as well as providing some evidence about outcomes of care or

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[295] Work package 4 – DACHA Study

		the care received so that survey questions don't need to be asked. If cases had unique IDs, there would be potential for care providers to be notified of which cases have been selected for the survey on the basis of their characteristics. Providers could then submit the identifiable data needed to send out the mailings to a secure central location used only for this purpose. A similar approach could be taken using the anonymous client level data (CLD) which would be submitted by LAs to NHS Digital in the future[296]. Legal and technical matters in the sharing of identifiable information from digital social care records or client level data for sending out surveys would need to be addressed. CQC patient surveys are run centrally, using samples of eligible patients provided by trusts. This may be more challenging for LAs, as they are not supported by Commissioning Support Units (CSUs), but should not be insurmountable. At present some local authorities subcontract the survey administration for the ASCS and SACE and so there must be agreed methods of sharing personal data for such purposes. Central administration would remove a large burden from LAs and increase consistency.
The surveys should continue to use local authority provided samples.	Surveys should be administered centrally and should be broader than those in contact with the local authorities so the sample should be	This was not discussed. As the coverage of LA samples expands, local records may be less limited. There is potential to use health record samples as

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[296] https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/collection-of-client-level-adult-social-care-data-no-2; and https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns/client-level-adult-social-care-data

	derived from a new source e.g. follow ups to a large scale general population survey.	records are integrated. GPPS[297] uses the central Personal Demographic Service administered by NHS Digital for sampling. This contains contact details, date of birth and NHS number. By itself this could not be used to sample people with social care needs but there is potential for linking with other sources of information e.g. Hospital Episode Statistics to identify sub-groups as was done on the CQC COVID inpatients study in 2020.[298] If information about NHS number was recorded in the national minimum data set drawn from digital social care records or in CLD this could potentially be used (if it can be shared for research purposes) to identify eligible individuals who could then be contacted using Personal Demographic Service (which also contains mobile numbers for about 80% of the population, including those aged over 65 and email for about 20%). Follow up from large scale surveys would not provide sufficiently large numbers of eligible people in an LA area and local analysis is important so this approach may not be effective.
Surveys should be the main way local authorities gather experiences of care services from people with care and support needs and carers locally.	Local authorities should carry out other forms of data collection locally to complement these surveys.	In the future real-time data will become more important and the surveys should adapt in a context where more information may be available from operational records. The surveys are of value for identifying a specific local issue but further local level investigation would be

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[297] GP Patient Survey. Sample details are available here: https://gp-patient.co.uk/Downloads/2021/GPPS_2021_Technical_Annex_PUBLIC.pdf

[298] https://www.cqc.org.uk/publications/themed-work/inpatient-experience-during-coronavirus-covid-19-pandemic

		needed to understand it further. LAs already carry out other research to complement the surveys but this has been limited by capacity.
New audiences should be included in the existing survey to avoid burden.	New audiences need a different type of survey and so will involve additional surveys being administered.	The timing and frequency of surveys of groups such as short-term users, equipment and IAG needs to be different from long-term user surveys. Some LAs already run these and others do not. One option would be a menu of surveys from which LAs could choose.
The local authority spending saved from a move to a central survey should be re-allocated centrally to fund a central survey by a change to LA funding.	The local authority spending saved from a move to a central survey should be used for further analysis of data or running other forms of local data collection.	LAs do not make as much use of the surveys as they would like because of capacity issues. This varies but overall, more resource is needed to ensure the findings can be properly analysed, interpreted and used for insight. Greater use could potentially be made of developments such as the Power BI tool provided by NHS Digital for analysis of ASCS and SACE. This tool could be developed further and information on its potential uses and value shared with LAs and other data users.
No incentives are offered so money can be spent elsewhere.	Incentives are offered to recognise the burden on participants and reduce non-response bias.	This was not discussed. Where incentives were mentioned by one participant it was felt that explaining the benefit of the surveys was more important than a financial incentive as previous experience suggested these did not have much impact.

5.6 Survey Delivery: Mode

Aim: Review the potential to use technology solutions to deliver the surveys online.

Option A	**Option B**	**Conclusions**
(We do not recommend retaining paper only on SACE).	Transition SACE to a push-to-web approach (which leads with online with paper as an option provided at a reminder mailing and on request after the first mailing).	There was an appetite for push-to-web among carers and LAs, providing paper is an option. There is a pilot going on and the findings from those about the optimal approach for response and representativeness should inform how any online approach is rolled out. Any push-to-web questionnaire should be device agnostic so it can be completed on smartphones.
Continue with paper self-completion for ASCS.	Transition ASCS to push-to-web for all groups (leads with online with paper as an option provided at a reminder mailing and on request).	The findings of the SACE online pilot should inform plans for ASCS going forward. Any mode change should be piloted. The previous pilot on ASCS led with paper and was not successful. Any future online option should be push-to-web to get the full financial benefits from going online and encourage online responses. The decision should be based on a variety of factors including overall response, representativeness and cost.
	Transition ASCS to a push-to-web approach for some but not all groups initially, retaining paper only for some (such as older people in residential care)	This should be the subject of pilots or decided after piloting with all groups and identifying which groups it is most effective for, bearing in mind increasing use of digital in all groups

5.7 Survey Delivery: Frequency and timings

Aim: Understand the best options for the timings of delivery of the surveys. As the survey needs to cover those in long-term, short-term, transient and integrated care as well as information and advice seekers who do not go on to receive any formal care, options should be presented for how to time the delivery of the surveys that will maximise responses across all the different kinds of user groups.

Option A	Option B	Conclusions
The ASCS should continue to be annual.	The ASCS should switch to every other year to alternate with SACE.	There was consensus that the frequency of the surveys should be the same for the two surveys (the ASCS and SACE). Resource constraints, burden on LAs and participants and the difficulty of analysing data fully every year suggests that on balance the ASCS should become biennial (every other year) rather than SACE becoming annual.
	The ASCS should switch to every other year to be in the same year as SACE so LAs only do this type of fieldwork every other year.	The advantage of alternating is that it spreads out the burden. However, if the surveys are centralised and LAs provide the sample rather than running them and the questionnaires are largely online and administered by a third party it would be most efficient to run them at the same time. This was not mentioned during the research but this would have the advantage that carers could be told they have their own questionnaire to encourage them to reflect the views of the person they support when helping with completion. The disadvantage is the burden on carers who may have two surveys to complete at the same time.

The SACE should continue to be every two years.	The SACE should become annual like the ASCS.	There was consensus that the frequency of the surveys should be the same for the two surveys (the ASCS and SACE). Resource constraints, burden on LAs and participants and the difficulty of analysing data fully every year suggests that on balance the ASCS should become biennial (every other year) rather than the SACE annual.
Both surveys should retain current frequency and any more frequent data needs should come from other sources.	The surveys should be carried out more often to provide more real-time information.	The ASCS and SACE should not be any more frequent for the current groups. However, surveys of short-term users, equipment and IAG should take place soon after the service has been delivered.
The new audiences should be sampled annually/ every other year with a snapshot sample (e.g. had contact in last 3 months).	There should be a rolling programme for the new audiences with fieldwork every 3 months.	While there was agreement that surveys should take place it was not clear whether this should be once a year with a sample of those who have recently used the relevant service (e.g. in the three months before the annual survey) or multiple times a year (e.g. every three months so that anyone who uses the service during the course of a year would be sampled). This will depend on numbers in the LA and whether sufficient sample can be generated with an annual dataset as well as whether there is seasonality.
	There should be a rolling programme for the new audiences with fieldwork at the end of contact with the council (e.g. end of short-term care/ after signposting from LA).	This is already done by some LAs but such an approach could only be administered locally rather than centrally. This feedback could also be collected

		as part of the routine reviews or end of service contact.
The timing of the surveys within the year should stay the same for consistency and to avoid seasonal effects in comparison of data.	The timing of the surveys should change to avoid the winter season for fieldwork/ fit better with LA workloads or updating of sample frames.	The timing should be consistent from year to year. Avoiding the winter season and SALT returns was felt to be a good idea, though it should be noted that the timing of the ASCS was originally designed to align with the provision of SALT for efficiency.
The time from fieldwork to results should be retained as this is needed for processing and quality control.	Results should be provided more quickly to make them more useful.	It did not appear that LAs could deliver the surveys any more quickly with the current delivery model. There were no strong calls from others for data to be delivered more quickly and given the acceptance of biennial surveys it suggests that more rapid delivery of data is not necessarily a key priority.

6 Final Conclusions and Recommendations

6.1 Overall approach

Any changes to the surveys need to **take place in steps**. Incremental change with small changes every wave should be avoided but since it is not possible to make all changes at once (as some of the wider changes to the system are not in place), we propose an **interim set of changes** to realise some improvements as soon as possible, **with further changes following**. In the meantime various activities could be undertaken to prepare for these further changes. The surveys carried out in the next two years could also be used to test and develop new elements or approaches. The time taken to develop, test and implement more substantial changes aligned with other developments in the sector should not be under-estimated.

A **deliberative approach could be taken to agreeing on the purpose of the surveys** so that central government, local government, other organisations with responsibility for assuring or providing guidance on social care, and people with care and support needs and carers and organisations which represent them can reach a consensus to ensure that the resulting adapted or new content or approach are accepted by all stakeholders.

Any developments need to be carried out in a way in which stakeholders feel is **co-produced** or at least co-designed with a genuine opportunity for the ASC sector, people with care needs and unpaid carers to have a place at the table to shape the content and approach to collecting the data and how the findings are analysed and presented. This is essential because of their critical roles in running, facilitating or completing the surveys.

Lack of resources (staffing and financial) has affected the ability of local authorities to run the surveys and for local authorities and other stakeholders to use the findings effectively for sector improvement up to now. The developments and approaches suggested below need to be **adequately funded and resourced**.

6.2 Deciding on the purpose of the surveys and their place in adult social care evidence

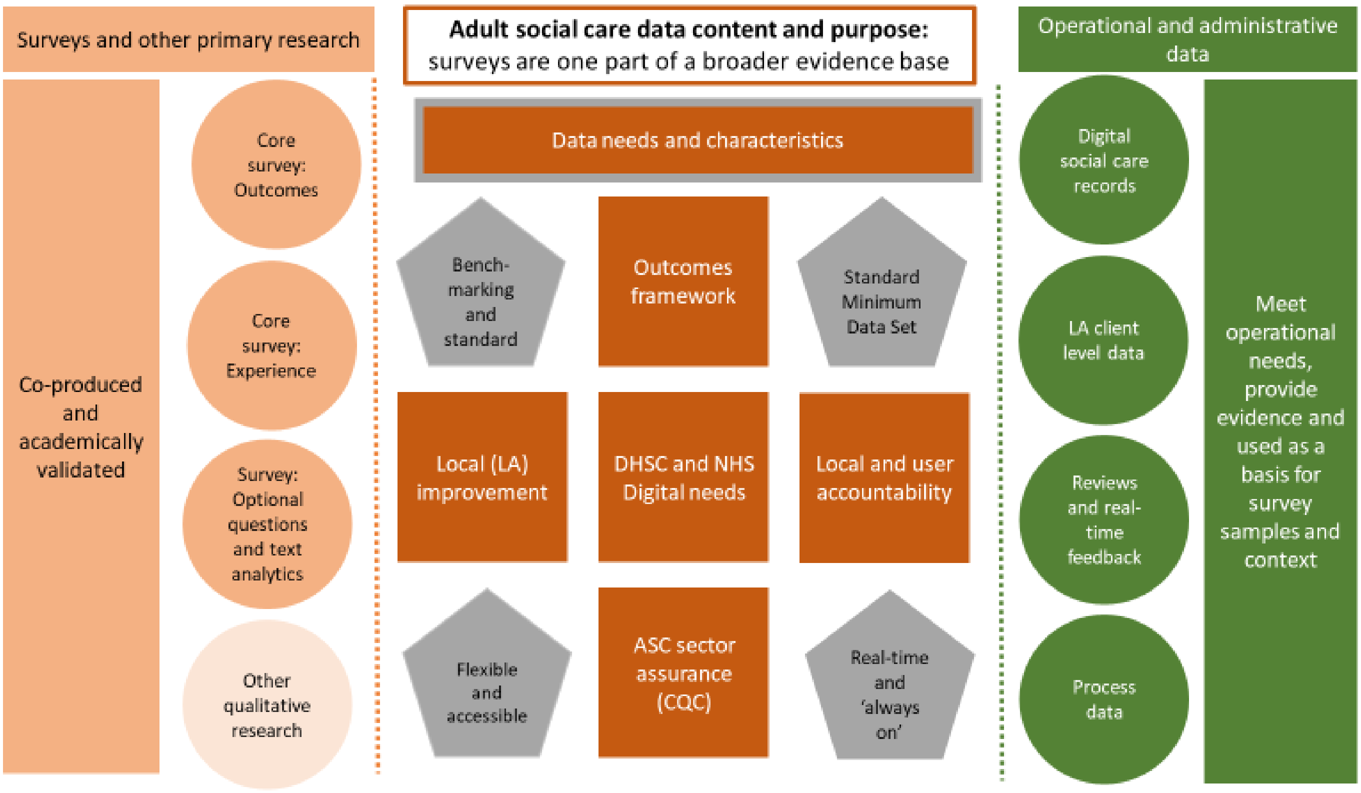
Agreeing on the purpose of the surveys is fundamental to any decisions made about future developments. We would recommend that a final decision on this needs to be made by DHSC after deliberation and consensus building with stakeholders in the sector. The diagram which follows shows a way of looking at this in the context of what this discovery review has shown and wider evidence in the sector.

Since DHSC funds and commissions the surveys their needs were agreed to be a priority. However, it was clear that the surveys are seen as having wider current or potential roles in the adult social care sector, beyond DHSC information needs and the outcomes framework (currently ASCOF) which the surveys feed into. In a situation of limited resource in which what is measured influences what is done, it was felt that the surveys should also contribute to wider assurance processes, local accountability, and LA led improvement and that these additional purposes help to secure buy-in from local authorities. The dark orange squares in the centre of the diagram show the potential purposes which could partly be met by the surveys (pale orange circles on the left) and other operational or real-time evidence (green circles on the right). The surveys can provide evidence beyond the outcomes framework (ASCOF) but ASCOF and the other purposes into which the surveys feed can also rely on other sources of evidence. The mix of evidence, whether research based or administrative data based should include elements which are standard for comparison and benchmarking but also elements which are flexible, accessible and responsive.

The grey pentagons show the attributes or characteristics of the evidence. This includes surveys and other research with people with care and support needs and carers (left) and administrative data (right). The core survey provides standard information for benchmarking, while other approaches and optional content would be more flexible and accessible. The administrative data could provide a standard set of records which are updated periodically and some of which is more regularly, constantly updated in the process of providing care and support (real-time) and shared at appropriate intervals.

Improved operational data is also key to ensuring effective targeting of the surveys to the potential participants in the right format or language and in identifying proxy participants or support for completion.

Research would be needed to help develop core standard parts of the surveys, supplemented by optional or rotating content as well as alternative and flexible qualitative approaches which run alongside the surveys to meet information needs which the surveys and operational real-time data cannot provide. This research could be supported by Research Practice Partnerships to facilitate co-design. Developments in the collection and sharing of operational data in the ASC sector should bear in mind the evidence needs and the surveys to ensure they work together without unnecessary overlap or duplication.



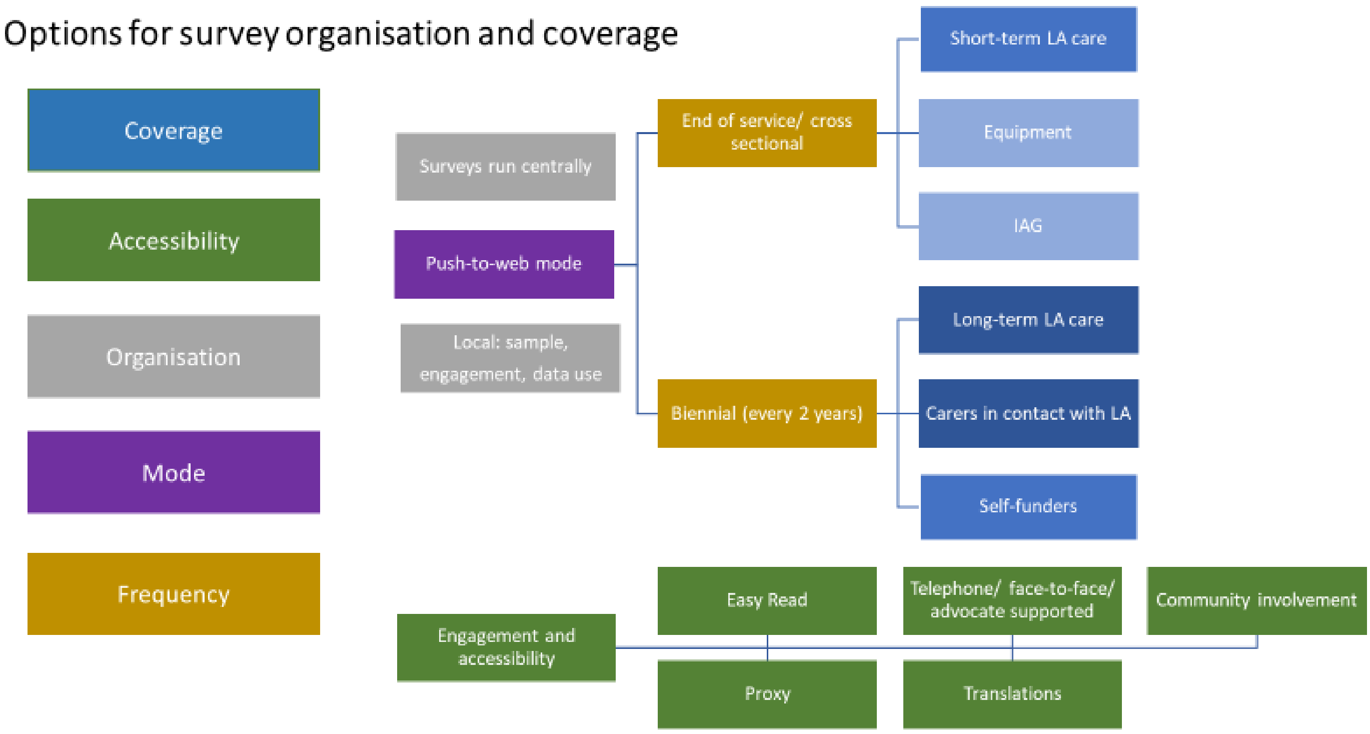
6.3 Options for survey organisation and coverage

The diagram below shows one potential long-term approach to running the surveys based on the findings of this discovery work.

In this potential approach, the coverage would eventually include all those groups covered by the Care Act with those shown in darker blue already covered, mid blue being the priority for extending the coverage, and light blue being the longer term aim or options for LAs to choose. The main surveys would take place every two years to be pragmatic about resources and to allow for full analysis and consideration of the implications – with the downside that ASCS data will be less up-to-date in the second year after publication. Other groups should be surveyed soon after they have received the service or contact which may be a cross sectional annual activity or quarterly activity, depending on numbers and resources.

It is recommended that in the long-term the surveys are run centrally with local LA control retained over sample selection, engagement and data. Since views on this are mixed, initially there may be an optional approach where LAs can choose central or local organisation. A push-to-web approach with surveys initially offered online with a paper option is recommended in the long-term but this will be subject to the findings of experiments and further development.

This approach of carrying out the ASCS less often, leading with efficient online approaches and running the surveys centrally should be more cost effective and the resulting savings could contribute to engagement and accessibility activities to ensure that everyone covered by the surveys is supported to take part and is motivated to do so because the approach is flexible and accessible and the purposes and impacts of the surveys are clear. The resourcing for these aspects of the surveys should reflect their importance in ensuring that the surveys are inclusive, representative and meaningful. Alternative formats and modes and the involvement of community and representative organisations are key elements of this.



6.4 A potential stepped approach

The changes described above will take time to develop and implement. Below we suggest one possible approach to making the changes to ensure that evidence continues to be collected, while allowing enough time for the co-production, development and full use of the data which is required.

The timings would need to align with and inform other developments which will inform and contribute to the approach. Several steps would run in parallel but they are presented as distinct activities below. Planning and preparation for these would need to start in 2022 and a systems approach which takes account of how these surveys link with, should inform and should be informed by other developments in the sector and is recommended.

Step 1: Improve and extend the existing surveys and build on developments

1A. Improve the existing survey (ASCS)

- Continue to run locally in LAs
- Retain same sample coverage
- Implement all the improvements that have already been developed for the surveys – new instruments (ER, Proxy, ASCOT-Carer etc)
- Pilot a push-to-web approach
- Potentially include additional optional questions online to identify whether there is appetite for this
- Include open text boxes and pilot using text analysis (if information governance allows)
- To improve engagement - show steps being taken in short-term and say longer term work is ongoing
- Engaging with gatekeepers and organisations to stabilise response rates
- Improving participant facing materials.

1B. Optional short-term users survey

- Building on questionnaire cognitive tested by NatCen, existing surveys used in some LAs and evidence needs
- Acts as a pilot but sufficient numbers in each LA to be of use in LAs which choose to take part
- Used to identify appropriate timing and frequency and pilot content.

1C. Build on developments (SACE)

- Retain same sample coverage
- Go push-to-web and administer centrally (host questionnaire centrally at least) if pilot shows these approaches are effective
- Include additional optional questions online (which could be tailored to specific circumstances using routing if numbers allow) to identify whether there is appetite for this
- Include open text boxes and use text analysis (if information governance allows).

Step 2. Development for full revisions to surveys

- Set up the systems at an LA and national level to collect and share the information needed to run the surveys effectively, using findings from this and other reviews to inform how they are developed. So they can be used for research purposes, client level data and a national minimum dataset digital social care records should include key information for survey administration (e.g. preferred language, mental capacity status and whether there is a carer available for support, and other characteristics needed for sampling, weighting and administering the surveys in an inclusive way), with appropriate technical and information governance procedures in place to permit use of this information. In addition, digital social care records or LA records held locally should include information such as mobile number and email where available, and name and contact details of carer (where there is one) to enable administration of a push-to-web survey with suitable reminders and opportunities for proxy responses.

- Work on information governance to ensure that provider and LA data can be shared safely for survey administration and relevant data can be linked, liaising with relevant bodies and other surveys with similar methodologies, while ensuring that the main client level data and national minimum datasets which are routinely provided are anonymous. This would involve working with those responsible for these developments.
- Identify partners to assist with consent processes and in person modes e.g. Clinical Research Network (CRN) or local Healthwatch.
- Carry out further research to identify appropriate frequency and timing of surveys for new groups which need more immediate surveys (building on short-term user survey in 2023).
- Partnership co-production or co-design deliberative project to agree purposes and develop the improved surveys which are likely to cover experience and outcomes – based on the best of ASCOT and current surveys but reflecting:
  - DHSC data needs
  - Changes to Care Act
  - New CQC local authority assessment framework
  - Extended groups in surveys
  - Full engagement of representative groups.
- Development, testing, piloting and validation of any changes to the questionnaires in partnership with the ASC sector (for main questions, proxy, Easy Read) once the purpose and information needs have been agreed. Such development would require sufficient time and resources. There is potential for different types of content:
  - Core content for all LAs and every year
  - Rotating topical content
  - Optional questions for LAs (potentially online only)
  - Open text (develop text analysis tool and information governance procedures for sharing outside LAs)
- Work with ASCOT team to ensure any IP (intellectual property) issues related to the amendment of ASCOT are correctly dealt with. Any changes to the ASCOT part of the ASCS and SACE questionnaires need permission and there is a preference to avoid numerous small changes which can impact on the validity of the measure.
- Further consultation with LAs and the wider sector about the appropriateness of central collection, based on sample selection and local level analysis still being controlled locally.
- Work to ensure the revised surveys fit into a coherent programme of social care statistics alongside admin , ‘real-time’ or regularly provided data returns as well as more flexible and innovative ways of seeking input
- No ASCS in 2024 as first step in moving to biennial (every other year).
- Note that projects of this type usually take 3-4 years so time is tight even to prepare for 2025.

Step 3. Revised and extended ASCS/ SACE run centrally

- Use individual level records shared with a central survey provider for the sample (with local control over exclusions).
- Centrally run survey (unless consultation suggests this should be optional rather than required).
- Push-to-web for all groups with resources for telephone and face-to-face to increase access.
- Core content available on paper. Online version includes further optional routed questions specific to circumstances.
- Includes proxy, Easy Read, translations etc. - all existing approaches retained and enhanced.
- Extend to new groups as metering and better records makes including self-funders feasible.

- Make short-term users survey a core part of the survey programme (with appropriate frequency).
- Equipment and IAG modules available as an option for LAs.
- LAs focus efforts during fieldwork on local promotion and partnerships.
- Provision of LA level outputs and LA level data.

Step 4. Maximising the use of the results
Coordinated programme to ensure data analysis and findings are:

- Accessible (IG and information sharing), including detailed data needed for analysis.
- Understandable to all stakeholders (accessible tools for examining data, insights and interpretation for a variety of groups, e.g. dashboards, data visualisation, infographics).
- Resourced – with support and capacity building in LAs and a cycle developed of data collection one year and analysis the next.
- Shared - e.g. NIHR funded research is disseminated in a variety of formats accessible to a wide range of stakeholders.
- Co-produced or co-designed, with input from user and carer groups as appropriate. A forum including the various stakeholder groups could assist with this. This group could set the focus of analysis, devise research questions, share and discuss ASCS and SACE research findings and help with dissemination and discussion in the sector.
- Feed into the survey cycle so that there is evidence of what the surveys are for and how they make a difference.

Maximising use of the survey findings would be part of a renewed culture in the ASC sector of seeking feedback as part of service delivery and review, with surveys forming part of this evidence. The integration of evidence from multiple sources, including the surveys, is needed as improved technology and systems and use of digital technology make real-time or regular feedback on experience easier, allowing for consistency and collation of data across providers/ parts of a local authority.

This improved sharing and use of survey and other data will rely on strong information governance and systems, with transparency in privacy policies so people in contact with local authorities and providers about their own or other’s care know how their information will be used.

Support from Research Practice Partnerships
Partnerships developed between academics and LAs and care providers could:

- Support the activities above – particularly the co-production, co-design and consensus building as well as building research capacity
- Enhance the additional research (outside the surveys) which takes place in LAs and care providers for areas which ASCS and SACE cannot cover including research which:
    - is sensitive to local context
    - reflects local need for improvement or understanding of changes – answers locally important questions
    - is flexible and allows people with profound or multiple difficulties to engage in the way in which they are able
    - enables the views and experiences of those who are too few in number for local level quantitative analysis, or who have specific cultural or health needs to be understood
    - is co-produced or co-designed with people with care and support needs and carers (agreement would be needed on whether co-production or co-design is most appropriate)

  - drills down into unanswered questions from the surveys by exploring issues raised and potentially following up sample from the surveys who agreed to recontact (though should also include people unable to take part in surveys)
  - could potentially be co-run with local community and voluntary groups or care providers to address issues they may want to raise or work together with the council on.

- Ensure funding and resource which can be used at a local level to meet local needs are set aside for research rather than service delivery.

In terms of timings, steps 1 and 2 could place from 2022 to 2025, with step 3 in 2026 and step 4 from 2025 to 2027. The timing will depend on other developments such as client level data returns.

6.5 Further research and activities needed

In the section above we suggested one potential overall programme of work which, once agreed, would need a detailed plan in place to implement. In the meantime, in deciding on the feasibility of the suggestions above, some more immediate activities are recommended.

6.5.1 Short-term needs to identify viable approaches

Information is needed from LAs on:

- The number of people in contact with the LA for different services overall in a year with information on seasonal patterns and flow through the year. This is needed in order to decide whether research with the last 3 categories can be done once a year as a snapshot or whether it should happen every quarter to generate enough cases for analysis in a year:
  - Long-term care
  - Short-term care
  - Equipment and technology
  - IAG.

- Whether they run in house surveys among these groups and the frequency, instruments, and materials used for these, as well as information on how the results are used.

Discussion is needed with other organisations on potential approaches:

- HRA Social Care Research Ethics Committee on how those lacking capacity could best be included in the ASCS in line with the Mental Capacity Act

- HRA Confidentiality Advisory Group (CAG) on approaches to central data collection and information governance around sharing identifiable data for survey invitations

- NIHR Clinical Research Networks (CRNs) on their potential involvement in consent, recruitment and data collection

- Healthwatch on their potential involvement in increasing accessibility

- CQC and NHSE, which commission centrally run patient experience surveys which involve data sharing, to understand the ways in which the sharing for research is permitted

- Commissioning Support Units (CSUs) which provide NHS organisations with IG advice about how this could potentially be extended to LAs, via ICSs to facilitate the agreements over information sharing for survey administration.

Ongoing discussion within DHSC is needed on:

- How these developments fit with plans for collecting evidence on paying for care (which are being developed as part of a separate project)
- How the timing and plans for the survey developments align with the timing and plans for refreshing the outcomes framework (ASCOF)
- Continuing to map the evidence needed within an outcomes framework, aligned with other frameworks and identifying which evidence and questions which would come from these surveys and which would come from elsewhere.

6.5.2 Short to medium term engagement

Engagement is needed with organisations to ensure that other changes in the sector and survey developments align:

- CQC over their LA assessment framework and how the evidence needed will align or differ from the updated ASCOF.
- NHSE and DHSC over digital social care records and national minimum data set and any information requirements needed for survey context (measures and format) and potential sample sources. Information governance requirements related to the use of these records for research and service evaluation through the surveys should also be discussed.
- NHS Digital over LA client level data and any information requirements needed for survey context (measures and format) and potential sample sources.
- NHSE about how integration plans affect the links between NHS patient and social care evidence, and in particular how the integration index methodology could inform these surveys, how any groups which cannot be covered by these surveys (e.g. those on continuing health care funded services) fit into the wider evidence base across integrated health and social care.
- Care providers on the feasibility of planned approaches to enhancing engagement and accessibility and the role they could play in this.
- Digital record providers (software providers) or representative organisations such as CASPA (Care Software Providers Association).
- Representatives of areas which have been early adopters of digital care records (e.g. Liverpool City Council which has bought a digital care record system for home care providers in the area).
- NHS Transformation Directorate (formerly part of NHSX) about plans for digital social care records and links to a national minimum dataset.
- Those involved in making decisions about data sharing and use of patient information for research to ensure that any plans for using new records or data sets for sampling are legal, technically possible and have the support and understanding of those involved, including people with care needs and their carers.

Glossary

ASCOF	Adult Social Care Outcomes Framework: a set of social care outcome indicators designed to capture the social care system's performance nationally, as well as to guide and influence decision-making by local authorities in strategic planning, oversight and commissioning.
ASCOT	Adult Social Care Outcomes Toolkit: measures the social care related quality of life of different aspects of service users' life (SCRQoL) in the ASCS and carer social care related quality of life (CarerSCRQoL) in SACE.
ASCS	Adult Social Care Survey – survey of adults in receipt of local authority funded long-term support
BEIS	Department for Business, Energy & Industrial Strategy
CAG	Confidentiality Advisory Group: an independent body which provides expert advice on the use of confidential patient information. Comes under the responsibility of the Health Research Authority (HRA)
CASPA	Care Software Providers Association
CASSR	Council with Adult Social Services Responsibilities
CHC	Continuing Healthcare: personal care services funded by the NHS
CQC	Care Quality Commission
CLD	Client Level Data returns: instead of providing summaries of their social care activities, LAs would provide NHS Digital with individual level anonymised data. This is not yet in place but is being developed.
DHSC	Department of Health and Social Care
DWP	Department for Work and Pensions
HRA	Health Research Authority: protects and promotes the interests of patients and the public in health and social care research. Responsible for Research Ethics Committees and the Confidentiality Advisory Group (CAG)
IAG	Information, Advice and Guidance
LA	Local Authority. Where local authority or LA is used in this report it refers to the authorities also known as CASSR – Councils with adult social care service responsibility. These are unitary, metropolitan or county councils, not district or borough councils.
LCC	Lacking capacity to consent - this refers to adults and is a term used with reference to the Mental Capacity Act.

LGA	Local Government Association: a national membership body for local authorities, working on behalf of member councils to support, promote and improve local government.
MCA	Mental Capacity Act: designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.
MDS	Minimum Data Set: a national, standardised data set of individual social care records, to be populated by registered care providers. It does not exist yet but is being developed.
MRC	Medical Research Council: an organisation which provides grants for academic research related to health.
NIHR	National Institute for Health Research: an organisation which provides grants for academic research related to health, including some research funded by DHSC.
NHSE	NHS England
PSSRU	Personal Social Services Research Unit. Now based at University of Kent. Led on development of ASCOT, ASCS and SACE.
RPP	Research Practice Partnership: partnerships developed between academics, local authorities and care providers to support co-production activities, consensus building and enhance research capacity.
QoL	Quality of Life
SACE	Survey of Adult Carers in England. Also called Personal Social Services Survey of Adult Carers in England. Survey of carers in contact with their local authority in the last 12 months.
SALT	Short and Long-Term support. Information on this is held by LAs and provided to NHS Digital.
SCRQoL	Social Care-Related Quality of Life
SSUSG	Social Services User Survey Group: advisory group for the ASCS and SACE, chaired by NHS Digital.
REC	Research Ethics Committee. ASCS and SACE require approval from an HRA REC.
UKRI	UK Research and Innovation: umbrella body for UK research councils which fund academic and other research.

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Appendix A

ASCS questionnaire content in relation to ASCOT, ASCOF and known issues

Q no.	Question	ASCOT	ASCOF	Notes
1	Overall, how satisfied or dissatisfied are you with the care and support services you receive? (7 categories)		3A. Overall satisfaction of people who use services with their care and support	Findings about Satisfaction sometimes contradicts other questions[299] Satisfaction can be affected by support needed to complete the survey with those receiving support from care and support workers to complete it expressing higher satisfaction[300]
2a	Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole? (7 categories)			
2b	Do care and support services help you to have a better quality of life? (Y/N)			
2c	Which of the following statements best describes how much choice you have over the care and support services you receive? (3 categories)			
3a	Which of the following statements best describes how much control you have over your daily life? (4 categories)	Yes - Control over daily life (1 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services. 1B. Proportion of people who use services who have control over their daily life.	
3b	Do care and support services help you in having control over your daily life?			
4a	Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation? (4 categories)	Yes - Personal cleanliness and comfort (2 of 8 domains)	1A. Social care-related quality of life.	

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[299] IPC (2020) ASCOF Refresh Part 1

[300] IPC (2020) ASCOF Refresh Part 1

			1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
4b	Do care and support services help you in keeping clean and presentable in appearance? (optional) Y/N			
5a	Thinking about the food and drink you get, which of the following statements best describes your situation? (4 categories)	Yes - Food and drink (3 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
5b	Do care and support services help you to get food and drink? (optional) Y/N			
6a	Which of the following statements best describes how clean and comfortable your home is? (4 categories)	Yes - Accommodation cleanliness and comfort (7 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
6b	Do care and support services help you in keeping your home clean and comfortable? (optional) Y/N			
7a	Which of the following statements best describes how safe you feel? *By feeling safe we mean how safe you feel both inside and outside the home. This includes fear of abuse, falling or other physical harm.* (4 categories)	Yes - Personal safety (4 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services. 4A. Proportion of people who use services who feel safe.	Testing of the satisfaction questions as part of a project exploring ethnic inequalities in satisfaction found that people expressed their overall experience of accessing and receiving social care services, not just their satisfaction with the specific service received.[301] Validation study for ASCOT shows feeling safe associated with the area they live in and whether they live with others suggests it is less about safeguarding than about general safety[302]

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[301] Gray et al (2014) Exploring Satisfaction with social care services.

[302] Malley et al (2012) An Assessment of the Construct Validity of the ASCOT Measure of Social Care.

7b	Do care and support services help you in feeling safe? Y/N		4B. Proportion of people who use services who say that those services have made them feel safe and secure	There was greater support for this question than the ASCOT question about feeling secure.[303]
8a	Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation? (4 categories)	Yes - Social participation and involvement (5 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services. 1I. Proportion of people who use services and carers, who reported that they had as much social contact as they would like.	
8b	Do care and support services help you in having social contact with people? (optional) Y/N			
9a	Which of the following statements best describes how you spend your time? (4 categories)	Yes - Occupation (6 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
9b	Do care and support services help you in the way you spend your time? (optional) Y/N			
10	Which of these statements best describes how having help to do things makes you think and feel about yourself? (4 categories)	Yes (linked to 8 of 8 domains) Does not feed into scoring but is asked to improve and support the response to the dignity item	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
11	Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself? (4 categories)	Yes - Dignity (8 of 8 domains)	1A. Social care-related quality of life. 1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	Note that feedback during stakeholder interviews indicated that some LAs thought there was no dignity item in the questionnaire – this item may not be recognised as being about dignity. This results in LAs adding another question about dignity.

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[303] IPC (2020) ASCOF Refresh Part 1

12	In the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits? (4 categories plus N/A)		3D. The proportion of people who use services who find it easy to find information about support	
13	How is your health in general? (5 categories)		1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
14	By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.			
14a	a. Pain or discomfort (3 categories)			
14b	b. Anxiety or depression (3 categories)			
15	Please place a tick (✓) in the box that best describes your abilities for each of the following questions (4 activities with 3 answer options)		1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
16	Please place a tick (✓) in the box that best describes your abilities for each of the following questions (4 activities with 3 answer options)		1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
17	How well do you think your home is designed to meet your needs?		1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
18	Thinking about getting around outside of your home, which of the following statements best describes your present situation?		1J – Adjusted Social care-related QoL – impact of Adult Social Care Services.	
19	Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members? (3 categories)			
20	Do you buy any additional care or support privately or pay more to 'top up' your care and support? (3 categories)			
21	Did you have any help from someone else to complete this questionnaire? (4 categories)			
2	What type of help did you have? (5 categories plus N/A)			
23	Would you be happy to be invited to take part in more research? (optional)			

SACE questionnaire content in relation to ASCOT, ASCOF and known issues

Q no.	Question	ASCOT (CarerSCRQol rather than current)	ASCOF	Notes
1	How old is the person you care for?			
2	Does the person you care for have....? (tick all that apply from 9 categories describing conditions and disabilities)			
3	Where does the person you care for usually live? (with me, somewhere else)			
4	Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months? (7 categories plus We haven't received any support or services from Social Services in the last 12 months)		3B. Overall satisfaction of carers with social services	
5	Has the person you care for used any of the support or services listed below in the last 12 months? They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. (11 Options with Y/N/DK). LAs have the option to add approved categories			
6	Have you used any of the support or services listed below, to help you as a carer over the last 12 months? They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. Please do not include any unpaid help from family and friends.(4 Options with Y/N/DK). LAs have the option to add approved categories			
7	Which of the following statements best describes how you spend your time? When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid	Yes – Occupation domain (1)	1D. Carer-reported quality of life (but note difference from current ASCOT measure)	

	work, caring for others and leisure activities. (3 categories)			
8	Which of the following statements best describes how much control you have over your daily life? (3 categories)	Yes: Control over daily life domain (2)	1D. Carer-reported quality of life (but note difference from current ASCOT measure)	
9	Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation? (3 categories)	Yes - Self-care domain (3)	1D. Carer-reported quality of life (but note difference from current ASCOT measure)	
10	Thinking about your personal safety, which of the statements best describes your present situation? By ‘personal safety’ we mean feeling safe from fear of abuse, being attacked or other physical harm. (3 categories)	Yes - Personal safety domain (4)	1D. Carer-reported quality of life (but note difference from current ASCOT measure)	
11	Thinking about how much social contact you’ve had with people you like, which of the following statements best describes your social situation? (3 categories)	Yes - Social participation and involvement domain (5)	1D. Carer-reported quality of life (but note difference from current ASCOT measure). 1I. Proportion of carers, who reported that they had as much social contact as they would like.	
12	Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation? (3 categories)	Yes - Feeling encouraged and supported (7)	1D. Carer-reported quality of life (but note difference from current ASCOT measure)	
13	Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? Please exclude the person you spend most time helping. (3 categories plus I don’t have caring responsibilities for anyone else)			
14	In the last 12 months, has your health been affected by your caring role in any of the ways listed below? (11 categories plus none of these)			

15	In the last 12 months, has caring caused you any financial difficulties? (3 categories)			
16	In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services. (4 categories plus I have not tried to find information or advice in the last 12 months). With optional ‘please tell us why’ box.		3D. The proportion of people who use services and carers wo find it easy to find information about support.	
17	In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services. (4 categories plus I have not received any information or advice in the last 12 months). With optional ‘please tell us why’ box.			
18	In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? (4 categories plus There have been no discussions that I am aware of, in the last 12 months)		3C. The proportion of carers who report that they have been included or consulted in discussion about the person they care for.	
19	In addition to your caring role, please tell us which of the following also applies to you? (8 categories about employment and other activities)			
20	Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation? (6 categories grouped by employment status)			
21	About how long have you been looking after or helping the person you care for? (8 categories)			
22	About how long do you spend each week looking after or helping the person you care for? (10 categories)			
23	Over the last 12 months, what kinds of things did you usually do for the person you care for? (11 categories)			
24	Do you have any of the following? (7 categories – list of conditions and none of these)			
25	How old are you?			

	LA may use admin data instead			
26	Are you male or female? LA may use admin data instead			
27	How many children aged 18 or under do you have parental responsibility for? (5 categories)			
28	To which of these groups do you consider you belong? (Ethnicity in 18 categories plus prefer not to say) LA may use admin data instead			
29	Did someone help you to complete this questionnaire? (Y/N) LA can seek further information on this if needed			
30	Thinking about your experiences during the Coronavirus (COVID-19) pandemic, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services? (7 categories plus We didn't receive any support or services from Social Services during the Coronavirus (COVID-19) pandemic)			New in 2021-22
31	Thinking about how much social contact you had with people you like during the Coronavirus (COVID-19) pandemic, which of the following statements best describes your social situation during this time? (3 categories)			New in 2021-22
32	Thinking about your personal safety during the Coronavirus (COVID-19) pandemic, which of the statements best describes how you felt during this time? By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm. We do not mean feeling safe from fear of contracting coronavirus. (3 categories)			New in 2021-22
33	Thinking about your experiences during the Coronavirus (COVID-19) pandemic, did you feel you were involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? (5 categories)			New in 2021-22

34	Please use the space provided below to describe any other experiences you would like to tell us about, or to write any other comments you would like to make? This box is for local use and can be committed, Councils do not need to return data to NHS Digital			New in 2021-22

Space and time to be yourself is a domain from the current carer’s ASCOT which is not included in the SACE: “
The carer feels that s/he has enough space and time in everyday life to be him/herself away from the caring role and the responsibilities of caregiving”

Mapping of ASCOT and ASCOT-Carer to Care Act carried out by Stacey Rand, James Caiels, Diane Fox, Ann-Marie Towers in February 2022.
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ASCOT[304] mapped to the Care and Support (Eligibility Criteria) Regulations 2014[305]

Outcomes specified in the regulations	ASCOT domain
Managing and maintaining nutrition	Food and drink
Maintaining personal hygiene	Personal comfort and cleanliness
Managing toilet needs	Personal comfort and cleanliness
Being appropriately clothed	Personal comfort and cleanliness
Being able to make use of the adult's home safely	Personal safety
Maintaining a habitable home environment	Accommodation comfort and cleanliness
Developing and maintaining family or other personal relationships	Social participation
Accessing and engaging in work, training, education or volunteering	Occupation (doing things I value and enjoy, including caring)
Making use of necessary facilities or services in the local community including public transport and recreational facilities or services	Occupation
Carrying out any caring responsibilities for a child	Occupation

Other ASCOT domains:

- Control over daily life
- Dignity

ASCOT-Carer mapped to the Care and Support (Eligibility Criteria) Regulations 2014

Outcomes specified in the regulations	ASCOT-Carer domain
Carrying out any caring responsibilities for a child	Occupation
Carrying out any caring responsibilities for another adult	Occupation
Maintaining a habitable home environment	N/A †
Managing and maintaining nutrition	Self-care
Developing and maintaining family or other personal relationships	Social participation
Engaging in work, training, education or volunteering	Occupation
Making use of necessary facilities or services in the local community including public transport and recreational facilities or services	Occupation
Engaging in recreational activities	Occupation

† This was not identified as a key outcome in the early development work for Carer SCRQoL (Fox et al, 2010), which was used as the basis for the ASCOT-Carer.

Other ASCOT-Carer domains:

- Control over daily life
- Personal safety
- Time and space to be yourself *
- Feeling supported and encouraged in caring role

*This is not included in the Carer SCRQoL in the SACE and reported in ASCOF.

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[304] www.pssru.ac.uk/ascot

[305] https://www.legislation.gov.uk/ukdsi/2014/9780111124185

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