Personal Social Services: Survey of Adult Carers in England

Information and guidance for the 2023-24 survey year

Document filename:	**Survey of Adult Carers in England**		
Project / Programme	**Adult Social Care**		
Project Manager	**Robyn Wilson**	Status	**Final**
Owner	**Liz Selfridge**	Version	**4.0**
Author	**Liz Selfridge**	Version issue date	**23/10/2023**

Document management

Revision History

Version	Date	Summary of Changes
1.0	01 June 2023	Dates updated where known and branded changed to NHS England. Below is a list of changes from the 2021-22 guidance, these are also highlighted in the guidance: Clarity on that additional response options for questions 5 and 6 should be sent to NHS England. Electronic versions can be sent to carers who could not otherwise participate. If the council does not provide the support to the cared-for person, but their records include the support reason, then councils can use their discretion as to whether to populate with the PSR or record as unknown. Validation reports. Section on key dates, changes to materials and FAQs added.
2.0	07 September 2023	Fix to fieldwork end date in appendix L Clarity on RHCs being voluntary for the 2023-24 survey.
3.0	13 September 2023	Removed references to webpage ‘Running and using social care user surveys’ as documents are out of date. Question references corrected in definition of what is a response.
4.0	23 October 2023	Updated key dates throughout Changed contact email address to Ssd.nationalservicedesk@nhs.net
5.0	20 December 2023	Clarity on responsibility for providing questionnaire and cover letter in different formats.

Reviewers

This document must be reviewed by the following people:

Reviewer name	Title / Responsibility	Date	Version
Robyn Wilson	Analytical Section Head	19/05/2023	1.0

Approved by

This document must be approved by the following people:

Name	Signature	Title	Date	Version
Robyn Wilson	RW	Analytical Section Head	19/05/2023	1.0

Glossary of Terms

Term / Abbreviation	What it stands for

Document Control:

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1. Introduction

1.1 This document sets out the guidelines for conducting the Personal Social Services Survey of Adult Carers in England (SACE). All Councils with Adult Social Services Responsibilities (CASSRs) with an eligible population of at least 150 carers, are required to carry out this biennial survey. SACE exists in a national policy context in which increasing consideration has been given to the role of carers (see Appendix A), and asks carers about their quality of life, the impact of services on their quality of life, and their general health and well-being.

1.2 The data collected are sent to NHS England and are used as the basis of analyses that are included in national level Official Statistics reports. Data are also used to populate several measures in the Adult Social Care Outcomes Framework (ASCOF); see Appendix B for further details. These data will be used to inform and support policy and decision making at both the local and national level; to improve care, services and outcomes for local populations; and to help carers make better choices about their support.

1.3 The survey was developed in conjunction with the Social Services User Survey Group (SSUSG). For more information see Appendix C.

1.4 If you are conducting the survey, then you must read the main body of this document in full before commencing work. More general information about the survey is included in the appendices.

1.5 It is vital that councils adhere to this guidance as closely as possible to ensure that the survey results from different CASSRs and regions are genuinely comparable. Also, the research design and materials have been approved by the Social Care Research Ethics Committee (SCREC) and any deviation may lead councils to fall outside its remit.

1.6 For the avoidance of doubt it is confirmed that the national data opt-out will not apply to the 2023 Survey of Adult Carers in England. Further work is underway with local authorities to support the implementation of national data opt-out across health and care. Further information and updates are provided on the national data opt-out webpages.

1.7 You may believe that you are faced with exceptional circumstances which makes it necessary to deviate from this guidance, for example if questionnaires cannot be distributed and returned in the given fieldwork period. In such instances NHS England must be contacted and advice/approval sought before any action can be taken.

1.8 If NHS England believes that councils have changed materials or practices in a manner which has compromised the robustness or comparability of the survey results, then it may be necessary to note these incidences in the Data Quality section of the survey report. This will enable anyone who uses the data to understand its strengths and weaknesses and to assess its usefulness for themselves.

1.9 If you have any comments or suggestions for improvements, or if you are unclear about what to do then please contact us.

1.10 You can reach the adult social care user survey team at NHS England by email (Ssd.nationalservicedesk@nhs.net) or by calling the NHS England contact centre on 0300 303 5678. The preferred method of initial contact is via email.

Figure 1: The survey process and associated timescales

Inform and engage senior management and obtain permission to send out questionnaires to carers

Finalise questionnaires and materials

These steps need to be completed prior to sending out questionnaires.

Extract the Eligible Population data including auxiliary information

Check eligible population data for completeness, accuracy and currency

Remove from the eligible population figure those carers known to have been incorrectly included due to records being out of date.

Eligible population can be extracted at any time between **1 July** and **30 September 2023**

Determine the required sample size

Select the primary sample

Select the reserve sample (if you wish at this point)

Determine which questionnaire to send to each carer

Identify those carers who should not be sent a questionnaire due to the reasons listed below

These steps need to be completed after the Eligible Population extract has been taken, and prior to sending out questionnaires.

Send out and book in questionnaires

Follow up non-respondents

Select the top-up sample to compensate for low responses if necessary (if a reserve sample has not already been determined).

Top up sample if necessary

Questionnaires should be sent out from **1 October 2023**. NHS England recommends that fieldwork is completed by **30 November 2023**.

Transfer questionnaire data to the data return

Validate the data return

Submit data to NHS England

SACE data for 2023-24 should be submitted by **29 February 2024**.

2. Overview

2.1 This section briefly reviews issues which CASSRs should consider from the outset of the project. It covers the importance of maximising response rates and lists the materials to be used by the council in undertaking the survey. It also covers the issues of engaging staff and public, maintaining confidentiality and relationships with third party providers.

Maximising response rates

2.2 As you read through this guidance it should become clear that the survey design is largely aimed at maximising the response rates. This is because surveys do not draw information from the whole population they represent. Instead, the views of those who participate in the survey are used to estimate the views and experiences of everyone.

2.3 It is natural that any estimate is subject to a degree of uncertainty, which is expressed statistically as a 'margin of error'. The higher that the proportion of survey respondents is in relation to the total carer population, the lower the margin of error. The requirement for the SACE survey is that the results have a margin of error of less than +/- 5 per cent. This means that if 50% of survey respondents say they are very satisfied with the services they receive, we can be reasonably confident that the figure for all eligible carers from that council will be between 45% and 55%. More information about margin of error calculations are available in Appendix D.

2.4 It is also important to maximise response to mitigate the problem of non-response bias, which occurs if there are significant differences between people who do and do not participate in a survey. If for example, those who are more likely to respond to a satisfaction survey are also more likely to be dissatisfied with the services they receive, then the results will overestimate the general level of dissatisfaction amongst carers. The higher the level of non-response, the greater this overestimation shall be. Simply increasing the sample size, without changing the response rate, cannot mitigate this problem.

2.5 The need to maximise response rates underpins the design of the materials. The questionnaire and covering letters are written to help carers understand that participation is a worthwhile activity. These documents guarantee confidentiality and highlight the steps to take if carers need help to complete the survey. The layout of the materials is aimed at helping respondents easily negotiate the questionnaires, for example by using Calibri font in 14-point to make the documents easy to read (see Appendix E for more details).

2.6 Consideration has also been given to enabling as wide a range as possible of potential participants to respond, including those whose who are not fluent in English, people with sensory and other impairments, people with limited literacy skills and anyone who might find it difficult to complete a questionnaire by themselves. In addition to the self-completion questionnaire NHS England has produced a range of materials (see Available materials below). Councils are also expected to give due consideration to the diversity of needs of the carers in their area in terms of provision of materials and assistance.

2.7 In past years, some CASSRs have chosen to use incentives to encourage responses to the survey. NHS England carried out some analysis on question responses for councils that used incentives compared to those that did not offer incentives. The analysis discovered that the use of incentives did not seem to have an impact on the overall response rate but there were differences in the question responses. To try and ensure the data is as comparable as possible, CASSRs are advised not to use incentives.

Available materials

2.8 In addition to this guidance NHS England has posted the following materials for CASSRs' use on the Survey of Adult Carers in England, 2023-24 guidance for local authorities webpage:

- Standard questionnaire
- Large print questionnaire
- Face-to-face interview script
- Telephone interview script
- Covering letter
- Reminder letter
- Consent form
- Translation request sheet
- Sample size calculator
- Survey data return document
- Translated versions of the questionnaires and letters in 17 languages. For a full list see Appendix F.

2.9 Councils may also wish to use the MAX toolkit, which is designed to maximise the local usefulness of the survey (see Appendix G).

2.10 Further information sources are listed in Appendix H.

Engaging council staff

2.11 Given their essential role in conducting the survey, council staff need to be committed to its aims and objectives. An understanding on their part of the aims of the survey is likely to be of key importance in gaining their commitment. Furthermore, staff who are not directly involved with the survey but work with carers, should be made aware of the survey and its aims. This way, if asked by carers, they may encourage response and allay concerns that response may affect services received. Another way of getting all staff to 'own' the survey would be to ensure that they have access to the analysis of the results of the surveys and have some involvement in making use of them.

2.12 Senior management must also be informed about the survey. It is an ethical requirement that participating CASSRs obtain senior management permission prior to sending out questionnaires to carers. Generally, it is in councils' interests that senior management are informed of the need to undertake the survey and engaged as early as possible. This way due consideration can be given to allocating resources to the survey administration (see Appendix I) and to make best use of the data obtained.

2.13 CASSRs may have to carry out a local ethical review if they do not run the survey in the way outlined in this guidance document, or if they choose to include additional questions in the questionnaires (see paragraphs below for information about additional questions).

Advance publicity

2.14 Councils should also consider engaging the public, especially carers, as early as possible. Giving the survey advance publicity should aid the response rate. This leads potential respondents to expect to receive a questionnaire and gives them some idea of what the survey is trying to achieve. Councils might issue a general press release through the local press or through relevant local carer group networks. It may also be useful to let local carers' organisations know about the survey, so they can publicise it with carers. A leaflet with a notice to carers may also encourage people to respond.

Confidentiality

2.15 It is essential that the confidentiality of participating carers is assured. Council staff, other than those administering the survey, cannot know whether individuals have completed a questionnaire or how questions were answered. The questionnaires, covering and reminder letters all contain assurances of confidentiality.

2.16 A unique code will need to be generated by councils so that returned questionnaires can be mapped back to the participant. This will enable survey teams to follow up those who have not initially responded to the survey, and to bring together information from a variety of data sources. CASSRs will therefore need to consider how information is handled within the council. Due attention must be paid to the new General Data Protection Regulation (GDPR) which has applied from 25 May 2018.

2.17 Importantly, access to the list of carers' details used to send out the questionnaire will need to be strictly controlled. Computer files need to be password protected and/or stored on a secure server, and access to these must be restricted to those involved in mailing out the questionnaire and responsible for either pre-coding the questionnaires or setting up codes for the analysis. Unsecured email must never be used to send content which includes the names or other personal details of carers. Completed questionnaires must be stored securely in locked cabinets.

2.18 Councils must retain paper copies of the questionnaires until the publication of the final 2023-24 SACE report. After this point you are free to securely dispose of paper copies, although you may wish to hold on to them for longer if you believe for example, that participants are likely to take part in any follow up studies. The treatment of paper and scanned copies must be in line with your local Information Governance procedures and meet the requirements of the GDPR.

Outsourcing the survey

2.19 Councils may consider outsourcing elements of the survey process to a third party. For example, a data capture company might be used to scan completed de-identified questionnaires into a dataset format. This approach may help councils to meet submission deadlines by removing the need to enter data manually.

2.20 In determining whether to outsource elements of the survey to a third party, councils should refer to their local Information Governance arrangements in the first instance, as they will need to ensure that all relevant information governance issues are considered throughout the process of exploring, making and implementing an outsourcing decision. Again, councils will need to attend to the new GDPR.

2.21 In running the survey, councils are likely to be acting as a data controller, outsourcing tasks, under clear instruction and with strict controls, to third parties who then act as data processors in carrying out the agreed work. Councils therefore are responsible for ensuring that any third party operates by an acceptable code of conduct, particularly around the issue of confidentiality.

Data sharing with service providers

2.22 If any of the carer services are outsourced, councils should ensure that the relevant systems and agreements for data sharing and protection are established with the relevant parties. Some councils have experienced problems persuading partner organisations, responsible for the provision of services, to share contact details in order to enable councils to send out questionnaires. It is recommended that data sharing requirements are written into contracts when setting up such arrangements to avoid this situation.

2.23 Where required, councils should also satisfy themselves that carers are made aware that data sharing with third parties may be required to ensure both the smooth running of the assessment and delivery process, and for evaluating the performance of providers and councils via mechanisms such as surveys. As with outsourced survey partners, this issue must be considered in the context of the GDPR.

3. Preparing the Survey

3.1 This section covers the actions CASSRs need to take to prepare the survey before questionnaires are sent out to participating carers. Ahead of this fieldwork period councils must complete a variety of tasks, including making necessary amendments to written materials, determining the eligible population and generating administrative information. Councils also have the option to formulate and submit to NHS England their own questions to include in the survey for local research purposes.

Finalising materials

3.2 CASSRs need to customise the materials provided by NHS England. Sections which require amending are identified with red text and yellow highlighting (all highlighting must be removed once amendments are completed).

3.3 Councils may also adapt the materials to match the formats they use to produce and process their other publications. This may include for example, making changes to enable the use of specialist survey software in the production of, and scanning of, questionnaires. Any such amendments must be minor and **must not** be made unless prior consent has been given by NHS England.

3.4 Ideally as soon as amendments to letters and questionnaires are finalised then you should email blank copies of your questionnaires, cover and reminder letters to the team directly at Ssd.nationalservicedesk@nhs.net . This will allow for further checks on the extent to which the survey has been carried out in line with this guidance. They **must** be sent by 30 November (the recommended fieldwork period end date). The materials submitted must be the final ones used for the survey. The review by NHS England forms part of the data quality assessment processes and is not to approve the materials before councils send them to users. If NHS England believes that councils have changed materials in a manner which has compromised the robustness or comparability of the survey results, then it may be necessary to note these incidences in the Data Quality section of the survey report.

Covering and reminder letters

3.5 CASSRs must insert the name of their social services department or relevant carer's team into the text where indicated along with relevant dates. CASSRs must add contact details including a postal and email address and a telephone number. Also, a telephone number must be included for carers to access independent support and advice to help them complete the questionnaire. The council's corporate logo and the Director of Adult Social Services' signature must be added. No other format changes are permitted. No other text may be withdrawn, added or amended.

3.6 In the covering and reminder letters, CASSRs are required to add contact details for the carer to make independent complaints. The contact details need to be independent of the Adult Social Care or Research team that is carrying out the survey. It is permittable to include contact details of the CASSRs complaint service provided this is independent of the survey.

3.7 Following the introduction of GDPR in addition to the cover letter, CASSRs must also provide additional transparency information to the carer to inform them of their rights. This information should be in the form of a separate printed information sheet and / or a link to the CASSRs online privacy / transparency notice. Further information on GDPR can be found on the Information Commissioner's Office website: https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-be-informed/.

Questionnaires

3.8 An appropriate location for a unique serial number for tracking respondents must be identified. This is so that the non-questionnaire information can be added to the questionnaire data on the data return, although not so that council staff can identify the respondent (see paragraphs above). This should be placed to minimise the opportunity for inadvertent removal by respondents.

3.9 Participating councils must also decide how many of the optional questions they wish to use. You may choose as many or as few as you wish and must remove those you do not use from the questionnaire. These include some optional free text questions as well as a question concerning participants willingness to participate in further research. If you choose to include an optional question in the standard survey, then it should also be included in the translated versions.

3.10 The questions asking the age, gender and ethnicity of participants should be removed if councils can provide NHS England this information from their records. They must remain in the questionnaires if this demographic data is not obtainable by other means.

3.11 Certain changes to the questionnaires **must not** be made and are not permitted under any circumstances. These include:

- Deleting any mandatory question.
- Changing the wording of existing questions.
- Changing the size or style of font used.
- Removing white space so that the questionnaire fits on fewer pages.
- Adding council details, corporate logos or other council branding.

3.12 Given that these unpermitted changes might undermine the survey results, then it is possible that if they occur they will be itemised in the Data Quality section of the survey report to allow those who use the data to assess its strengths and comparability.

3.13 The materials sent to carers must include only those needed to complete the survey. The survey must not be used to send out any other information such as promotional leaflets.

Additional questions

3.14 As already noted CASSRs may also add questions to the survey for local research purposes, subject to approval by NHS England. Councils could consider including questions in conjunction with other councils in the same region to provide benchmarking data to support locally focussed improvements. The inclusion of locally relevant questions may encourage participation and improve response rates.

3.15 Additional questions may take the form of discrete questions or free text boxes seeking further information on existing questions. You may also add response options to questions 5 and 6. Additional response options for questions 5 and 6 should be submitted to NHS England using the additional question form for information purposes. Please note that these do not count in the additional question cap.

3.16 Questions must be subject to cognitive testing to ensure that they are understood by carers in the way that is intended, unless they are known to have been used in previous surveys. They must also be approved in accordance with local research governance arrangements, since they will not have been accounted for in the research ethics clearance given by SCREC.

3.17 A selection of questions used in previous surveys is available in the 'Question Bank' on the NHS England website.

3.18 Any proposals for additional questions and free text boxes must be submitted to NHS England using the Additional Question Request Form. The form is obtainable at SACE, 2023-24 guidance for local authorities and once Section 1 is completed should be emailed to Ssd.nationalservicedesk@nhs.net . NHS England will reply to any request using Section 2 or by contacting the CASSR directly. The deadline for submission is **Friday 08 September 2023**.

3.19 Note that ALL proposals for additional questions need to be submitted for review by NHS England irrespective of whether these questions have been used before by the same or other organisations.

3.20 When considering the inclusion of additional questions, the following should be kept in mind:

- Questions must address a genuine research need and relate to the general purpose of the survey.
- The number of questions added must not be excessive. The inclusion of too many questions may be perceived as a burden by respondents and have a negative impact on response rates. NHS England advise no more than six additional questions and / or free text boxes are added to the questionnaires.
- When planning the use of further questions, thought should be given to why you are collecting the information and how it will be used. Unnecessary information should not be sought, as this would be an intrusion and a waste of the respondents' time.
- Consideration should be given to adding free-text boxes following existing questions as an alternative to adding whole new questions. These boxes allow respondents to provide contextual information which may be very relevant for local purposes.
- Additional questions should be placed towards the end of the questionnaire, before the final optional question on taking part in further research. This rule may be relaxed in

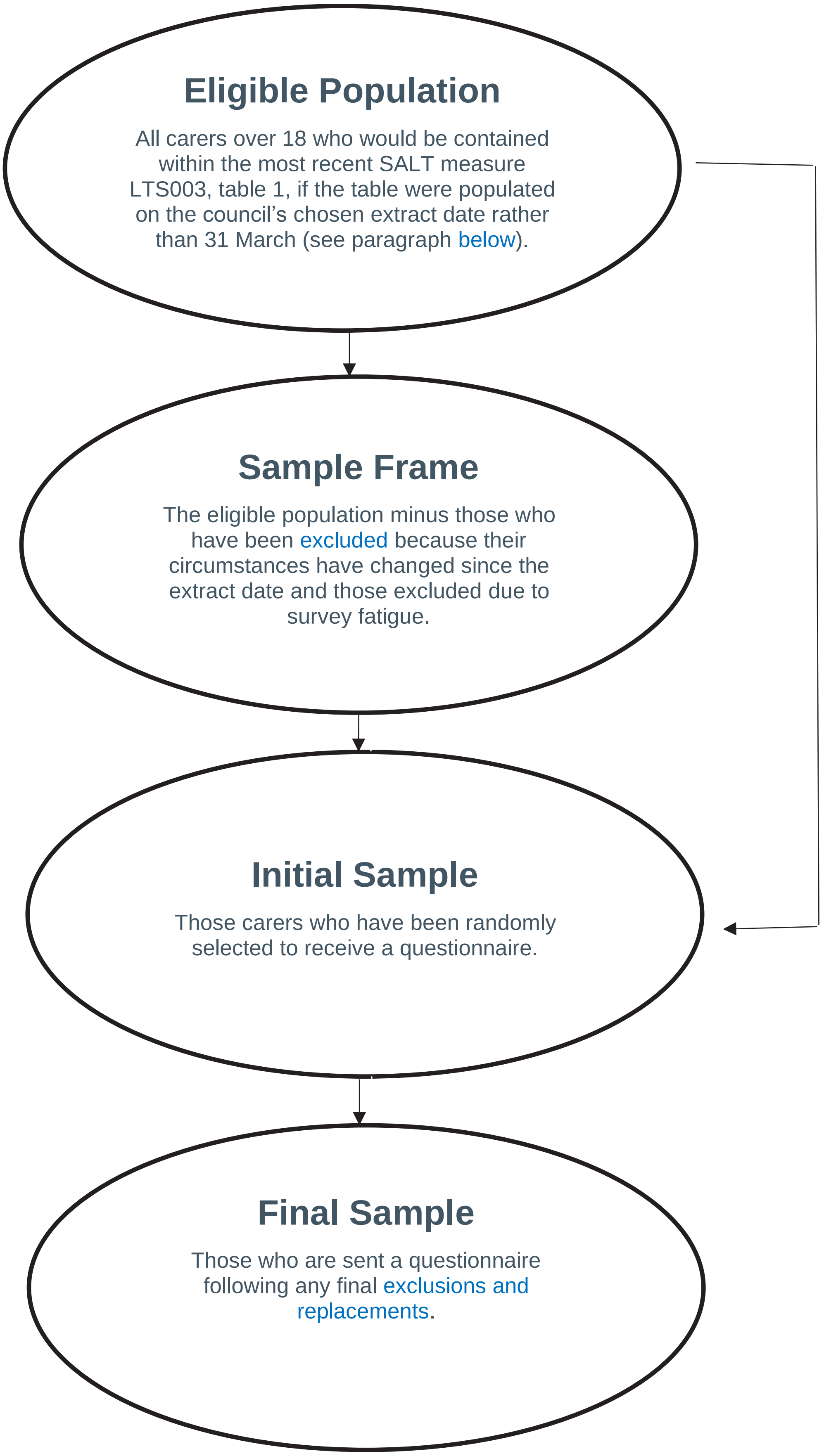
circumstances where an additional question clearly follows on from an existing question, and where it is clear that its placement will not affect the understanding of subsequent questions.

- It is advised that additional questions are included in the translated versions of the questionnaire.
- It is recommended that additional questions are relevant to all carers receiving a questionnaire; this will help to mitigate any potential negative impact on response rates that including additional questions may have. One way to ensure questions remain relevant to all carers is to include a ‘not applicable’ type option.
- Additional questions must not be used to gather information about the religion or sexual orientation of carers.
- Questions designed to assess reactions to proposed new services will not be permitted. This type of question may raise a respondent’s expectations about receiving such services and potentially influence their responses to other questions.

Determining participation

3.21 CASSRs will need to determine the list of people who are eligible to participate in the survey (the eligible population), the group from which the sample is drawn (the sample frame) and the list of those to whom questionnaires are distributed (the sample).

Figure 2: Path from Eligible Population to Final Sample



Eligible Population

All carers over 18 who would be contained within the most recent SALT measure LTS003, table 1, if the table were populated on the council’s chosen extract date rather than 31 March (see paragraph below).

Sample Frame

The eligible population minus those who have been excluded because their circumstances have changed since the extract date and those excluded due to survey fatigue.

Initial Sample

Those carers who have been randomly selected to receive a questionnaire.

Final Sample

Those who are sent a questionnaire following any final exclusions and replacements.

Eligible population

3.22 On any date between 1 July and 30 September 2023 inclusive councils must extract the population of carers who are eligible to participate in the survey.

3.23 The eligible population is all carers who would be contained within the last four rows of SALT measure LTS003, table 1 for 2022-23, if this table was populated in relation to the chosen extract date rather than 31 March (those who would be included in the yellow highlighted section of figure 3). These are all those aged 18 and over, and who either received “support direct to carer” or “no direct support to carer” in the 12 months prior to the extract date, irrespective of whether their cared-for person received respite care. The first row of this table is excluded because it contains carers who are aged under 18.

Figure 3: SALT LTS003, table 1

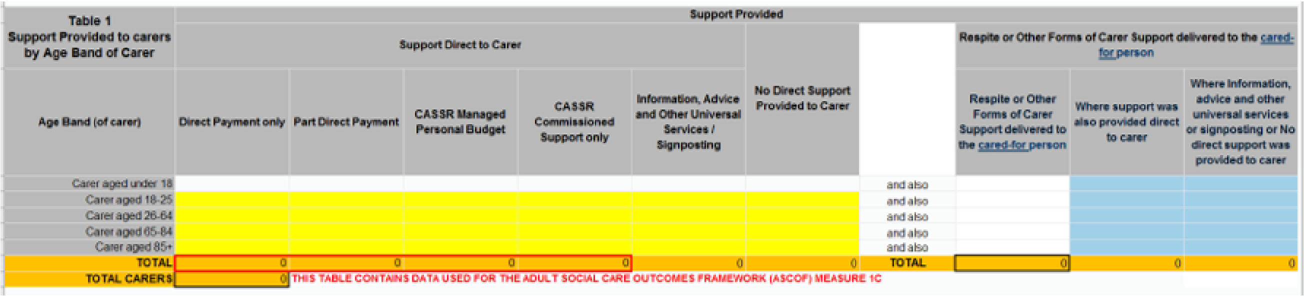


Table 1 Support Provided to carers by Age Band of Carer	Support Provided									
	Support Direct to Carer					No Direct Support Provided to Carer		Respite or Other Forms of Carer Support delivered to the cared-for person		
Age Band (of carer)	Direct Payment only	Part Direct Payment	CASSR Managed Personal Budget	CASSR Commissioned Support only	Information, Advice and Other Universal Services / Signposting			Respite or Other Forms of Carer Support delivered to the cared-for person	Where support was also provided direct to carer	Where information, advice and other universal services or signposting or No direct support was provided to carer
Carer aged under 18							and also		🟦	🟦
Carer aged 18-25	🟨	🟨	🟨	🟨	🟨	🟨	and also		🟦	🟦
Carer aged 26-64	🟨	🟨	🟨	🟨	🟨	🟨	and also		🟦	🟦
Carer aged 65-84	🟨	🟨	🟨	🟨	🟨	🟨	and also		🟦	🟦
Carer aged 85+	🟨	🟨	🟨	🟨	🟨	🟨	and also		🟦	🟦
TOTAL	0	0	0	0	0	0	TOTAL	0	0	0
TOTAL CARERS	0	THIS TABLE CONTAINS DATA USED FOR THE ADULT SOCIAL CARE OUTCOMES FRAMEWORK (ASCOF) MEASURE 1C								

3.24 Once the eligible population has been extracted councils should check that their records are correct, for example that all contact data are up to date.

3.25 As the data is checked it may be discovered that some records were out of date at the time of extraction, and that some subjects in the extract should not have been included in the eligible population figure, for example if a carer had died, moved away or stopped their caring over 12 months before the eligible population was extracted. In such cases the subjects must be removed from the eligible population figure.

Sampling frame

3.26 At this stage, depending on the completeness and quality of the data extracted, councils might also wish to flag and exclude members of the eligible population who cannot be selected to receive a questionnaire, thereby creating a discrete sample frame. Those to be excluded are people whose circumstances have changed since the data extract such as:

- Carers who have died
- Carers who will be in hospital at the time of the survey
- Carers who have moved into residential or nursing accommodation
- Carers who are in active dispute with the council at the time the survey is being sent out. A dispute is defined as a complaint that cannot be resolved by the council and moves on to be handled outside of the council by the ombudsman.
- Carers who are involved in an open safeguarding alert or investigation. Carers should also be removed from the sampling frame if their cared for person has an open safeguarding alert.

- Carers who have contacted the council in the past expressing a preference to opt out of surveys or complain about receiving a survey (please note that the national data opt-out does not apply to the 2023-24 survey)
- Carers whose cared-for person has died
- People who were carers for only a short spell that ends before the survey is carried out.
- Note, carers should not be removed if they have moved out of the area, if they are still supported by the council.

3.27 Note that it is not compulsory to undertake these checks and exclusions at this point. However, if you wait until after the sample has been drawn those who are then excluded will have to be replaced. It is likely that late in the survey process you will have to send out a larger number of questionnaires to carers drawn from a reserve or top up sample, to meet the required response rate.

3.28 You may also consider excluding eligible carers if they have recently participated in a survey and you believe that resurveying them could lead to “survey fatigue” and a low response rate. If you require advise on whether or not to exclude carers due to “survey fatigue”, please contact NHS England. However, such carers may be removed only if councils can still achieve a sufficiently large sample size to meet the minimum requirement, and if removing the previous survey’s participants would not cause this survey’s sample to be biased. Bias could occur for example, if your previous survey focused on carers in a certain geographical area or carers of people with dementia. If you are unsure about introducing bias into your sample frame then you must contact NHS England for advice.

3.29 It is essential that councils do not exclude carers on the basis that they have a reputation for complaining about services. This would seriously bias the results of the surveys and thus reduce their usefulness.

3.30 Potential participants should not be excluded purely on the basis that their cared-for person has moved into residential or nursing care since their last review.

3.31 It is important to remember that any carers removed for the above reasons, remain part of the eligible population, which is used to calculate the necessary response rate and is reported to NHS England.

Please note, this guidance has been checked following the introduction of GDPR and the guidance remains that if a carer chooses to be removed from the sampling frame they are still to be included in the eligible population.

Sample

3.32 Once the size of the eligible population has been established CASSRs must work out the size of sample necessary to ensure that the survey results have the required margin of error of less than +/-5 per cent. This is done by entering the number of the eligible population into the sample size calculator (available at SACE, 2023-24 guidance for local authorities), along with the predicted response rate. The predicted response rate could be estimated from local surveys of carers councils may have conducted, or the response rate to the last SACE.

3.33 CASSRs may choose to send out more questionnaires than needed to meet the minimum requirement, thereby reducing the margin of error and increasing the accuracy of the survey. If you decide to take this approach, then the sample calculator also allows you to estimate the precision of the survey.

3.34 It is also necessary to ensure that the sample is randomly selected. Councils must randomly list the carers in the sample frame. A random starting point and required sampling interval are calculated in the Sample Size Calculator spreadsheet on the worksheets entitled *Selecting the Sample-minimum* and *Selecting the Sample-more*. These tabs will be pre-populated, using the information entered to calculate the sample size.

3.35 At this point you may also choose to select a reserve sample, to act as a data source in cases where carers must be removed from the primary sample, or if you find that the response rate is insufficient to meet the margin of error requirement. By removing members of the initial sample from the sample frame and estimating the number of people you might need, you can use the sample size calculate to generate a reserve list.

3.36 Once the initial sample has been selected it should be checked for those who should not have been in the eligible population and those who should have been removed from the sample frame for the reasons described above. Even if checks had been made it is likely that between the eligible population extract date and the date the sample is generated some carers will no longer be suitable participants, for example those who have moved away or died. Replacement carers will also need to be randomly selected, either from the pre-existing reserve sample (see above) or from a new reserve sample.

3.37 After these checks and changes have been made you will have the list of those who are to be sent questionnaires. Once the sample has been finalised and questionnaires issued, nobody can be removed from either the sample or the Eligible Population; this includes carers that could have been removed after the sample was drawn due to the reasons described. The only event that can result in a change to the sample once questionnaires have been issued is the *addition* of people to the sample, where a top-up sample is required, usually in cases where response rates haven't been as anticipated and the overall margin of error requirement looks unlikely to be met.

Extracting administrative data

3.38 CASSRs should extract and check the administrative data from their stored records. This is the data which is to be included in the data return document in addition to the question responses. These are listed in Appendix J and include items such as the age and religion of the carer, the type of support provided to the carer and the funding status of the cared-for person.

3.39 It is important to remember that the data submitted to NHS England on the data return sheet must be correct as of the date the eligible population is extracted. If any information relating to a carer has changed since the extract date it must not be updated.

3.40 It may also be useful for councils to add local variables to the administrative data. Whilst these will not be returned to NHS England they might assist in local analyses. Councils are also advised to record the carer's address and contact details and whether the carer has requested an interview. This information should help facilitate the smooth running of the survey.

3.41 If a carer is caring for more than one person aged 18 or over, you may need to use local information to determine who the main person cared-for is and to populate relevant data items (for example primary support reason). If you are unable to identify this information, then you will have to select 'Unknown' for categories relating to the cared-for person on the data return.

This data should be recorded in a dedicated survey database or spreadsheet along with a unique serial number allocated by the council. You may wish to build other pieces of information that you might find useful into the code, for example local area or team codes.

Alternative formats

3.42 In most instances the appropriate format for participants will be the standard English questionnaire. However, to maximise response rates and represent the full range of carers, councils must identify any people in their sample who will need access to alternative versions of the survey. CASSRs must check their records for information about a carer’s likely communication needs, and whether it is likely that a carer would be able to complete a postal questionnaire unaided. If not:

- Is there someone who is already known to the participant who could help them complete the questionnaire?
- Is it necessary to arrange assistance for this carer?
- Does the participant require a large-print questionnaire?
- Does the carer require the questionnaire translated into a language other than English or the provision of an interpreter?

3.43 Much of the above information should be available from your carer database.

Sensory impairments

3.44 CASSRs should have on record the information and communication needs of carers with sensory impairments now that organisations that provide publicly funded adult social care must conform to the Accessible Information Standard. In the case of people with sensory impairments, consideration should be given to the best means to make initial contact and provide details of options for taking part. For example, it might be worth inviting people who are known to have severe visual impairments by telephone. Carers who might require assistance from a sign language interpreter could, if there were no alternative, be first approached by someone known to them, such as a social worker.

3.45 In addition to the large print version supplied by NHS England, councils will have to make the questionnaire and covering letters available in any additional formats or languages that are requested by carers, including (but not limited to):

- Braille
- Easy read

- Audio for visually impaired people
- An electronic version of the questionnaire to be sent and returned via email. Note that this option is currently only open to carers who could not otherwise participate.

Please note that it is the council's responsibility to make the materials available in other formats to carers.

An alternative would be to offer a telephone or face-to-face interview for carers who request this. Note however, that this should not be the standard way of obtaining a response from this group.

Non-English speakers

3.46 It is recommended that all councils store details of the first language and communication preferences of carers in their social care records. Councils must arrange for translated documents locally if survey materials are required in language versions other than those provided by NHS England (see Appendix F).

3.47 A summary on what documents to send out is below:

- Where the carers users first language is known to be English – send the English version of the materials
- Where the carers first language is known and is not English and the preferred language is either not known or not English – send the English version of the materials and the relevant translated materials
- Where the preferred language is known to be English (even if the first language is not English) then councils can send out an English version of the survey only, alongside the translation request sheet
- Where the carers first language is not known by the council – send the English version of the materials and the translation request sheet.

3.48 In some instances, councils could consider having the questionnaires administered as face-to-face interviews by interpreters (see paragraphs below). Given that response rates to postal questionnaires from ethnic minorities are traditionally low, using interpreters may enable more carers from this group to be included. This could be done by family and friends where available, although the use of professional interpreters is recommended. The use of professional interpreters should help to ensure that response options are translated accurately.

3.49 Interpreters will need to be able to speak to respondents in colloquial versions of their languages. In addition, the work of interpreters should be monitored to ensure they are not cutting corners or editing respondents' answers before translating and recording them. One way of doing this would be to have all translated interviews tape-recorded and to arrange for, say, 1 in 10 to be re-coded by a second interpreter as a check.

Providing assistance

3.50 In addition to making additional formats available councils will have to determine if other assistance is required, usually in response to calls to the additional help contact number on the cover and reminder letters. The council must ensure however, that if the participant needs help to complete the questionnaire that the helper is not involved in delivering services. This would breach confidentiality and decrease the likelihood of carers feeling able to voice criticisms of the service they receive, thereby biasing the survey results. It is acknowledged that this might be difficult to implement, especially in cases where carers are used to turning to staff for help. It is therefore recommended that councils are proactive in offering alternative forms of help to carers to complete a questionnaire, by encouraging friends and relatives to assist them.

3.51 As noted above it is possible to administer the survey as a face-to-face or telephone interview. This may be the appropriate course for example, for respondents who have sensory impairments or limited literacy skills. Interviews should only be offered to carers who request them in response to the initial mailing or reminder letter and where it is not possible to find appropriate support to enable them to complete a postal questionnaire. Overall the number of interviews completed should be small in relation to the size of the sample. Councils could also consider using advocacy services, although this is only recommended when the carer already has an ongoing relationship with an advocate.

4. Collecting and returning the data

4.1 This section covers the final stages of the survey. Again, there are several tasks to consider, including distributing the questionnaires and cover letters to the final sample, sending reminder letters to those who have not responded to the initial posting, and adding carers to the sample if necessary to meet the required response rate. This is also when councils will provide any assistance they deem necessary to help carers complete the survey. Councils will also record and check all data, before submitting the completed data return to NHS England. Councils will also have to consider whether any carer’s responses indicate that their confidentiality should be breached to protect their health or safety.

Doing the fieldwork

4.2 The fieldwork period, which is the period when the questionnaires are distributed and collected, should begin on 1 October and be completed by the 30 November. A questionnaire, along with a copy of the covering letter and a pre-paid envelope to return the questionnaire, must be sent to each member of the final sample. Three weeks later a reminder letter must be sent to all those who have not responded, i.e. those who have neither returned the questionnaire by the return date given by the council nor contacted the council to indicate that they do not wish to participate in the survey. A second copy of the questionnaire should be included with the reminder letter.

4.3 Within this period (remember to give time for respondents to complete and return the questionnaires) councils have some latitude in how they schedule the fieldwork. Councils may choose to issue all questionnaires in one week and all reminders three weeks later. Alternatively, councils may consider developing a timetable in which questionnaires and reminders are sent out in waves, so that the workload is spread out over all the available weeks. An example timetable for issuing questionnaires and reminders in four waves is available in Appendix K.

4.4 Note that councils must send reminder letters to all those who have not responded to the issuing of the first questionnaire, even if the overall level of response is already sufficient to meet the +/- 5 per cent margin of error and therefore the confidence interval requirement. This must be done to counter non-response bias. Given that it is likely that the type of people who respond to the initial questionnaire post are different to those who would respond only once prompted by the reminder letter, adherence to this protocol is necessary to ensure consistency of results between CASSRs.

4.5 If there are insufficient responses after the reminders have been sent then councils have the option, if time allows, to draw from the reserve sample, or to generate an additional top up sample. It is recommended that councils consider this possibility when planning their fieldwork schedule.

Interviewing respondents

4.6 If face-to-face or telephone interviews are administered to those who have requested them in response to the cover or reminder letters, then the following must be considered.

4.7 Interview scripts will need to be customised by the council, in the same manner as the cover letters and postal questionnaires. The person conducting the interviews should be trained and experienced. They should be briefed about the aims of the survey. It must be assured that they understand the importance of confidentiality and will ensure participant’s confidentiality. It is expected that councils already have established practices in this regard.

4.8 If an interview is held, a more active approach to establishing informed consent is needed because of the increased level of intrusion involved. Before asking any questions, the interviewer must explain the purpose of the survey and stress that the carers can decide to withdraw their consent or stop the interview at any time. The interview scripts will guide the interviewer in this regard. If the interview is face-to-face, the participant must be asked to sign the consent form (see Appendix F).

Transferring data onto the data return

4.9 Using the unique code CASSRs will need to merge the questionnaire and administrative data and transfer them onto the data return workbook. You should read the *Instructions* worksheet of the data return before commencing this task.

4.10 All those who have been sent a questionnaire (the final sample) must be recorded on the data return. A response must be recorded for a questionnaire returned that includes answers to at least one of questions 1 to 27 (mandatory or optional) from the questionnaire documents supplied by NHS England. A non-response must be recorded for:

- a questionnaire that is not returned
- a questionnaire returned completely blank

- a questionnaire returned containing only answers to locally-added questions and/or optional question 32 (concerning participants' willingness to take part in further research)

4.11 If a carer has removed their unique number-code by for example tearing off the corner of the questionnaire which contained it, these respondents should still be included in your data return. You should mention the number of respondents doing this in the first box in the *Validation_Tables* tab of the data return. You should however still be able to answer some of the mandatory fields for these respondents such as whether a translated version was used etc. This will then enable the responses to be included in as much of the summary analysis as possible.

4.12 There may be instances in which a respondent has answered a questionnaire in a contradictory manner. If two or more boxes are ticked for a question in which only one box should be ticked, then the response must be recorded as "Unknown" (-9). All other cases, for example if a respondent has chosen conflicting answers for a question that asks them to "tick all that apply" or for two different questions, must be recorded as reported.

4.13 The CASSR should record which version of the questionnaire was used, i.e. either the original or the reminder. If the questionnaire was completed on the original version but after the reminder letter was sent out, the respondent should still be coded as replying to the original version. If the carer returns both the original and reminder version of the questionnaire, the CASSR should review which questionnaire was most completed and use this data in the data return. If the completion is the same for both questionnaires, then the reminder survey should be used.

Breaching confidentiality

4.14 It is at this point that councils may discover that carers have given responses suggesting that their health or safety is at risk. It is at the council's discretion to decide what should trigger a breach of the confidentiality clause. However, it is acceptable to do so in circumstances where:

- The respondent indicates that their health and safety is at risk, in response to question 10, any other survey question or though free text comments.
- The responses of the individual indicate that they are experiencing a serious issue with any aspect of their care.
- The respondent uses the questionnaire to make a comment about an aspect of their care and the comment shows a clear expectation that this will be followed-up by the council.

4.15 Whilst the most negative response to question 10 would clearly indicate a threat to safety you might also consider that a combination of answers to other questions might constitute grounds for contacting the survey participant.

4.16 Contact must be made with the respondent in the first instance to check whether they are happy for their comments to be passed on to an appropriate member of staff for consideration. Initial contact should not be made by a social worker or the person's care worker. Once consent has been obtained CASSRs should follow local protocol for dealing with the issues raised.

Checking the data

4.17 The data return must be checked prior to submission. You should be sure that all survey data are included; worksheets have not been corrupted by the addition or removal of columns; there are no blank rows in the main data worksheet; and all data correctly represent administrative records and questionnaires as appropriate. Even the deletion of unused columns (pertaining to voluntary fields and optional questions that councils have chosen not to record) will corrupt the data return.

4.18 The workbook contains features to help quality assure the data before submission to NHS England. Conditional formatting has been applied to the cells in the *Carers_Data* worksheet to show where data are missing or may not be correct. The rules for these formats are detailed on the *Carers_Data - Formats* worksheet. You should also review the *Validation_Tables* worksheet which displays the results of aggregate checks on data input on the *Carers_Data* worksheet. If a check yields a query for you to investigate, for example if data is missing or if a result falls outside its expected range, then the appropriate cell is shaded red until an explanation is input.

4.19 Councils must take care to avoid deleting or overriding these validations, especially if cutting and pasting data from other workbooks.

4.20 Once the data has been sent to NHS England, a validation report will be sent to the council. Further information on this will be sent to council contacts.

Submitting data to NHS England

4.21 The completed data return must be submitted to NHS England by the first mandated deadline, **29 February 2024.**

4.22 The data will be collected by the data collections team using the Strategic Data Collection Service (SDCS), which is a secure data collection system. The team will contact those registered to upload the data with instructions on the submission procedure in due course.

4.23 As already noted (see above) NHS England requires that blank copies of final questionnaires, cover and reminder letters are emailed to Ssd.nationalservicedesk@nhs.net by 30 November at the latest, although preferably as soon as amendments are finalised.

4.24 We also welcome comments on the survey process, for example:

- thoughts on how it might be improved
- suggestions of practice to share with others
- other questions that might be collected nationally

4.25 Some of your views can be communicated in the data return, especially the final comments box in the *Survey Process Information* tab.

4.26 NHS England will check the validity of data returns which have been completed and submitted by the first mandated deadline. Feedback will be provided to councils who will then be granted the opportunity to resubmit data.

4.27 Where council data contain significant data quality issues it is likely that they will be named in the data quality section of the final NHS England report to ensure that anyone using the data is aware of any potential anomalies.

4.28 If a council fails to submit by the first mandated deadline then this will also be included in the data quality report to ensure that anyone using the data is aware that it has not been validated.

Appendix A: Policy Context

The Survey of Adult Carers in England (SACE) exists in a national policy context in which increasing consideration has been given to the role of carers. In 2008 the government introduced the national carers strategy, concerned with the provision of support to ensure carers' financial, mental and physical wellbeing. The strategy moved towards focusing on the capacity of carers to fulfil their educational and employment potential; to recognise themselves as carers; to have a family and community life; and as expert care givers, to be involved in designing care provision at a local and individual level.

In 2014 the Care Act put carers on an equal footing with the people they care for. It allows for provisions such as simplifying assessments, giving carers a legal right to support if they are eligible and setting the minimum level at which carers become eligible for support. The Act consolidates past legislation and regulation and aims for greater transparency, accountability and personalisation in health and social care.

Since 2012-13 SACE has provided additional outcome-focused intelligence information on carers and the services they receive. It measures the extent to which services improve carers' ability to care and live a life outside the caring role. The need to assess the impact on carers of the provision and quality of services provided to service users is also important.

Data from the survey is not just intended to be used to monitor performance through national outcome measures but also to be used locally to inform delivery of service and support and to monitor and develop standards. Whilst some councils may undertake regular feedback via their agreements with service providers, this survey gives a greater insight into outcomes for carers and provides a consistent basis for comparing results across different areas. Recent feedback from councils has confirmed that NHS England user and carer surveys have played an important role in monitoring and improving local service provision.

The purpose of the survey will be to provide assured, benchmarked local data on outcomes, to support local services to think about ways of improving outcomes in a very challenging financial climate. It also allows councils to benchmark against their comparators. The survey is constructed so that an individual outcome can be disaggregated into constituent groups. Therefore, as well as providing an overall quality of life index, the survey provides intelligence on whether specific groups experience better outcomes, whether services are meeting all outcome needs, and, in time, the value-added by social services.

On completion of the survey councils might consider sharing the questionnaire locally with other organisations especially voluntary organisations and health partners. This will enable CASSRs to obtain similar information about carers not known to Social Services and may yield interesting local level data for comparison. This should only be done after the SACE fieldwork has been completed to avoid a potential problem of carers known to both councils and voluntary organisations receiving two questionnaires. If councils do decide to do this however, then this should be used to complement local analysis and should not be returned to NHS England.

Appendix B: Populated ASCOF measures

B.1 This survey is used to populate the following outcome measures in the Adult Social Care Outcomes Framework ASCOF:

- 1D: Carer reported quality of life.
- 1I: Proportion of people who use services and carers, who reported that they had as much social contact as they would like.
- 3B: Overall satisfaction of carers with social services.
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for.
- 3D: The proportion of people who use services and carers who find it easy to find information about services

B.2 The definitions for these outcome measures can be seen on the Department of Health and Social Care's (DHSC) Adult social care outcomes framework: handbook of definitions.

Appendix C: The Social Services User Survey Group (SSUSG)

C.1 The survey, methodology and this guidance has been designed in consultation with the Social Services User Survey Group (SSUSG). SSUSG exists to recommend a programme of social services user experience surveys, develop their content and advise on the methodology.

C.2 The group includes DHSC, NHS England statisticians, council representatives, the Care Quality Commission (CQC) and researchers from the Personal Social Services Research Unit (PSSRU).

C.3 SSUSG reports to the Data Delivery Action Group (DDAG), which reports to the Data and Outcomes Board (DOB); DOB is co-chaired by the Association of Directors of Adult Social Services (ADASS) in England and the Department of Health and Social Care (DHSC). The survey has DHSC and ADASS approval.

Appendix D: Calculating the sample size

D.1 The sample size calculator spreadsheet enables councils to estimate how many carers they need to sample to achieve the minimum required margin of error of no more than +/-5 per cent.

D.2 As a rough guide, table 1 from the sample size calculator spreadsheet shows an example for a council with 1000 eligible carers and a predicted response rate of 40%. The table shows that for this scenario, the total number of completed questionnaires needed is 278 which implies that 696 questionnaires need to be sent out to allow for non-response.

Table 1: Example sample size calculation

The Eligible Population	The anticipated response rate based on previous surveys (%)	Number of returned questionnaires needed to meet +/- 5% requirement*	Sample Size - Number of questionnaires to be sent out based on anticipated response rate	Margin of Error	Sampling interval needed to select every nth carer
1000	40%	278	696	5.0%	One in every 1.44 cases

D.3 The spreadsheet also allows councils to consider sending more questionnaires than needed to fulfil the minimum requirement in order to increase the level of precision of their survey estimates, or in other words, to reduce the margin of error. As a rough guide, table 2 from the sample size calculator spreadsheet shows what happens if the number of questionnaires sent out is increased from 696 to 900. It can be seen that the margin of error reduces from 5.0% to 4.1%.

Table 2: Example sample size calculation – reduced error

The Eligible Population: the number of carers the sample is drawn from	The anticipated response rate based on previous surveys (%)	Number of returned questionnaires needed to meet +/- 5% requirement*	Sample Size - Number of questionnaires need to be sent out based on anticipated response rate	Margin of Error	Sampling interval needed to select every nth carer
1000	40%	360	900	4.1%	One in every 1.11 cases

Selecting the sample

D.4 To ensure that the results of the survey are representative of all carers, a random sample of eligible carers should be chosen. If the first 400 of a list of carers were chosen for example, then a random sample will have been selected only if the list is ordered randomly. It is more likely that this approach will yield a list of selected carers with similar characteristics, for example all living in a particular area within the council.

D.5 A common and easy way to select a random sample of carers is to take a systematic random sample. A systematic random sample is one in which, say, every 6th or 10th individual is selected.

D.6 The sample calculator spreadsheet has two additional tabs entitled *Selecting the Sample-Minimum* and *Selecting the Sample-More*. These tabs will be pre-populated based on the information already entered. The following example in Table 3 shows which carers should be selected if a council is aiming to meet the minimum requirement when selecting the sample. Each CASSR should be able to estimate how much it will have to spend on the survey by drawing on its experience of running previous surveys as well as consideration of the process outlined in the guidance.

Table 3: Selecting a random sample

The Eligible Population)	**1000**
Sample Size - Number of questionnaires needed to be sent out	**696**
Sampling interval needed to select every nth carer	**1.44**
Random Start	**2**

The record that should be selected from the list of eligible carers	
Elig Pop Number	**Flag**
1	
2	**1**
3	**1**
4	**1**
5	
6	**1**
7	**1**
8	
9	**1**
10	**1**
11	
12	**1**
13	**1**
14	**1**
15	
16	**1**
17	**1**
18	
19	**1**
20	**1**

Appendix E: Design and response

E.1 The main advantage of postal questionnaires is that they are relatively cheap to administer and easier for non-survey organisations to administer than face-to-face interviews or telephone interviews. They also allow respondents more time to consider both the questions and their answers. Hence to achieve acceptable response rates thought must be given to reducing the burden of participating in the survey, assuring the confidentiality of the participant and helping the participant to understand that taking part is a worthwhile activity.

E.2 The questionnaire is designed to minimise the burden on respondents. To make it easier to read the standard questionnaire for this survey it has been printed in a large, clear font – Calibri – and in 14-point type. A large print version is also available. In terms of content a limited number of question styles have been used and the use of graphic features such as emboldening, italics, indentation and the positioning of tick boxes have been employed consistently to help respondents find their way easily through the questionnaires.

E.3 Question routing has not been used in SACE, because respondents to postal surveys often find even the most rudimentary routing, e.g. “go to question 8”, difficult to deal with.

E.4 The covering and reminder letters include information required by the Social Care Research Ethics Committee (REC), including a guarantee of confidentiality, and an explanation of what respondents should do if they need help completing their questionnaire with details of a number they can ring if they have any queries that need to be addressed. They also stress the importance of the information in informing local and national level policy.

Appendix F: Materials for participants

F.1 The following materials are available at SACE, 2023-24 guidance for local authorities

- F1_SACE_Questionnaire_2023-24_English
- F2_ SACE_Questionnaire_2023-24_English_Large_Print
- G1_SACE_2023-24_ Face-to-Face_Interview_Script
- G2_SACE_2023-24_ Telephone_Interview_Script
- H1_SACE_2023-24_ Covering_Letter
- H2_SACE_2023-24_ Reminder_Letter
- H4_SACE_2023-24_ Consent_Form
- H4_SACE_2023-24_ Translation_Request_Form

Translated materials

F.2 NHS England also provides translated versions of the questionnaire, cover and reminder letters and consent forms. The languages provided are:

Arabic, Bengali, French, Greek, Gujarati, Hindi, Italian, Mandarin, Polish, Portuguese, Punjabi, Somali, Spanish, Tamil, Turkish, Urdu, Vietnamese.

Appendix G: Maximising the value of the survey data (MAX)

G.1 Councils may find it useful to refer to the MAX toolkit which contains guides and tools (including Excel-based analysis tools and training materials) associated with the key stages of the survey process – planning, analysis and interpretation, and reporting – and is designed to support council staff to maximise the local relevance, value and use of data from the adult social care and carers' surveys to inform local performance improvements.

G.2 The individual elements of the MAX toolkit were developed in response to the barriers and practices reported by 139 staff from 95 CASSRs during earlier fact-finding activities and consultations, and amalgamates recommended practices for stakeholder engagement, analysis and reporting.

G.3 The MAX toolkit is designed to supplement the survey guidance provided by NHS England and is free to use. To find out more about the MAX project or to access the MAX toolkit please visit the max project website or email maxproject@kent.ac.uk.

Appendix H: Further information sources

H.1 There is a considerable overlap of methodology between this survey and the Adult Social Care Survey which was reviewed in 2010-11 by the Office for National Statistics (ONS). Their report *Review of Methodology for the National Adult Social Care User Experience Survey* and the response from the Social Services User Survey Group (SSUSG) can be seen in the 'Related Information' section on the NHS England Social care user surveys webpage.

H.2 The Personal Social Service Research Unit (PSSRU) at the University of Kent and London School of Economics and Political Sciences produced a document about the development and testing of SACE: The Personal Social Services Survey of Adult Carers in England – 2009-10: Survey Development Project Technical Report. This contains details about the rationale of the design of the questionnaire and highlights any issues in relation to particular questions in order to aid interpretation of the survey results. In addition, this document contains examples of question wordings which carers found confusing, making it a useful resource on what to avoid for future survey design.

H.3 Another useful document is Developing a Carer's Experience Performance Indicator: PSSRU Discussion Paper 2734. This outlines the development work undertaken by PSSRU in developing questions 7-12 of the survey, which are scored and summed together to form the carer social-care related quality of life measure (Carer SCRQoL), and which is used to populate ASCOF 1D.

H.4 There are also a number of ways in which CASSRs can learn from each other, and from other organisations, in relation to completion of user surveys:

- The CASSR members of SSUSG are able to facilitate the sharing of knowledge about the surveys, and often have links to regional Association of Directors of Adult Social Services (ADASS).
- Linking with colleagues in other CASSRs, particularly those where survey results and ASCOF outcomes differ.

Appendix I: Elements to consider when assessing the cost of running the survey

I.1 Each CASSR should be able to estimate how much it will have to spend on the survey by drawing on its experience of running previous surveys as well as consideration of the process outlined in the guidance. Costs will involve: The fields needed for the data return are as follows:

- Staff time: surveys are staff intensive activities. CASSRs might consider appointing a project manager to ensure all the necessary stages of the survey progress according to timetable and to take responsibility for selecting the sample and negotiating with social workers. More routine activities could be allocated to other staff, for example checking the sample, getting all the necessary documents printed, sending out questionnaires and reminders, monitoring response and booking in returned questionnaires. More specialist activities such as local level analysis of the results could be allocated to trained staff.
- Stationery: not only will copies of questionnaires have to be printed but also covering letters to carers in the sample and reminder letters. Envelopes will have to be provided and stuffed, address labels will have to be attached and postage paid.
- Other costs: on the few occasions when the respondent requests the questionnaire to be administered by telephone or face-to-face interview, the cost of phone bills and interviewers needs to be accounted for.

Appendix J: List of data items to be sent to NHS England

J.1 Below is what will be included in the *SACE Data Return Document*. This is the information that will be collated nationally. The Data Return contains further guidance and is available on the SACE, 2023-24 guidance for local authorities. Councils may choose to populate the 'columns for local use' for additional data collected locally but these must be removed before submission to NHS England. Any completely blank lines (for carers initially selected but subsequently removed from the sample before the questionnaires are distributed for the reasons listed above), must also be removed.

J.2 It does not matter if record numbers are no longer consecutive so long as councils know to whom each submitted record refers should NHS England raise a query.

J.3 Note that lines for non-respondents should not be removed and the items highlighted in yellow (mandatory fields) should be completed for non-respondents as well as for respondents. This will enable response bias to be assessed.

J.4 The fields needed for the data return are as follows.

Carer Data Sheet

J.5 The carer data sheet collects the following administrative data and the question responses for everyone in the sample.

J.6 Additional guidance on the unknown Ethnic Group codes is provided in the Carers Data – Codes worksheet of the Data Return.

- Administrative data
- Method of Collection
- Whether the carer has responded or not
- Age of carer
- Gender of carer
- Ethnicity of carer
- Sexual orientation of carer
- Religion of carer
- Method of assessment or review, i.e. whether the carer was assessed jointly with the cared-for person, separately from them, or whether no review or assessment took place during the year (SALT Measure LTS003, Table 3a).
- Support provided to carer – the form of support provided to the carer (Direct Payment only, Part Direct Payment, CASSR Managed Personal Budget, CASSR Commissioned

Support only, Information, Advice and Other Universal Services / Signposting or No direct support provided to Carer) (SALT Measure LTS003, Table 1a columns).

- Support involving the cared-for person i.e. whether or not any respite or other forms of carer support were provided to the cared-for person (SALT Measure LTS003, Table 1a, “Respite or other forms of Carer Support delivered to the cared-for person” column).
- Funding Status (cared-for person) – whether the cared-for person is supported and funded by the CASSR; pays the full direct costs of the services they receive, but whose support is arranged by the CASSR; self-funds the services they receive with no involvement from the CASSR; or is not known to the CASSR. Where the cared-for person is partially funded by the CASSR i.e. they pay some of the cost themselves, this should be coded as funded by the CASSR.
- Delivery Mechanism of Long-Term Support for the cared-for person – the form of support provided to the cared-for person by the LA (Direct Payment only, Part Direct Payment, CASSR Managed Personal Budget or CASSR Commissioned Support only – Community setting only – SALT Measure (LTS001).
- Primary support reason of the cared-for person. Some carers assessed will not have a cared-for person linked on the client database or the cared-for person may not have a Primary Support Reason (PSR) identified. In such cases the category ‘unknown’ should be selected. If the council does not provide the support to the cared-for person, but their records include the support reason, then councils can use their discretion as to whether to populate with the PSR or record as unknown.
- Reported Health Condition (RHC) of the cared-for person. This data should be recorded as it appears in council records. To bring recording in line with ICD-11, a new RHC ‘Autism Spectrum Disorder’ (ASD) has been added to the data return. As it may take some time for councils to implement this change, **all** RHCs are voluntary for 2023-24. The new ASD RHC will be mandatory for all future surveys and the previously used RHCs of ‘Autism (excluding Asperger Syndrome / High Functioning Autism)’ and ‘Asperger Syndrome / High Functioning Autism’, will be removed. All other RHCs will remain voluntary.
- Whether an advocate has been used
- Whether they need an interpreter.
- Whether a translated version was used
- Whether the carer responded to original postal questionnaire or a reminder – voluntary field

Questions

1. How old is the person you care for?

2. Does the person you care for have....? (e.g. Dementia, Alcohol Dependency).

3. Where does the person you care for usually live?

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?

5. Has the person you care for used any of the support or services listed below in the last 12 months?

6. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

7. Which of the following statements best describes how you spend your time?

8. Which of the following statements best describes how much control you have over your daily life?

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?

10. Thinking about your personal safety, which of the statements best describes your present situation?

11. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?

12. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

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 (always, sometimes or never have enough time, or don't have additional caring responsibilities).

14. In the last 12 months, has your health been affected by your caring role in any of the ways listed below? (for example tired, depressed, loss of appetite)

15. In the last 12 months, has caring caused you any financial difficulties?

16. How often do you feel lonely?

17. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?

18. In the last 12 months, how helpful has the information and advice you have received been?

19. 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?

20. In addition to your caring role, please tell us which of the following also applies to you? For example, retired, employed full-time, employed part-time)

21. Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?

22. About how long have you been looking after or helping the person you care for?

23. About how long do you spend each week looking after or helping the person you care for?

24. Over the last 12 months, what kinds of things did you usually do for the person you care for?

25. Do you have any of the following? (for example physical impairment or disability; sight or hearing loss; a mental health problem or illness)

26. How many children aged 18 or under do you have parental responsibility for?

27. Did someone help you to complete this questionnaire?

31. 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?

32. Would you be happy to be invited to take part in more research?

Eligible Population

J.7 The Eligible Population sheet collects data on:

- The eligible population broken down by age group and gender.
- The number of carers excluded from the sample.

J.8 At a basic level these items of information are required to calculate confidence intervals for the data and assess response rates.

Validation Comments

J.9 The *Validation_Tables* tab has been included in the data return to help validate the data within the *carer data* sheet. This also provides a series of comment boxes to complete should the return have missing data. This is where explanations for any boxes left blank should be recorded. This is required to remove unnecessary validation queries from NHS England.

Survey Process Information

J.10 The *Survey Process Information* sheet asks about the survey process and methodology, pertaining to for example, the minimum requirement for responses and the use of additional questions. There is also a space to make general comments about the survey. This information is used by NHS England to understand how CASSRs have experienced the completion of the survey and to inform future development.

Appendix K: Example fieldwork schedule

K.1 As noted in paragraph above councils have some flexibility in how they schedule the fieldwork. Councils may choose to issue all questionnaires in one week and all reminders three weeks later. Alternatively, councils may send out the questionnaires and reminders in waves, so that the workload is spread out over a number, or all available, weeks. The following example timetable for issuing questionnaires and reminders in four waves so that the fieldwork can be completed by the end of November.

Table 4: A suggested timetable for sending out questionnaires and reminders in four waves

W/C	02 Oct	09 Oct	16 Oct	23 Oct	30 Oct	06 Nov	13 Nov	20 Nov	27 Nov
Qnaires sent out	Week 1 Sample	Week 2 sample	Week 3 Sample	Week 4 Sample					
Initial return date (end of week)			Week 1 sample	Week 2 Sample	Week 3 Sample	Week 4 Sample			
Reminder				To week 1 sample	To week 2 sample	To week 3 sample	To week 4 sample		

Appendix L: Key dates, changes and FAQs summary ample fieldwork schedule

This appendix highlights the key dates and changes in the 2023-24 Survey of Adult Carers in England (SACE). It should be used alongside the guidance document above.

Key dates

Below is a summary of the key dates for the 2023-24 SACE.

- Eligible population can be extracted any time between 01 July and 30 September 2023
- Additional question requests need to be submitted to NHS England by Friday 08 September 2023
- Fieldwork period is 01 October to 30 November 2023
- SACE data return to be submitted to NHS England by 29 February 2024
- Data quality reports to be sent out by 13 March 2024
- Final deadline 03 April 2024

Changes to the 2023-24 materials

Below is a summary of the changes made to the 2023-24 materials. Please ensure you use the materials on the 2023-24 guidance page: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-carers-survey-2023--24.

Data return

New question on loneliness added.

COVID-19 questions removed.

Questionnaires

A question on loneliness has been added as question 16 and subsequent questions renumbered.

A free text box has been added as question 10b.

Slight change to end of questionnaire to encourage email option for sending out the report.

COVID-19 questions in section 7 removed.

Letters

The survey has been reclassified so approval from the Social Care Research and Ethics Board is not required every year. The line of who has reviewed the study has been removed from the cover letters.

An extra line has been added in the ‘What happens to my answers” section to explain answers are linked with some demographic details using a unique code.

Additional question form

The additional question form is now in Excel. All questions need to be submitted on one form. Additional responses for questions 5 and 6 should also be sent to NHS England for information purposes. The additional responses for questions 5 and 6 do not count towards the maximum of 6 additional questions or free text boxes.

Frequently asked questions

Q1) What do we do if a carer cares for more than one person?

Answer) If a carer is caring for more than one person aged 18 or over, you may need to use local information to determine who the main person cared-for is and to populate relevant data items (for example primary support reason). If you are unable to identify this information, then you will have to select 'Unknown' for categories relating to the cared-for person on the data return.

Q2) Do we need to fill in an additional question form for to use questions from the question bank or ones we have used before?

Answer) Yes, all proposed additional questions need to be submitted for review and approval to NHS England, irrespective of whether these questions have been used before. contra

Q3) How do we code contradictory answers?

Answer) If two or more boxes are ticked for a question in which only one box should be ticked, then the response must be recorded as “Unknown” (-9). If a respondent has chosen conflicting answers for a question that asks them to “tick all that apply” or for two different questions, the responses must be recorded as reported.

Q4) Do we need to send out paper copies of the report to carer?

Answer) Carers should have the option to request a paper copy of either the national or a local report. Councils can choose whether they want to send out the national or a local report.

Q5) How long do we need to keep the paper copies of the questionnaires?

Answer) Councils must retain paper copies of the questionnaires until the publication of the final 2023-24 SACE report. After this point you are free to securely dispose of paper copies, although you may wish to hold on to them for longer if you believe for example, that participants are likely to take part in any follow up studies. The treatment of paper and scanned copies must be in line with your local Information Governance procedures and meet the requirements of the GDPR.

Q6) Can we make changes to the questionnaire to reduce white space?

Answer) Councils need to customise the materials by amending the sections identified with red text and yellow highlighting. Any other changes need prior approval by NHS England. Section 3.11 of the guidance highlights the changes that are not permitted, these include changing the wording of questions, change the font or removing white space.

Q7) How long can we accept the questionnaires until?

Answer) Although the fieldwork should be completed by the 30 November 2023, councils can decide how long they will continue to accept the returned surveys for after the fieldwork period has ended. This will not affect the mandated deadline. Councils should note how many surveys were accepted after the fieldwork period ended in their data return.