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Representativeness of Adult Social Care Surveys: Summary

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A main report with more detail on the findings has also been published, alongside a review of the methodology and a literature review.

Summary of findings and recommendations

Background and aims

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

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

Methodology

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

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

Under-representation in the surveys

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

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

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

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

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

Issues related to sampling from the eligible population

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

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

Barriers and facilitators to responding to the survey

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

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

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

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

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

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

Innovations in methodology

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

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

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

Suggested areas to improve survey representativeness

The recommendations from this research are grouped under several themes and full details can be found in the main report. Here we highlight some of the main areas for improvement. Any changes to the ASCS and SACE need to be considered in the light of other reviews and developments (such as the ASCOF review), client level SALT returns and debates about improvements to adult social care statistics.

Defining the eligible population and managing the sample

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

The organisation, consistency and content of records could be improved to include standard information on characteristics such as language needs or ethnicity. The information submitted by local authorities about the eligible, issued and responding population should facilitate easy analysis of under-representation. Analysis of this should be provided to local

authorities as a standard part of the survey process to enable them to address under-representation at a local level.

Research tools

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

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

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

Support to take part

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

Engagement

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

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

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