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Representativeness of Adult Social Care Surveys

Literature Review

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1 Introduction

This literature review forms part of a project that seeks to understand how representative the Adult Social Care Survey (ASCS) and Survey of Adult Carers in England (SACE) are of the populations they are intended to cover. These surveys are carried out by local authorities using a paper questionnaire.[1] The ASCS is carried out annually and the SACE every two years. The sample design and core questionnaires for both surveys are determined by NHS Digital, but local authorities follow NHS Digital guidance to select their own samples based on local social care user and carer population data. They can also add questions to the questionnaires, subject to NHS Digital approval. There are concerns that these surveys exclude or under-represent some groups of service users and carers so the Department of Health and Social Care (DHSC) has funded research to explore this. This literature review is one element of a multi-stranded project.

A more detailed review of the methodology of both surveys has also been prepared as part of this project.[2] A main report brings together the key findings from the literature and methodology reviews, secondary analysis of data from the surveys, and primary research with stakeholders, including service users and carers, and presents recommendations from the project as a whole.[3]

The ASCS intentionally excludes short-term users of social care. The eligible population for the ASCS is therefore service users in receipt of long-term support services funded or managed by the local authority. The eligible population for the SACE is carers who have been in contact with their local authority.[4] Some service users and carers within these eligible populations are excluded from the sample frame for each survey using guidance from NHS Digital, at the discretion of local authorities. This includes those living in residential care who lack mental capacity (ASCS), involved in an open safeguarding alert (both surveys), or in hospital (both surveys). In both surveys, there is also an unintentional under-representation from some groups who have a low response rate, which may relate to barriers they face in taking part in the surveys.

This literature review covers two elements which could help to explain and identify strategies to address issues related to under-representation resulting primarily from low or differential response rates. These elements are:

- Research with hard to reach groups,
- Best practice and innovation in survey methodology.

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[1] A pilot of an online approach was carried out in 2018-19 on both SACE and ASCS and telephone and face-to-face scripts are available for use by local authorities. For more details see Aznar et al (2020) Methodology review

[2] Aznar et al (2020) Methodology review

[3] Aznar et al (2020) Main report

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

2 Methodology for the literature review

2.1 Approach

The review was carried out using a pragmatic approach that focussed on rapid evidence gathering and an assessment of relevance by researchers with a background in health and social care. The relevant findings were then thematically analysed. The aim was to take a robust but proportionate approach taking account of the time and resources available within the context of the wider project.

First, we searched and reviewed grey literature and relevant online content as well as peer reviewed literature, using:

- Conventional search engines (Google Scholar);
- Literature search engines (e.g. Research Gate, Wiley online library);
- Key journal websites (methodological, social care, and disability related) (e.g. Journal of Aging and Health, Ageing & Society, Health & Social Care in the Community);
- Relevant websites collating evidence related to social care and research with hard to reach groups hosted by organisations (e.g. CQC: Care Quality Commission, BASW: British Association of Social Workers, SRA: Social Research Association, SCIE, Pew Research);
- Research and evidence pages of charities or interest groups relevant to the groups identified as being under-represented in the surveys e.g. carers organisations, charities supporting specific disabilities such as sight loss or dementia (e.g. Race Equality Foundation, Age UK);
- News and research from academic departments or units which specialize in this type of research (Qoru: Quality and Outcomes of Person-Centred Care Policy Research Unit, PSSRU: Personal Social Services Research Unit, Social Care Workforce Research Unit, King’s College London).

We also consulted with experts in the field and added to the literature reviewed as recommendations were made or based on references within the initially reviewed literature.

2.2 Search terms

Search terms, used in appropriate and varied combinations, in methodology literature were: “innovation”, “innovation panel”, “surveys”, “online”, “mode”, “research apps”, “real time measurement”, “digital”, “device agnostic”, “technology”, “social care survey methodology”, “best practice”.

Search terms, using appropriate combinations, in literature on hard to reach groups were: “research”, “surveys”, “feedback”, “measuring satisfaction”, “experience of services”, “outcomes from care”, with terms such as “people lacking capacity”, “people with high needs”, “care and support needs”, “dementia”, “mental health” as well as “informed consent” and “ethical issues in research”.

The searches covered research about service delivery, as well as, research methodology as the barriers faced in accessing or receiving services can be relevant for participation in research. The review also included literature suggested by members of the advisory group and those interviewed as part of the primary research for the project.

Using these methods, we identified and listed all relevant literature with key information, such as:

- Type of evidence,
- Title,
- Authors,
- Journal/source,
- Date of publication,
- Brief summary of key words and its (potential) relevance to the study,
- Location of research/geographical source of evidence.

2.3 Criteria for inclusion

The criteria for inclusion in both hard to reach groups and innovations in methodology were:

- Worldwide, with a priority placed on research and evidence from the UK, Europe and other industrialised countries with relevant literature published in English e.g. US and Australia.

The criteria for inclusion in methodology literature were also:

- Published since 2014: The last five years (at time of initial review) was selected since we were looking at innovations in methodology. These needed to be relevant for the current situation with widespread use of the internet and smartphones. The final literature reviewed included articles from 2012 and 2013 which were included because of their relevance, despite falling outside the initially suggested reference period;
- Concerning surveys or other real time approaches such as the use of apps for gathering data.

The criteria for inclusion in hard to reach groups literature were:

- Published since 2000, with a priority for evidence published since 2009;
- Concerning surveys or other approaches to supplement or replace surveys where they are not practical for a population whose views need to be included;
- Concerning relevant context about relevant hard to reach groups.

This list was then pragmatically reviewed to decide which sources were most relevant based on location, timing and focus of the research. The initial review identified 79 articles, of which 18 were screened out after an initial high-level review. In addition, a further five articles were added after the initial review based on later recommendations or because they were published after the initial review. The relevant sources (66) were reviewed in detail and thematically analysed. Where literature was very specific to the administration and running of the surveys, it has been reviewed or discussed in the methodology review published as part of this wider research project, to avoid duplication.[5]

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[5] Aznar et al (2020) Methodology review

3 Challenges in delivering the ASCS and SACE

3.1 The administration of the ASCS and SACE

This section outlines the challenges related to delivering the ASCS and SACE before moving onto specific approaches to improving participation.

The ASCS and SACE are designed to measure the outcomes experienced by service users receiving long term adult social care or carers in contact with their local authority. The measures feed into the Adult Social Care Outcomes Framework which is published annually. The surveys thus have a particular remit and focus, which means they have some inherent limitations, relating to the overall design and purpose rather than how effectively they are run. These are mentioned here for context but are not the main focus of this review. For example, a review by the Kings Fund identified three drawbacks in the current way the ASCS operates:

1. It does not include people who self-fund their care,
2. The sample base is not big enough to compare the performance of individual providers,
3. It explores satisfaction with services and not overall experiences.[6]

The Office for Statistics Regulation published a review of adult social care statistics in 2020.[7] This identified the reliance on data collected by local authorities among their social care service users as a limitation of current data on social care. The review suggested that data collections need to be 'expanded and transformed' to reflect the wider service being delivered and the role of unpaid carers.

Previous literature has also identified challenges in the operation and effectiveness of the ASCS and SACE in local authorities. Although these are not the focus of this review they are mentioned as they may impact on the resource available for tackling the under-representation of certain groups in the achieved samples. Previous research investigated barriers to the effective use of the resulting data and outputs and identified five challenges in delivering the ASCS and SACE effectively. These are:

1. Identifying local information needs and strategies to fulfil them,
2. Knowing the best way to analyse data and understand the findings,
3. Insufficient time and resource in local authorities,
4. Perceptions surrounding the use and value of the ASCS and SACE,
5. Lack of engagement from stakeholders.[8]

Staff, senior management and leadership are integral to promoting the use of Quality of Life (QoL) survey data for performance and quality improvement. Lack of engagement from stakeholders was highlighted as the key challenge in effective delivery of the surveys[9]. Understanding the barriers in using the QoL data (linked to the perception of value) provides insight into the barriers to engaging stakeholders and gatekeepers in facilitating survey completion. The key barriers are stated as:

- Lack of time (to synthesise and disseminate reports),
- Lack of knowledge (in how to use the data).

Suggested enablers were:

- Training clinicians to interpret, analyse and use data (e.g. using corpus linguistic[10] techniques),[11]
- Training sessions on how to use data and understand how the data is relevant to their goals,
- Creating a team that is responsible for analysis.[12]

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[6] Kings Fund (2013)

[7] Office for Statistics Regulation (2020)

[8] Forder et al. (2016)

[9] Forder et al. (2016)

[10] The study of language in 'real world' text samples, with a range of tools capable of dealing with large data sets available

[11] Brookes et al. (2017)

[12] Razik et al. (2014)

3.2 Causes of exclusion from the survey data

Turning to the issue of under-representation and exclusion from the final data, whilst it is rarely possible to determine which category a non-respondent falls into; non-response can be divided into four categories for the ASCS and SACE:

1. Being excluded from the sampling frame,[13]
2. Failure to receive the survey request (e.g. non-delivery or interception by gatekeepers),
3. Refusal to participate,
4. Inability to respond (e.g. illiteracy in English, physical or cognitive impairments).[14]

Adults who have cognitive or memory impairments, such as dementia or learning disabilities, are highlighted as being particularly susceptible to being excluded from the sample, owing to the rules for administering the survey, the role of gatekeepers or being unable to respond.[15] However, the issues listed above can affect a wide range of service users and carers. More detail is provided below.

3.2.1 Being excluded from the sampling frame

Having identified the eligible population for the surveys, local authorities need to create a sample after excluding certain groups. A key group which are excluded from the ASCS are residents of care homes who lack mental capacity. Working with care homes to carry out the necessary checks is challenging for local authorities for several reasons. For example, gatekeepers (care home managers) may be uncertain about the purpose of the survey and are consequently unwilling or slow to conduct mental capacity checks.[16]

3.2.2 Failure to receive the survey request

Care home staff who have a role as gatekeepers may be reluctant to permit engagement in the survey by residents. Although assurances are provided that the surveys are not designed to evaluate services, there is some feeling that such suspicions may account for the reluctance of some care home managers and staff to take part.[17] Among those living in their own homes, failure to receive the survey request owing to non-delivery may result from poor quality or out of date contact information on the sample. This may affect some groups more than others depending on their level of contact with the record keeping organisation (local authority or third party delegated to deal with carer support) and how frequently they move home.[18]

3.2.3 Refusal to participate

Once the issued sample has been identified and invitations sent, the main source of under-representation is low response to the survey. Social care recipients may choose not to complete the survey for a variety of reasons which may affect service users, carers and gatekeepers (such as care home staff). These include:

- Not understanding the aims of the research,
- Being uncertain about whether received services are delivered by the council,
- Survey fatigue and lack of motivation.[19]

Concerns about the impact of taking part on future receipt of services may also impact on the willingness to participate. This may lead to under-representation of those who have these concerns, though it may be hard to identify this particular group with existing demographic information. One study notes that many people, regardless of age, ethnicity and gender, prefer to participate anonymously and are

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[13] Smith and Malley (2012)

[14] Malley and Fernandez (2012)

[15] Smith and Malley (2012)

[16] Heath et al. (2015)

[17] Heath et al. (2015)

[18] Smith and Malley (2012). This has been explored as part of the primary research for this project.

[19] Heath et al. (2015)

reluctant to describe their experiences of health and social care services for fear that it will have consequences for the services they receive, or that the information will be used for other purposes.[20]

3.2.4 Inability to respond

Even where people wish to respond, potential participants face barriers in completing a paper survey. The impacts of barriers such as language, literacy, sight or physical impairments, or cognitive impairments vary between ethnic, age and support need groups and so can contribute to under-representation.[21] This is explored in more detail in Chapter 5.

3.3 Impacts of under-representation on survey data

All four broad reasons for not being included in the final survey affect some groups more than others. Some groups like those with cognitive impairment or those from minority communities face barriers at several stages of the process. It is the differential impact of these reasons for not being included which leads to the under-representation of particular groups in the survey data. Under-representation matters because the survey data may not be representative of the whole population, just those who respond and this may affect the survey estimates. This impacts on the usefulness of the resulting survey data for local authorities carrying out the surveys.

Sometimes those who respond may be different from those who do not take part (because they are excluded from the sample or do not respond) in ways which can be measured. For example, if older people in residential care homes are under-represented, the percentage of that group in the survey data can be compared with the percentage in the eligible population. The extent of under-representation can be measured and potentially corrected for through weighing. However, sometimes, those who respond may be different from the eligible population in ways that cannot be measured but may affect survey results. Survey results on satisfaction with social care tend to show very high satisfaction and little variation between participants, particularly among service users. One explanation could be generally high levels of satisfaction among service users. However, other explanations for this include:

- acquiescence response (agreeing with statements regardless of the content),
- social desirability bias (giving answers they expect the researcher wants to hear),
- extreme response (giving the most extreme answer).[22]

These issues are beyond the scope of this review, but it is useful to remember that even if the issue of under-representation of particular known groups can be addressed, those who respond may be more acquiescent than those who do not or may have stronger views which prompt them to respond, potentially contributing to bias in the data. It is also possible that those who respond may be those with more positive experiences, so although their responses are not biased, the sample is, thus impacting on the measurement of satisfaction.

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[20] Manthorpe et al. (2009)

[21] Smith and Malley (2012)

[22] Rosalind Willis et al. (2015)

4 Barriers in access to services and participation in research

Although non-response can be found across all groups, there are some groups which face greater barriers to participation than others and are sometimes referred to as hard to reach. Before we look at specific groups that are under-represented and may be regarded as hard to reach, it should be noted that hard to reach is a contested and ambiguous term that is commonly used in social care and health, especially in discourse around health and social inequalities. The term hard to reach is attributed to the service (non) user rather than the service even though the barriers may be put up by the service or researchers.[23]

Key barriers to engagement with service users as a whole include the following. These barriers may result in those who are affected by them to a greater extent, appearing to be hard to reach.

1. Failure to adapt materials to the needs of the participants e.g. translation;
2. Relying on one methodology or question format e.g. excluding people with cognitive impairments or gathering biased and unreliable data from them;
3. Lack of time and resource excluding people who need time or support to process information and acting as a barrier to researchers collecting data through multiple methods;
4. Accessibility e.g. if required to travel;[24]
5. Different priorities between fund giving and recipient organisations;
6. Inadequate staff expertise (e.g. health and social care professionals not having expertise in engaging with service users);
7. Lack of cultural knowledge and racial prejudice.[25]

In the context of health and social care research it is not only the characteristics of users but the behaviour of the organisations delivering the survey that can affect response rates. This was expressed by a service user in these words: “I am not hard to reach, generally people don’t know how to reach me”.[26] The behaviours and characteristics listed above, are examples of barriers which could lead to service users not being reached. Non-participation is not a constant attribute of a person and different sets of influences act on the sample members to determine their likelihood of participation. [27]

There are three key reasons for under-representation in health and social care research and the first two relate to research processes rather than the characteristics of hard to reach groups:

1. Assumptions in the design phase (methods or sample) which can be accentuated by the requirements of ethical approval and the complexity in the process of gaining consent.
2. Defining and recruiting seldom heard groups:
    a. Difficulty in defining groups due to individual differences,
    b. Underuse of services as a barrier to contact, and a limitation to sample size,
    c. Timing: participants being too ill or viewing themselves as too recovered to contribute,
    d. Gatekeepers: making decisions about who to involve or not communicating the research,
    e. Lack of trust in research and concerns about potential harmful impacts of taking part hampers recruitment,
    f. Some people are over-researched as they are easiest to contact.
3. Characteristics of specific populations:
    a. Cognitive impairments or difficulties with communication,
    b. Language and cultural differences (e.g. beliefs prohibiting participation or discussing health issues being regarded as ‘sensitive’, particularly if female, older, or young),[28]

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[23] Flanagan and Hancock (2010)
[24] Beadle-Brown et al (2012)
[25] Hernandez et al. (2010)
[26] Flanagan and Hancock (2010)
[27] Smith and Malley (2012)
[28] Billie Bonevski et al. (2014)

c. Physical or sensory disabilities or long-term conditions which can create barriers to responding to self-completion surveys including postal. [29]

4.1 Groups identified as hard to reach or 'seldom heard'

Four groups are predominantly named as being difficult to reach or engage in research:
1. Those with intellectual disability,
2. Older adults, particularly those with dementia,
3. Those with mental health conditions,
4. Those from minority ethnic groups.[30]

SCIE (Social Care Institute for Excellence) identifies a further two groups of hard to reach people, not included above, as:
5. Homeless people with addictions,
6. People with communication impairments.[31]

Some of the literature concerns service users being hard to reach in the delivery of services. Although this is different from participation in research, it is likely that those who health and social care services find hard to reach, may also experience barriers in access to research so a consideration of these hard to reach groups is also relevant.

Other evidence names younger people and people with substance misuse problems as those with the highest non-response rates. There is also evidence that visual and physical impairments, sensory impairments, proximity to death, and hospitalisation (meaning they do not receive the survey) affect response rates to postal surveys,[32] and there is a small focus on other groups being termed hard to reach such as self-funders, homeless groups and those who identify as LGBT.[33]

Notably, LGBT people are frequently referenced as experiencing health inequalities, negative experiences in health and social care settings and being exposed to a lack of essential knowledge from health and social care professionals.[34] [35] [36] The limited experience of health care providers in meeting the needs of older transgender people also presents unique challenges.[37]

There is some indication in the literature that service users living in rural areas have different care and support needs to those living in other areas[38] and deprived urban neighbourhoods are especially vulnerable to the withdrawal of services, disproportionately affecting older, already disadvantaged, people.[39]

The literature also shows how individuals may belong to multiple groups and may experience multiple layers of disadvantage in access to services or having their voices heard. The English Longitudinal Study of Ageing (ELSA) indicates that 50% of all those aged 60+ experience multiple disadvantages, with women and the oldest old identified as most likely to be multi-disadvantaged. The most disadvantaged individuals were typically women, aged 80 and older, unmarried and lived alone, who rented their home and had no qualifications.[40] Other groups, such as various groups within 'white other',

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[29] Beadle-Brown et al (2012)
[30] Beadle-Brown et al (2012)
[31] Age UK (2011)
[32] Malley and Fernandez(2012)
[33] Beadle-Brown et al (2012)
[34] Julie Fish (2010)
[35] Neville et al. (2006)
[36] Riggs et al (2014)
[37] Persson (2009)
[38] Cornes et al. (2008)
[39] Scharf et al (2002)
[40] Becker et al (2009)

may be excluded because they are numerically smaller and concentrated in certain localities or are extremely dispersed.[41]

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[41] Manthorpe et al (2009)

5 Barriers and facilitators for particular groups

The following sub-sections provide more detail on some of the groups identified as being seldom heard or hard to reach in service delivery or research, exploring the particular barriers they face, and facilitators identified from previous research experience or literature about inclusion in research and access to services. Although access to services and involvement in research have different implications for individuals, the barriers and facilitators may be similar.

5.1 Older people

Previous research has identified general barriers for older people, but also highlights barriers faced by particular subgroups of older people (those in deprived areas, ethnic minority older people and those over 80 years).[42]

Barriers to participation for older people include:

- Poor health and multi-morbidity,
- Feeling too tired,
- Lacking support from family members/carers.

In one project, those feeling too tired were offered a shorter version of an assessment interview to avoid them being unable to take part at all. It is advised that more time and resource be given to involving family members and carers. Other recommended strategies for engaging older people largely echoed the overall principles of flexibility in approach, with face-to-face contact reported as a consistently successful engagement strategy.[43]
Recommended recruitment strategies in a study of older people living in rural areas of the US include[44]:

- sensitivity to the community's structure,
- working with well-established community groups,
- negotiating with a key contact person (gatekeepers, group facilitators, members of the clergy),
- direct mail invitations to general practices,
- advertisement in citywide newspapers,
- telephone-administered surveys.

Incentives can also provide a small reward (notably suggesting mugs rather than monetary incentives), though a clear message was that caring for the person, not just the data they can provide, is essential to obtaining their trust and participation.[45]

Relevant advice for clinical researchers in care homes includes:

- Obtaining consent (or assent) is complex and very time consuming,
- Incentives may need to be offered to homes and practices,
- Researchers should take account of the high level of cognitive and communication impairment of this population; multiple visits are inevitable.[46]

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[42] Iliffe et al. (2017), Ljjas et al. (2017) BMC Public Health

Ljjas et al. (2017) BMC Public Health

[44] DiBartolo et al. (2003)

[45] DiBartolo et al. (2003)

[46] Zermansky (2007)

5.2 Ethnic minority groups

The term ethnic minority covers a wide range of diverse groups with different experiences. The same groups may also have different experiences in different cultural contexts (e.g. in Europe and North America). Some examples are provided below; these are often specific to particular groups and contexts.

An important point to note in exploring under-representation in ethnic minority populations is that population-based sampling strategies are unlikely to produce sufficient numbers of ethnic minority individuals for reliable analysis, and proactive strategies may be needed to achieve higher recruitment yields when eligibility is rare. Literature suggests that too many restrictions on eligibility may limit both the ability to generate sample sizes sufficient for statistical power and the degree to which the sample represents the target population.[47] This limitation may also apply to the ASCS and SACE which are carried out among finite populations of service users or carers in a particular local authority. The overall numbers of ethnic minority service users or carers may be limited. This means that even if response is good among those groups, there could still be insufficient numbers for analysis of the experience of ethnic minority service users or carers as a whole or for particular subgroups at a local authority level. This limits the usefulness of the data for the local authority and the motivation to improve representativeness among these groups.

Available evidence suggests strategies such as multiple methods of contact and media campaigns for recruiting ethnic minorities to a clinical register may enhance participation, with researchers concluding that a media campaign was more beneficial than the clinic registry in recruiting Hispanic women in the US.[48]

A study on recruiting informants in hard to reach groups found that for the African-Caribbean community, interpersonal networks such as churches, schools and informal events/meetings with an African-Caribbean focus served as important recruitment resources. The research focus on the African-Caribbean community and the ethnic matching of interviewer and interviewee was a crucial motivation for participation.[49]

In Pakistani-Kashmiri groups, personal contact within appropriate socially prescribed boundaries were of key importance. Authors suggest that matching interviewer and interviewee, not only upon gender and ethnicity but also age and area of residence, facilitates access to communities characterised by closed intra-community networks. Personal acquaintance or introduction is also vital.[50]

Community involvement may be more critical to retention than to initial recruitment of African Americans and Latinos, and the authors of one study found that mass mailing is effective in recruiting African Americans to clinical trials. Survey response rates are likely to be improved by telephone follow-up in African Americans and advance notice letters may be effective in this group. Incentives are also likely to produce modest increases in survey response rates, but their timing does not necessarily matter.[51]

5.3 Older people in ethnic minority groups

Ethnic minority individuals report poorer health outcomes than white British people and are also less likely to use GP services. Pakistani and Bangladeshi elders, both among men and women, experience a clear disadvantage compared with other ethnic groups in self-reported limiting health and self-rated health.[52] Professionals who work with older ethnic minority groups suggest that strong family connections, a desire to ‘take care of their own’ and a reluctance to engage with services can result in

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[47] Yanceyet al. (2006)

[48] Lai et al. (2006)

[49] McLeanet al. (2003)

[50] McLeanet al. (2003)

[51] Yancey et al. (2006)

[52] Evandrou et al. (2016)

underuse of care and aids available for family care.[53] They are also likely to be under-represented in clinical research and have greater difficulty in accessing health and social care services.[54]

Many older ethnic minority groups have negative perceptions of local councils and view existing representative structures as insufficiently effective or independent from official authorities.[55] Older ethnic minority people receive poorer quality services due to:

- Barriers to access, such as lack of knowledge of available services and how to access them – older ethnic minority people with dementia reportedly access services when dementia is already severe;
- Stereotyped assumptions among health and care professionals about their needs and preferences based on their ethnicity, rather than individual preferences. At the same time, services may also be designed based on the concerns of the dominant majority thus underestimating differences between and within different ethnic groups;
- A lack of suitable good quality services.[56]

A case is made for an integrated approach, with information available in different languages/formats and bilingual workers,[57] again highlighting the importance of trust and perception in engagement with research, and the need for multiple formats. [58]

In one study, older African American adults were more reluctant to participate in telephone interviews than in interviews in the home.[59] In another, some older people from ethnic minority groups were reluctant to receive home visits.[60] This may reflect the setting (e.g. views may be different in the US and UK, or in urban and rural areas) or the minority groups being considered. This suggests the need for flexibility and an approach which takes account of personal preferences and people's cultural backgrounds and circumstances.

A health study reports that a focus group approach facilitates recruitment of older African Americans and that researchers can overcome the reluctance of older adults to participate in telephone surveys by using a multi-method approach combining telephone and face-to-face interviews.[61] Older ethnic minority people may also be more willing to participate if they are ethnically matched with the researchers. [62]

Echoing the principles of being flexible, having cultural awareness and harnessing service user involvement, suggested strategies for engaging older ethnic minority people include:

- working with partner organisations to collate data,
- including older people's forums,
- consulting expert older citizens,
- building up trust through existing networks,
- meeting older women in their homes or places they usually gather,
- being aware of patriarchy issues.[63]

Communication with older people from ethnic minority communities should consider the possibility of hearing loss, illiteracy and visual impairment as well as language needs, including the use of plain English.[64] Access to formal interpreters is of key significance, particularly those who incorporate the

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[53] Liljas et al. (2017) The Lancet

[54] Liljas (2017) BMC Public Health

[55] Manthorpe et al. (2009)

[56] Moriarty (2008)

[57] Moriarty (2008)

[58] Smith and Malley (2012)

[59] Chadiha. et al. (2004), in a US based study of Older African Americans.

[60] Liljas (2017) BMC Public Health, in a study in a UK city.

[61] Chadiha et al. (2004)

[62] Liljas (2017) BMC Public Health

[63] Manthorpe et al. (2008)

[64] Plain English is language intended to be clear and concise and is often used in the context of official communications

features of personal trust into professional good practice e.g. an ongoing relationship and commitment.[65] A poor translation can distort the meaning of the participant's words, which may generate misleading conclusions.[66]

5.4 Those with mental health problems

Literature related to research with those with mental health needs often focusses on the needs of particular groups such as those from ethnic minority groups or refugees as their experiences differ. There has also been work on the role of service users in carrying out research.

A national cross-sectional online questionnaire survey used a snowball sampling approach to gather the views of service users involved in mental health research. The survey revealed a qualified service user research workforce. Participants reported drawing on extensive service use and passion for service improvement to challenge the perceived clinical academic dominance of research. The support of peers was crucial to this involvement, which typically enhanced mental health but for some, pervasive stigma and scrutiny undermined self-confidence and practical difficulties challenged equitable participation. Recognition of the service user research workforce was supported by the authors as a way of amalgamating the academic and experiential expertise needed to shape investment in mental health research.[67]

People with serious mental illnesses, particularly members of racial and ethnic minority groups, are rarely included in prioritising research topics or developing the tools and measures for improving their care. Community-based participatory research holds promise toward reducing mental health disparities. However, initiating research partnerships with community stakeholders is challenging and does not always lead to sustainable community health improvements.

Barriers to community-based participatory mental health care research, with racial and ethnic minorities:
- concerns among community stakeholders,
- complex research methods,
- uncertainty among academic partners,
- unclear partnership decision-making protocols.

The primary facilitators were:
- meaningfulness of the research topic to the community,
- the presence of a well-established community-based organization,
- academic financial investment,
- co-learning activities,
- flexibility.[68]

It is also well established that the incidence, prevalence and presentation of mental disorders differ by gender, ethnicity and age, and there is evidence that there is differential representation in mental health research by these characteristics.[69] There are a wide range of barriers, encompassing:
- transportation difficulties,
- distrust and suspicion of researchers,
- stigma attached to mental illness.

Strategies to overcome these barriers included:
- the use of bilingual staff,
- assistance with travel,
- avoiding the use of stigmatising language in marketing material,

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[65] Manthorpe et al. (2008)

[66] Liljas (2017) The Lancet.

[67] Patterson et al. (2014)

[68] Delman et al. (2019)

[69] Woodall et al. (2010)

- a focus on education about the disorder under investigation.

There are few evaluations of such strategies, but there is evidence that in the context of research with mental health service users from ethnic minority communities, ethnically matching recruiters to potential participants did not improve recruitment rates and that educational strategies are helpful and increased recruitment. Mental health researchers are advised to consider including caregivers in recruitment processes, provide clear descriptions of study aims and describe the representativeness of their sample when reporting study results.[70]

Engagement with refugees and asylum seekers within mental health research is also explored and supported. Key design considerations in studies sampling refugees and asylum seekers in mental health studies are:

- a prior aim to recruit a representative sample,
- a reliable sampling frame,
- recording of response rates,
- implementation of long recruitment periods,
- using multiple non-probability sampling methods and, if possible, including a probability sampling component.

Again, it was recommended that rigorous reporting should take place in future studies so that the representativeness of samples of these groups in research can be more readily assessed.[71]

5.5 Those with cognitive impairment

Including people with dementia in research can be challenging because of the complex and time-consuming processes for obtaining ethical consent for research with this group. Among those with dementia, the process of obtaining consent may cause confusion and they may be anxious about forms. Recommendations for addressing this include involving people with dementia on research advisory groups to advise on ethical issues and the presentation of information.[72]

In one study, there was considerable variation in decision making capacity within three diagnostic groups; outpatients with schizophrenia, mild to moderate Alzheimer's, and type 2 diabetes, so consideration of an individual's capacity to consent to research may be warranted. Cognitive ability was the only consistent correlate of decision making capacity, particularly in understanding of the information materials. The authors suggest it is inappropriate to draw conclusions about an individual's capacity for meaningful consent based solely on their diagnosed condition. Sensitive brief questionnaires targeting key aspects of disclosed information may also provide an effective means of screening for whether participants can give informed consent. In that study a three item questionnaire was used to judge decisional capacity. It was tested and compared favourably with a more comprehensive tool (MacArthur Competence Assessment Tool for Clinical Research)[73]

If people with dementia are included in research, their participation is usually limited to those in the early stages of dementia who can give informed consent. However, the experiences of people with early and later-stage dementia differ greatly.[74] Caregivers of people with dementia have previously been asked to rate quality of life (QoL) using proxy measures. This is because dementia patients are considered incapable of verbally communicating their thoughts and feelings, or because the thoughts and feelings of those living with dementia are considered to be of questionable validity.[75] However, caregivers consistently under-estimate people with dementia's own perceptions of their QoL. Therefore, there are

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[70] Woodall et al. (2010)

[71] Enticott et al. (2017)

[72] Brooks et al. (2016)

[73] Palmer et al. (2005)

[74] Brooks et al. (2016)

[75] Brooks et al. (2016)

some suggested tools for engaging dementia patients directly and understanding their thoughts and feelings:

- Life story work, recording aspects of a person's past life, present interest and future plans and wishes. The aim is to create a tangible item that can be shared with others.
- DEMQoL[76] and QoL-AD[77] are reliable and valid measures of QoL for people with mild to moderate dementia, but there is less evidence of successful use for people with severe dementia. Pictorial aids, coloured paper and face-to-face interviews are helpful, but these methods are resource intensive and require researchers to build relationships with dementia patients.[78]

As it is difficult for surveys to be self-completed by this group, a cohesive approach to assessing the care related QoL of older people with a cognitive impairment is only viable if participants interact with researchers, who use cognitive interviewing strategies, 'staggered reveal' and 'talk loud' approaches.[79] Staff need support and encouragement to improve communication with people with dementia, indicating the importance of staff training for fostering participation. More simply, for a group of participants with aphasia, staff captured non-verbal communication and double-checked they had correctly interpreted what the person wanted to convey.[80] It should be noted that the ASCS and SACE use self-completion methods. However, participants do receive help in completing the questionnaires from family, friends or care workers and the ideas above could be used to provide guidance to those supporting service users or carers in completing the ASCS or SACE.

A study about designing and selecting apps for dementia patients to use for self-management and meaningful activities provides the following recommendations[81]:

- Minimal amount of typing required to navigate within the apps,
- Using warm colours,[82]
- Placing important information first and highlighting it,
- Providing clear headings for text,
- Providing enough space between app and tablet buttons,
- Providing ample time to read information,
- Avoiding pronouns or any language requiring the person with dementia to recall previous information,
- Must be designed and developed in close co-operation with the users and other important stakeholders, such as formal carers and experts (designers, developers and researchers), to ensure user-friendliness.

There is evidence that people with dementia can use a tablet and its apps. However, despite varying degrees of performance, people with dementia need support to operate the tablets and its apps. This appears to reflect the individual's physical and cognitive condition.[83]

5.6 Hospitalised patients

The ASCS excludes patients in hospital at the time of the survey, however findings from research in hospitals are relevant for service users living in residential care or nursing homes because the health

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[76] DEMQol is a 28 item patient reported outcome measure which is designed to enable the assessment health-related quality of life of people with dementia.

[77] QoL-AD is a tool to measure quality of life among those with Alzheimer's Disease.

[78] Brooks et al. (2016)

[79] Phillipson et al. (2019). 'Staggered reveal' involves sharing information bit by bit rather than in one large chunk. 'Talk aloud' involves asking participants to say what they are thinking as they answer questions. Cognitive interviewing is a method usually used for testing questionnaires but the techniques can also be used in a qualitative interview to explore issues such as comprehension, recall and choice of responses.

[80] Hernandez (2010)

[81] Kerkhof. et al. (2017)

[82] The colours were not specified in the article but warm colours are generally those on the red, orange and yellow side of a colour wheel.

[83] Kerkhof. et al. (2017)

needs of participants, restrictions on timing and presence of health and care staff may have similar impacts in both settings. The study described below involved face-to-face research administered by researchers but the findings would be relevant for care homes and family and friends considering how they could assist service users in the completion of the ASCS.

A study into engaging hospitalised patients in face-to-face research found[84]:

- It was sometimes necessary for researchers to interview in 15-20 minute intervals, returning a few times to complete the interview;
- The researcher needs substantial interpersonal skills;
- The time needed to access vulnerable clients should be realistically considered;
- Some patients gave different responses or may have been afraid to answer negatively with the nurse present, which can be resolved by ensuring the nurse is not present;
- The particular health needs of patients affected their participation. For example, some patients' ability to articulate their answers were hampered by respiratory problems. For visually impaired older people, researchers read each item out loud or use enlarged print. For patients with hearing loss, researchers reduced the pace at which questions were delivered, spoke more loudly and ensured they were facing the patient. When seeking consent from hospitalized patients, researcher-nurses spent time chatting to the patients as well as using the MMSE scale and the Barthel Index[85].

A possible solution to overcome the challenges in research with acutely ill hospitalised patients is to ask them to complete the questionnaire following discharge, though validity of questionnaires that rely on memory is questionable. In the context of the ASCS where the service being received may be long-term residential care, this would not be practical.[86] However, this approach would be appropriate when considering how to include short-term care users in a survey.

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[84] Hancock et al. (2003)

[85] MMSE is the Mini Mental State Examination which gives an assessment of cognitive impairment. The Barthel Index is an instrument designed to capture difficulties with Activities of Daily Living as a measure of functional independence.

[86] Hancock et al. (2003)

6 Increasing participation and representation in research

6.1 Common facilitators

The previous section has identified several groups which may face particular barriers to participation in research. It outlined barriers affecting certain groups more than others as well as facilitators which may overcome those barriers for particular groups. However, it also showed that even within groups, subgroups may have distinct needs and requirements. At the same time, the literature about the needs of specific groups showed several areas of commonality in how access to services for hard to reach individuals and groups could be improved. These strategies are also relevant for facilitating their views to be heard in research, regardless of their individual needs and which sub-group(s) they may be a member of:

1. Respectful treatment of service users.
2. Establishing trust with service users (whilst noted as an important barrier to participation, there is a reported lack of evidence on building trust).[87]
3. Flexibility in order to meet individual needs:
    a. in method (focus groups, telephone interviews, home visits and observation as well as self-completion survey);
    b. in recruitment strategies (face-to-face contact to build rapport and trust, working with community groups and grassroots organisations);
    c. in materials, providing information in multiple formats e.g. easy read, use of colours and pictures, audio/video format and having an audio consent option);
    d. including additional time and flexibility at each stage of the research process.
4. Partnership working with other organisations.
5. Harnessing service user and stakeholder involvement in the design process and testing of measures, letters and schedules. [88] [89] [90]

The way in which health information is presented can influence attitudes and intentions, especially among those with higher levels of medical mistrust (which can be more common among those in groups regarded as hard to reach). Strategies for improving intervention fidelity suggest framing health information in a positive way by emphasising progress achieved in the health area.[91] Similarly strategies for improving response rate may lie, in part, in the framing of the research and explaining its usefulness and purpose.

Providing incentives is a well evidenced method for increasing response rates in seldom heard groups. Unconditional prepaid incentives are more effective than conditional incentives, though there are concerns that incentives are a subtle form of coercion.[92]

6.2 The role of gatekeepers

Strategies for addressing the barriers presented by gatekeepers[93] specifically include employing gatekeepers as project recruitment officers and involving them in the research. Ultimately, it is advised that to tackle the challenges of research with socially disadvantaged groups, and increase their representation in health and medical research, researchers and research institutions need to

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[87] Smith and Malley (2012)

[88] Flanagan, Hancock (2010)

[89] Beadle-Brown et al. (2012)

[90] Davies et al. (2010)

[91] Bonevski et al. (2014)

[92] Smith and Malley (2012)

[93] A gatekeeper is a person or organisation that acts as an intermediary between a researcher and potential participants. A **gatekeeper** may also have the power to grant or deny permission for access to potential **research** participants.

acknowledge extended timeframes, plan for higher resourcing costs and operate via community partnerships.[94]

Unpaid caring by family members and others is of significant and increasing importance in the context of an ageing population, growing pressures on public finances and increasing life expectancy at older ages.[95] Unpaid carers are likely to become more prevalent as potential gatekeepers, supporters and enablers of those they care for participating in research so it may be wise to consider their circumstances as well as service users and recipients of the ASCS. The pressures faced by carers may also affect their own participation in the SACE.

There is a strong geographical pattern in levels of illness and of unpaid care and there are associations found between rates of unpaid caring and a person's age, gender, ethnicity, social class and the carers own health status. Caring relationships are different for people who provide care within or outside of their own household, and unpaid carers who do not live with people they care for are likely to face different demands.[96] These differing circumstances will need to be considered when engaging unpaid carers and considering impacts on the ASCS and SACE data.

6.3 Involvement and co-production in design and delivery

A literature review on equity of access to services suggests that reliance on normative assumptions about need relative to 'some apparently privileged though often ill-defined reference groups' risks failing to identify problems in access for that group.[97] This highlights the importance of careful consideration of who to involve in the design and testing processes for both services and research.

Age UK report that older people want to be involved in impactful projects, not to be tokens and to know the scope and usefulness of the project, and this likely applies to other seldom heard groups. Age UK advise that projects should focus on the need to communicate effectively and think about how the audience receives the information,[98] ensuring the promotion of meaningful discussion and sensitivity to access needs and support.[99] [100]

One study also suggests that personalised and individualized approaches are the best way of supporting access, and co-production of resources with intended audiences is viewed as essential.[101]

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[94] Bonevski et al. (2014)

[95] Robards et al. (2015)

[96] Norman and Purdam (2013)

[97] Dixon-Woods, M. (2006)

[98] Age UK (2011)

[99] Kaspiew et al (2018)

[100] Hernandez et al. (2010)

[101] Chinn and Homeyard (2017)

7 Methodological approaches and innovations for facilitating participation

In this section we explore how particular methods, modes for surveys and innovations can improve participation in research for hard to reach groups, while potentially presenting barriers to others. We also describe how the way these approaches are implemented could be adapted to improve engagement with under-represented groups.

7.1 Approaches to sampling

A systematic review of methods for reaching hard to reach groups in order to improve health and medical research provides the following strategies to improve sampling:

- Respondent-driven recruitment,
- Venue based time-space sampling,
- Targeting sampling,
- Capture-recapture,
- Adaptive sampling and over sampling of low prevalence population subgroups.

Selection bias and gatekeeper bias are the primary limitations of these strategies.[102]

Some of these may not necessarily be relevant to the samples available for the ASCS and SACE or the approach used, but the principles behind them may be relevant. For example, involving service users, visiting venues such as care homes to speak to residents and their families, and over-sampling could be considered.

7.2 Questionnaire design

Four key methods to enable participation in postal surveys are:

1. Ensuring the study information section of a postal survey is designed to be relevant to participants to avoid the information being a barrier to participation;
2. Adapting the questionnaire to reflect the individualised needs of the participant e.g. different language or easy read;
3. Employing alternative methods of data collection alongside the postal survey e.g. face-to-face or telephone interview (well supported and most evidenced that it improves response rates);
4. Encouraging and/or providing support to complete the survey.[103]

It also is important to consider the education level of the survey population when designing questions. Questions should be written in plain English, avoiding double negatives, jargon and unfamiliar abbreviations. Avoiding potential bias and emotional provocation should be considered in choice of language. Participants with a lower level of formal education have a greater tendency to agree with statements in an agree-disagree format, due to acquiescence bias, so it is better to offer participants a choice between alternative statements (as is the case in the ASCS and SACE already).[104] This is important when considering the representativeness of surveys, as the barriers presented by complex questions and offence caused by inappropriate language may affect some groups more than others and result in a decision not to complete the questionnaire at all.

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[102] Bonevski et al. (2014)

[103] Smith and Malley (2012)

[104] Pew research centre

It is also suggested that data collection can be improved by shortening questionnaires,[105] and prioritising questionnaire sections based on importance, time to complete and common sense.[106]

Researchers should ensure that questionnaires reflect the situation participants are being asked about in a way which means they can answer the questions. Caregivers rating the health of care recipients indicated that the questions did not truly reflect the way in which the health of care recipients fluctuated from day-to-day, even during a given day. This means responses to questions about satisfaction with services may also fluctuate. Researchers in one study included an item that captured the dynamic nature of the health status of elders.[107] The perceived relevance of the questionnaire may impact on response and could lead to under-representativeness of groups who consider the questions not to be relevant to them.

Questionnaire design for older people requires considerations of the impact of declining information processing and working memory on both question order and response options.[108] Considerations of the capacity for orientation and attention, language and communication skills should also be included for surveys to be used with people living with a cognitive impairment or dementia.[109] [110]

7.3 Mode of the survey

The choice of mode can affect both the quality of data and completeness of response within a questionnaire. One study found high reliability and validity in computer assisted telephone methods when compared to face-to-face interviews. Another trial found that telephone interviews resulted in more complete data than mailed health surveys.[111] Mode can also affect response rates, and differentials in response between different groups. Changes to mode have the potential to lead to both improvements and deterioration in under-representation.

7.3.1 Postal surveys

An investigation into methods for increasing response rates in postal surveys found that pre-notice letters were not effective, but postcard reminders were, increasing response rate by an average of 5.7%. The length of survey is again evidenced as important, with redesigned letters and shorter questionnaires increasing the response rate by an average of 2%. Notably, the postcard reminders and redesigned letters marginally increased the proportions of people aged 25-44 and people in work in the overall sample, though slightly decreased the proportions of those aged 65+ and in retirement.[112]

7.3.2 Web surveys

Self-administered surveys on the web have many advantages but there are still issues to be dealt with. Coverage bias is modest, but it is not absent entirely as some people do not use the internet and many others decline to respond in this mode. As a result, measures of technology use are likely to be biased, especially for certain sub-populations where the segment of the group comfortable with the internet may be very different from those who are not.[113]

Sending invitations to surveys via text message in addition to by email encourages participants to complete the survey sooner and boosts the amount of people responding on a smartphone, compared with those who received only an email invitation. However, some surveys are better suited for completion

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[105] Bonevski et al. (2014)
[106] Davies et al. (2010)
[107] Dilworth-Anderson et al. (2004)
[108] Schwarz (2006)
[109] Mozley et al. (1999)
[110] Ready and Ott (2003)
[111] Bonevski et al. (2014)
[112] Nicolaas et al. (2015)
[113] McGeeney et al. (2015)

on a desktop e.g. due to length. This did not increase the ultimate response rate over a longer period compared with sending notifications by email only. The demographic profile of the achieved sample did not differ between the group which received text message and email invitations and the group which received email invitations only.[114]

7.3.3 Adapting surveys for smartphones

There are concerns about the quality of responses received from those completing online surveys on smartphones as opposed to other devices. Smartphone survey data might be of lower quality because:

- Generally, surveys take longer to complete on smartphones;
- Participants are significantly more likely to drop out before the end of the survey;
- Participants tend to give a less detailed response;
- There is an increase in rates of non-substantive answers, straight lining and multi-code selection;
- It's not feasible to test a survey across the whole range of mobile devices.[115]

Initially online social surveys in the UK discouraged smartphone completion. However, there is increasing recognition that online surveys need to be designed with mobile use in mind as participants will complete them using smartphones. The characteristics of those completing on smartphones are also different from those completing on computers, being younger, more likely to have children in the household and of higher socio-economic status. Women are also more likely to use smartphones than men. This means that data quality impacts from smartphone use can have differential impacts on different groups in the sample. It also means that impacts on response when surveys are not optimised for smartphones may have differential impact on representation.[116]

However, there is little evidence that the quality of data is any lower when young people use smartphones compared with other devices. Keeping in mind small-screen devices whilst designing online surveys can minimise the risk of decreased quality, for example keeping answer lists and question wording short to minimize scrolling.[117] More research is needed on impacts of smartphone use to complete surveys among a wider age range.

7.4 Real-time feedback (RTF)

Related to demonstrating value to gatekeepers, collecting data through technology in hospitals and engaging staff by showing them the results is viewed as valuable, though the techniques used are resource intensive.[118] It is possible that these approaches could be extended to social care staff, particularly in the context of assessing the experiences of short-term users of social care.

There is potential for using digital modes of administration of RTF as an agent for improving service delivery. Patients and staff are willing to engage though, for RTF to be impactful, delivery strategies need to be put in place across all levels of digital maturity.[119]

7.5 Easy read

People with learning difficulties are more likely to respond to the ASCS questionnaire. Several factors could be at play here, including the targeting of easy read questionnaires to people with learning difficulties and finding that support to complete questionnaires was very high amongst this group.[120]

A new version of the Adult Social Care Outcomes Tool (ASCOT) easy read (ER) questionnaire was originally co-developed and beta tested with younger people with intellectual disability and autism to

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[114] McGeeney (2016)
[115] Hanson et al. (2016)
[116] Maslovskaya et al. (2019)
[117] Matthews et al. (2017)
[118] Käsbauer et al. (2017)
[119] Khanbhai, M. (2019)
[120] Malley and Fernandez (2012)

address their reported difficulties accessing standardised research tools. It was found to be easier for people with learning disabilities to interpret and answer. However, there is scope for systematic testing of the new ASCOT-ER. It is particularly important to explore validity and reliability, including the relationship between responses to the individual items and other indicators theoretically related to these concepts e.g. other quality of life and wellbeing measures.[121] Work has also been carried out to explore the use of easy read with older people with cognitive impairment and dementia. The easy read format helped with comprehension and meaning but researchers found it was the cognitive interviewing and qualitative interactions with researchers during the testing which were most helpful. Questions remain over whether the easy read version would be suitable in a self-completion format for this population.[122]

Visual methods such as easy read have been reported as useful in exploring and contextualising questions for people with dementia,[123] and have been recognised and utilised in other sensitive areas, such as the development of 'Talking Mat' conversations.[124] However, there is limited research on the usefulness of images in creating clarity for people with cognitive impairments.[125] [126] [127] In some cases, adding pictorials can decrease comprehension, rather than aid it. In particular the use of Clipart or the use of symbols when users are not familiar with them did not improve understanding.[128] [129] The addition of pictures is only helpful for older people with cognitive impairments if there is also text which supports it and the pictures are relatively big, high contrast, clear and communicate specific concepts that represent all dimensions of the intended topic.[130]

7.6 Use of Proxies

For those who cannot participate for capacity and consent reasons, the suggested methods are:

1. Using proxies (asking for their views rather than their thoughts on the patients' perceptions)[131]
2. Using observers.[132]

The systematic exclusion of people who are unable to self-report their QoL may contribute to issues of sample size, missing data, bias, equity and inclusion. Using proxy respondents is a potential solution to this problem, however there are measurement-related challenges, including proxy respondents systematically underestimating QoL compared to self-report.[133]

Challenges involved in assessing outcomes by proxy, from the perspective of carers, include:

- Whose perspective to provide answers from;
- The potential impact of differing proxy perspectives (from the person in question) and motivations, which lead to bias;
- Difficulty in answering questions that are perceived as 'abstract', e.g. around dignity.

Provisions proposed to improve validity and acceptability are:

- Providing two sets of response options for each proxy perspective (one for the proxy and one from the view of the care recipient);
- A comments box to explain their response, especially where they indicate unmet needs;
- Providing clear guidance on what is expected of the proxy respondent;

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[121] Turnpenny et al. (2016)
[122] Phillipson et al. (2019)
[123] Banks and Zeitlyn (2015)
[124] Talking Mats (2018)
[125] Chinn & Homeyard (2017)
[126] Codling and Macdonald (2008)
[127] Hurtado et al (2014)
[128] Brennan et al (2005)
[129] Poncelas and Murphy (2007)
[130] Phillipson et al. (2019)
[131] Beadle-Brown et al. (2012)
[132] Smith and Malley (2012)
[133] Brooks et al. (2016)

- The proxy should be very familiar with the care recipient, as well as their needs and care provision, and the relationship between the proxy and care recipient should be given in the survey.[134]

These findings highlight the benefits of developing and testing proxy measures in a robust way, as opposed to simply making grammatical changes to a standard version.[135] [136]

Proxy reports should not be viewed as substitutes for self-report as a proxy is unlikely to utilise the same judgement criteria as the recipient would have used. Family members are usually found to report lower QoL than is self-reported whereas professionals often report higher levels of QoL than is self-reported.[137]

Observational approaches are recommended for reaching those who cannot fill in forms themselves (because of cognitive impairment or learning disability). An observational framework can be used to structure what is recorded during a visit to observe care being provided. Concerns about the Hawthorne effect (care workers modifying behaviour in response to an awareness of being observed) could potentially be overcome by having a close family member or friend present to comment on the extent to which the observed visit reflects the quality of care usually provided.[138]

7.7 Innovative methods

One study on innovative qualitative methodologies[139] explored creativity and innovation in research methodology. Innovation can include both the use of totally new methods as well as extending existing methods to new participants or new disciplines or adapting existing methods. Innovative approaches are suggested as a way to find solutions to problems. Several new qualitative methods were suggested:

- online interviews, observations or focus groups,
- photography and other visual methods,
- sensory ethnography,
- soundscapes,
- creative writing from participants,
- text chat, instant messaging, or SMS texting dialogues,
- social media listening/observing (thematic analysis of online discussion postings).

These were considered in relation to the population as a whole, not just service users or carers and so not all may be applicable to all groups in these populations. However, another form of innovation suggested was extending research to new groups such as hard to reach populations and people with disabilities.

They suggested several new ways of thinking about research such as:

- drawing in autobiographical practices,
- practitioner-led research,
- multi-modal research practices,
- combining textual with visual,
- combining qualitative and quantitative methods.

Whether or not to use innovative methodologies such as these is contested. The reasons for their use are:

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[134] On the ASCS participants record the type of help received and whether it is from a care worker, someone in their household or someone outside their household. The SACE records whether help was received but not the type of help. However, when the questionnaire is completed on someone's behalf completely it is not clear whether the proxy would always record themselves as the helper as the question asks 'Did you have any help?'.

[135] Rand et al. (2017)

[136] Caiels et al. (2019)

[137] Smith and Malley (2012)

[138] Kings Fund (2013)

[139] Fields (2014)

- Theoretical reasons – aiming to improve shortcomings within the research process, such as validity, analysis or data collection methods;
- Moral or ethical reasons – wanting to understand the emotional aspects of a topic to build a more holistic picture of findings, or to increase collaboration or to reduce risk of harm;
- Practical reasons – improving the quality of participant responses and engagement with the process, overcoming problems of accessing hidden populations and handling online data.

Arguments against or barriers to innovation are:

- Researchers prefer to draw on current understanding;
- Researchers sometimes do not know when to innovate or what extent to do so;
- Some researchers might feel insecure about trying something new;
- Innovation is sometimes only considered when existing methods are incapable of doing what they are supposed to do;
- Not all creativity in research methods will lead to sustained innovative research practice;
- Experimentation and the risk of failure is often not an option when research is publicly funded;
- There are moral and ethical issues with experimentation which makes it difficult to develop and test methods;
- Interdisciplinary challenges of communication, collaboration and weak disciplinary grounds make the development and adoption of new methods difficult;
- Issues of transparency and clarity can arise due to the employment of new methods.[140]

The ASCOT domains have been utilised as an approach involving open conversations with service users, care workers and family members for care planning. This approach can uncover issues that may be missed through more conventional approaches and refocus attention onto wellbeing. These conversations are reportedly well received by residents and their families whilst increasing staff understanding of how they could support residents’ social and emotional needs,[141] highlighting the importance of use in practice to encourage participation. This approach could be extended beyond care planning to research.

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[140] Fields (2014)

[141] Towers et al. (2019)

8 Key implications

The implications and recommendations from the research as a whole are covered in the main report from this research.[142] However, here we outline some of the key points from the literature review on hard to reach groups and methodological innovation.

- Hard to reach is a contested term and an approach which places the emphasis on how researchers can adapt the approach to reach seldom heard groups is likely to be more effective than placing the emphasis on the characteristics of under-represented groups.
- Within hard to reach groups there is diversity of experience and preference and any research approach needs to be responsive to the needs of individuals.
- The involvement of service users and carers in agreeing the purpose of the research. This should consider its usefulness for service users and those working with them, in order to increase the opportunity for the findings to improve services in the future. Researchers should strive to add and demonstrate value in practice once the research is completed.
- Service users and carers should be involved in designing the research approach and materials. This will improve the accessibility and is likely to be helpful in facilitating participation, particularly among under-represented groups.
- Building trust and working with community and other groups can assist in improving response rates generally and for seldom heard groups.
- Flexibility to allow for differing needs in terms of format and approach is important, however in the context of ASCS and SACE this may have implications for comparability and time series.
- Face-to-face methods of recruitment and data collection may be effective for some seldom heard groups but may be resource intensive.
- Hearing the views of those with cognitive decline is a widespread issue and the approach needed for those lacking mental capacity may be different from those with mild to moderate cognitive decline.
- In reaching those with care needs, the role of gatekeepers is important and needs to be considered in the design and engagement process.

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[142] Aznar et al. (2020) Main report

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