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Recruiting participants for adult social care studies: challenges and mitigating strategies

METHODS REVIEW

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Key words

Social care, research, recruitment, research participation

Disclaimer

The views expressed in this review are those of the authors and do not necessarily represent the views of the National Institute for Health Research (NIHR) or the Department of Health and Social Care.

ABSTRACT

Challenges are often encountered in recruiting participants into adult social care research studies, while strategies to overcome them are not widely understood or shared.

This Methods Review aimed to describe the challenges in recruiting organisations and individuals for adult social care research and identify possible strategies to address them.

In semi-structured interviews, 17 senior researchers in the social care field were asked about their experiences of recruitment of research participants.

One of the main barriers to recruitment was variation among provider organisations, so recruitment strategies needed to be adjusted for different organisations, many of which lacked capacity for research participation. The rapidly changing nature of adult social care organisation and delivery in England also means that recruitment strategies often need to be adapted while research is in progress. Building partnerships between researchers and providers and offering financial and other incentives were suggested as mitigating strategies. In recruiting individuals, a lack of understanding of research benefit and organisations' gatekeeping arrangements were common difficulties. Interviewees suggested: raising public awareness of adult social care research; building relationships with user/carer groups; using a variety of recruitment strategies and offering a range of participation routes. Researchers and funding bodies should allow sufficient time and resources to recruit representative samples. Researchers should share recruitment knowledge.

A limitation in this review is that the individuals who participated in the review may not be representative of all adult social care researchers.

This review highlights opportunities for developing recruitment in adult social care research, such as improving recruitment and participation methods; investing in research support and research capacity and increasing public engagement with adult social care research.

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

General

- Increase public engagement with adult social care research and awareness of research benefits.
- Secure advanced consent for use of data from individuals using adult social care services, and from current participants.

Research funders

- Invest in research capacity-building, including from professional groups.
- Support building networks and relationships to exchange knowledge (include researchers, practitioners, user/carer organisations and groups).
- Support partnerships with non-academic organisations, include holding budgets.
- Provide research support costs for adult social care organisations.
- Ensure adequate compensation for time provided by individuals/participants.
- Allow sufficient time allocation for planning/recruitment tasks.
- Ensure appropriate methods/measures are used and also tested.
- Ensure involvement is effective throughout projects.

Researchers

- Communicate research aims to emphasise their relevance to practice and to organisations.
- Build relationships/partnerships with individuals, groups and organisations.
- Offer benefits to organisations for participation, including quick wins or feedback early on, and tangible outcomes at project end (e.g. workshops/training), where appropriate.
- Involve people/organisations from the beginning and throughout projects and retain their engagement.
- Make is as easy as possible for volunteers to participate, offer different ways of taking part.
- Allocate realistic timelines and resources to recruitment activities.
- Use a range of recruitment methods to overcome a range of biases of different approaches.
- Set realistic recruitment targets.
- Report recruitment issues (including reasons for non-participation) and strategies to overcome them.

Contents

1. INTRODUCTION

Since the 1980s, local authorities (LAs) in England gradually moved from delivering most of their adult social care services 'in house' to the majority being provided by private companies, charities or social enterprises. More recently, further changes in the organisation, delivery and funding of adult social care have included the development of direct payments/personal budgets for eligible citizens and arrangements with the NHS to pool some budgets, develop joint commissioning and integrate some services. The Care Act 2014 reorganised the overarching legal framework for much of adult social care and introduced new responsibilities for local authorities, including the prevention of need and of delay in deterioration. More recently, difficulties in contracting adult social care services (such as local commissioning not being in line with the rising cost of service provision) have led to more than half of private providers returning contracts to LAs because of funding pressures (Sector Pulse Check 2019). These changes are taking place in the context of a reduction of nearly 50% in central government funding for LAs since 2010/11 (NOS 2018), while the NHS has had the largest reduction in spending in its history (as a proportion of GDP; Appleby 2018).

Arguably, using robust research evidence to inform decisions about adult social care is more crucial than ever given these reforms and mounting pressures facing the sector (Woolham et al. 2016). However, adult social care research has been recognised as a sector in need of greater investment and capacity-building if it is to respond to the rising need for robust research evidence to help improve policy, practice and outcomes (Corbett et al., 2017, NIHR Trainees Coordinating Centre 2017, Knapp and Richardson 2012, Marsh and Fisher 2005). For example, it has been argued that adult social work needs to move to an approach more engaged with, and grounded on, research evidence (Croisdale-Appleby 2014). Over the last decade, adult social care research has benefitted from some additional investment, most notably the establishment by the National Institute for Health Research of the School for Social Care Research (NIHR SSCR). More recently, NIHR has begun to move more resources to support adult social care research. The regionally organised NIHR Research Design Services have been developing their understanding of the sector to support researchers to develop better grant and fellowship applications. The Clinical Research Network (CRN[1]) now provides support to adult social care research, for example, with recruitment to studies. The NIHR Academy has begun to support work to further develop capacity in research in the adult social care sector. Different funding streams of NIHR have also begun to commission more research in adult social care. Other funders, such as the Economic and Social Research Council of UK Research and Innovation and some charitable funders of research have also begun to take more interest in supporting research in the field.

It is in this context of need for more high-quality research, and low but growing investment and levels of infrastructure support for research in adult social care, that we sought to identify the key issues facing recruitment of participants into studies in the sector. If the sector is to make productive use of the growing investment, researchers and aligned infrastructure need to make evidence-informed decisions about what works for recruitment to studies, what we know is of limited value, and what are the key issues that remain to be better understood and addressed.

Our starting point was to examine the existing literature concerning recruitment to adult social care studies in the UK as well as evidence on the (much larger) healthcare research sector. Next, we interviewed a sample of senior researchers in adult social care to expand the knowledge gained from the literature, and to find out their views on what works in research recruitment in the changing social care landscape. We describe the recruitment issues that researchers found challenging and present the strategies they suggested for mitigating them.

1.1 Literature review

We searched PubMed and PsychINFO for literature on recruitment to social care research. We included papers on recruitment in healthcare studies if they were relevant to adult social care, for example, studies reporting on relationships with gatekeepers or collaborations with partner organisations. We also conducted a Google Scholar search to find 'grey' literature such as reports and policy papers. No

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[1] www.nihr.ac.uk/explore-nihr/support/clinical-research-network.htm

geographical restriction was applied but only English language publications since 2000 were included.

Recruiting participants is a challenge in most studies (e.g. Newington and Metcalfe 2014, Walters et al. 2017), but these difficulties are heightened in adult social care research and apply to individuals (e.g. service users, carers, care staff), care settings (e.g. home care and care homes), private providers and LAs.

Recruiting specific groups of users, carers and professionals and developing recruitment strategies appropriate for the context of adult social care provision can be particularly challenging (McAveavey and Das 2013). For example, difficulties recruiting participants from diverse backgrounds have been reported in social work and population surveys (Rugkåsa and Canvin 2011).

Some groups have been consistently underrepresented in adult social care research, such as people from black, Asian and minority ethnic (BAME) communities (McLean and Campbell 2003). It has been shown that different recruitment strategies attract different categories of participants (Rugkåsa and Canvin 2011) and should be adapted to take account of the gender, ethnic and socioeconomic characteristics of the target groups (Renert et al. 2013, Amador et al. 2006). It has also been reported that study accessibility and recruiters' skills can have a greater impact on recruitment and retention rates than the characteristics or demographics of the target group (Feldman et al. 2008, Rugkåsa and Canvin 2011).

To ensure that participation is accessible to all population groups, recruitment methods need to be flexible, multi-faceted and, where necessary, targeted towards under-represented groups (Renert et al. 2013, Feldman et al. 2008). For example, social media may reach specific population groups better than traditional recruitment methods (Kurtzke et al. 2013). Also, research registers where volunteers can indicate their interest in research participation have been recommended as a recruitment tool. Registers have been shown to provide good infrastructure and reduce recruitment barriers, such as geographical distance, but their usefulness depends on their design and on-going maintenance (Krysinska et al. 2017).

Also, recruiters' experience and relationships with gatekeepers and potential participants have been shown to affect recruitment (e.g. Miller et al. 2003, Archibald and Munce 2015). Organisations' gatekeepers have been shown to often control access to a particular group, community or institution, and may either facilitate or inhibit recruitment (Miller et al. 2003, Namageyo-Funa et al. 2014). Gatekeepers can enhance researchers' credibility and some groups are more likely to participate when the study is accessed through trusted organisations (Miller et al. 2003, Brett et al. 2014).

Also, gatekeepers can influence individuals' decisions to participate. It has been suggested that developing collaborative relationships with partner organisations, especially their gatekeepers, may save research time and resources (McAveavey and Das 2013). Previous health studies proposed that partner organisations (such as providers) should be involved from a project's planning stages to understand their recruitment role and responsibilities (Miller et al. 2003), otherwise researchers must rely on staff availability and goodwill.

Some studies reported providing financial incentives to healthcare organisations in exchange for their participation, or establishing reciprocal relationships, such as offering advice or expertise in exchange for assistance (Rugkåsa and Canvin 2011). For example, some researchers have sought additional funding to cover recruitment costs by increasing capacity of home care staff (Miller et al. 2003). However, it may be difficult to quantify the staff time and resources required to support recruitment (Goodman et al. 2011).

Previous healthcare studies found that researchers have difficulties estimating the resources required for recruitment, as recruitment challenges and the strategies used to remedy those are often not reported (Rugkåsa and Canvin 2011, Archibald and Munce 2015). Consequently, researchers may underestimate the time and resources needed for their empirical work, while overestimating the willingness of participants or the ability of recruiters (Gul et al. 2010, Archibald and Munce 2015).

The aim of this review was to describe recruitment challenges in adult social care research and identify possible strategies to address them.

2. METHODS

2.1 Sample

A total of 23 senior adult social care researchers were identified as potential participants by their experience in the field (e.g. being principal investigators of medium- or large-scale studies) and by snowball sampling.

2.2 Interviews

A semi-structured interview schedule was developed, based on our literature review and consultation with experts in adult social care research. Interviewees were asked about recruitment of organisations, such as local authorities and private or voluntary service providers; care settings, such as residential or community care; and individuals, such as people who use social care services, carers, paid care staff and managers of organisations or care settings. Interviewees' experiences of recruitment planning, methodologies, measures, and user/carer involvement were also explored. They were asked about any strategies they had used or would recommend, to improve the number and representativeness of participants.

2.3 Ethical review

The review underwent ethics review in keeping with the London School of Economic and Political Science's Research Ethics Policy and Procedures.

2.4 Procedure

Potential participants were contacted by email and invited to participate in telephone interviews. If they agreed, an interview was arranged.

All interviewees provided consent by email. Electronic notes were taken during the interviews and, immediately afterwards, typed into a detailed record of each interview.

2.5 Analysis

Interview data were coded and categorised, and an initial analysis framework was developed by the interviewer (EC). Additional categories were created as new topics emerged. The data were analysed using the revised framework and any new topics were noted.

3. RESULTS

3.1 Participants

Of the 23 researchers contacted, 17 agreed to be interviewed after email contact. By the seventeenth interview, no new information was being generated and therefore no further interviews were pursued (Saunders et al. 2018).

The interviewees were employed by eight research institutions in England (16 were from seven universities and one from a social care improvement agency); eight were professors or equivalent grade (of those, four were directors of research units); 11 were women.

3.2 Clusters

The results are organised by the clusters of challenges raised by interviewees, along with their suggested strategies for overcoming them. Inevitably, some themes span more than one cluster. The clusters are as follows: recruitment of social care organisations; approaches to recruiting individuals; the influence of funding bodies; the impact of research governance and ethical review; and the role of the research community.

3.3 Recruitment of social care organisations

For the purposes of this review, adult social care organisations include LAs, as providers and/or commissioners of services; and private companies, voluntary sector providers or social enterprises contracted by LAs to provide services.

Challenges to recruitment to studies

- **Variation in social care provision, funding and governance** – Most interviewees noted that the shifting landscape of adult social care organisation and funding presented a challenge for researchers. Some pointed out that providers' funding was less secure than previously, and services were often undergoing a reorganisation or suffering high staff turnover. Consequently, it was difficult to develop constructive relationships with staff as potential gatekeepers or participants.

Fluctuations in the use of private and voluntary sector providers versus LA provision meant that researchers often had to adapt their projects and recruitment strategies while in progress, particularly for those projects covering longer periods.

> It is often hard to find out who we should be speaking to, the titles changes, churn is big in LAs. You thought you had someone and then they change.

- **Variation among social care providers** – Variation in LA processes and hierarchies made recruitment complicated. The widespread use of private providers meant wide variations in the ways that providers collect and manage data, so each participating organisation may require a bespoke approach to sampling and contacting potential participants.

- **Lack of dedicated research funding** – Nine interviewees said that most organisations did not have a budget or staff support to help recruit participants, and that they did not receive such funding from funding bodies of either services or research.

> [It would help] if there was this support cost - both the financial compensation and the acceptance that research is legitimate activity for them to be involved in.

- **Lack of capacity for research** – In some LAs, the teams who might collaborate in research may also be responsible for dealing with crises (for example, linked to failing private providers), and understandably they may not prioritise research when these crises arise. Small organisations were thought less likely to have the capacity to participate and the poorest services were seen as much less likely to engage in research. This can affect the representativeness of organisational samples.

> A lot of providers are having crises; there isn't enough supply in the market for the LA to say OK, collapse. The entire contract team ends up sucked into dealing with the providers. It can be managed in a big LA, but in small ones it is a disaster. It affects how representative our sample is. We may end up losing them anyway as they can't do it in the timescale.

Four interviewees pointed out that individuals may be willing but not able to help. For example, numbers of eligible service users may not be as high as envisaged, or they may not be able to gain the co-operation of others within their organisation.

In addition, private and charitable providers are not usually contractually obliged to participate in research. This is in contrast to health research, where organisations are more likely to have contractual requirements to support research, financial incentives to do so, and existing structures and policies to facilitate research participation.

Nine interviewees commented on differences between health research and adult social care research. For example, variations in the way adult social care support is organised and delivered were perceived to make recruitment more expensive than in some health care research.

> If you have a team in hospital, they are used to gaining access, they can do it well, but the model doesn't transfer that well to social care settings. In a hospital outpatient clinic, you can hang out as a researcher, but you can't do that in social care, you have go out to each person."

> There isn't a mechanism that would just run smoothly; you always have to push [in adult social care research].

There has been less investment in routine data collection in adult social care compared to the NHS, and researchers thought that available data in adult social care were poor quality in terms of facilitating recruitment, and for other analyses.

■ **Perceived lack of benefit for organisations** – Almost all interviewees thought that one key barrier to recruiting organisations was that both LAs and providers did not believe that they would benefit from participating in research. Interviewees felt that, often, research was not perceived as a legitimate use of time or a priority in LAs. Interviewees thought that successful recruitment often depended on individuals' willingness to help.

■ **Perceived risk to reputation or funding** – Six interviewees mentioned that organisations were reluctant to participate if they perceived a risk that the research would highlight poor standards. Both LAs and providers may, for example, have concerns about cost comparisons with other services, or not want to support research that could identify or promote cheaper ways of service delivery. LAs were perceived as often not motivated or wanting to share data with researchers due to concerns about reputation.

Strategies

■ **Research time allocation** – Ten interviewees recommended that researchers should allocate sufficient time in their plans to allow them to adjust and negotiate recruitment strategies, and to accommodate any changes in care provision during a research project. They also emphasised the need to include the time taken to:

- identify the sample/data source; identify access to the sample/the owners of the data;
- make contact with gatekeepers/individuals who control the data;
- build a relationship to gain their trust and provide them with the information they would need to feel confident to promote or recruit to the research/to supply the data;
- ensure compliance with the Data Protection Act 2018 (Great Britain 2018);
- deal with any queries about the way the data are collected; supply the collaborators with any reports/feedback that were offered as part of the agreement.

The interviewees' experiences suggested that these processes may take many months.

■ **Financial incentives for social care organisations** – Eight interviewees thought that financial incentives would be useful for engaging organisations, not only to reimburse their costs, but also to acknowledge their contribution. It was strongly suggested that payments should be offered to referrers (e.g. service providers), as is the case in NHS trusts, who get accruals for completed consents or interviews. However, one interviewee thought that current funding in adult social care research would not stretch to such incentives.

■ **Non-financial incentives** – Interviewees also suggested that researchers could encourage organisations to participate in research by ensuring that their research is relevant to care practice. Other suggestions included establishing reciprocal relationships, quick feedback during projects, and tangible outcomes at the end of projects, such as workshops or training. Ensuring that participation is not too onerous was seen as a deciding factor in organisations' participation.

■ **Contractual arrangements** – Two interviewees said that research would benefit if LAs' contracts with providers included a requirement that, under agreed conditions, they co-operate with research projects and facilitate research, e.g. by providing timely and accurate data for research purposes.

■ **Building relationships** – Most interviewees thought that every opportunity should be used to build relationships with all potentially useful contacts and organisations, as this could pave the way to successful collaborations later on. Working reciprocally with LAs was seen as a way of maintaining relationships.

> Face-to-face contact as much you can with the people who you need to do the recruitment or with gatekeepers. If you take the time to go out and see them, you increase that network, it shows that it is important to you, that can be a big change; it makes a difference.

> [You have] got to do it in advance, the more you can do, the more successful you are. You get buy-in at the early stage. The old way to scramble around for a partner, it is hit and miss.

■ **Flexibility** – Eight interviewees emphasised the importance of flexibility and creativity in recruitment as important strategies for managing uncertainty in adult social care research.

3.4 Recruitment of individuals to studies

Challenges

■ **Limited public engagement with social care research** – Several interviewees thought that the benefits of adult social care research were not obvious to most potential participants. In addition, some commented that some care users had research fatigue or were not keen to participate, especially if they had had a poor experience of care.

■ **Participant diversity** – Securing participant diversity and sample representativeness were noted as challenges. Interviewees thought that the majority of participants were middle class, white British, English-speaking, while very few were from BAME groups (unless they were the specific target group). Current recruitment strategies to include BAME participants were thought to be ineffective, resulting in skewed samples.

> We had information sheets in various languages, a phone line translating service, and still we didn't recruit anybody who was not English-speaking.

■ **Gatekeepers** – In general, having to rely on a third party for recruitment was seen as a study complication. Gatekeepers were experienced as generally hindering access to potential participants in adult social care studies, creating a recruitment bias.

> You can get gatekeeping in a residential setting, not having a direct contact: [People think] "they may not tell a good story about us."

Some care practitioners were reported as screening out potential participants. For example, people with dementia or learning disabilities might be excluded by gatekeepers.

> Recruiting practitioners screen people out, [they] give us people with good capacity, more recently referred, with less needs, even if we offer to check capacity on the day of the interview.

> The service manager at social services said, "I'm not sure I am happy that you are going out interviewing this person with dementia. You might upset them, they don't have capacity".

■ **Few structures for user/carer involvement** – Public involvement in research has been defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (INVOLVE 2019). Involvement of people with lived experience of social care needs or as a carer was seen by some respondents as less established in adult social care than in some health research, although that would not be a universal view. Eight interviewees said that user/carer involvement was too limited or tokenistic, often comprising only reading materials or attending a meeting.

> We try hard to [include service users] in the beginning, but some of it happens too late. Depending on funding, they make you do more of that. [Universities] don't always make people [involve service users], they are keen to get started.

However, it should be noted that interviewing a different group of respondents might have resulted in a different experience of involvement in research, as some researchers ensure extensive and meaningful involvement in their studies.

■ **Recruitment networks and research registers** – Eight interviewees mentioned recruitment networks and research registers of people interested in participating in social care research, but they expressed concerns about biases in the group of people who sign up. It was advised by interviewees that registers should be used alongside other recruitment methods.

Mixed experiences were reported with the Join Dementia Research (JDR[2]) register; some found it helpful, others did not recruit the desired participants.

> I used JDR. I think it is a fantastic idea, but the quality depends on the currency of the information it holds.

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[2] www.joindementiaresearch.nihr.ac.uk/

Only two researchers expressed views about the Enabling Research In Care Homes (ENRICH[3]) network, which is designed to link researchers with care homes that are said to be ready to host research. They did not find the network helpful, as some of ENRICH's care homes were not prepared to participate in research.

Similarly, only four interviewees discussed the CRN, which was said to be "not working in some places", "not understanding non-NHS research" or "getting in the way". One interviewee thought that CRNs were helping. As noted above, the CRN is a diverse 'network of local networks' and has only recently started supporting adult social care research, whilst some of these comments from researchers reflected experience from a longer period.

Strategies

■ **Raising public understanding of social care research** – Interviewees suggested that raising awareness of the benefits of adult social care research and publicising its potential impact could attract participants. Learning about the motivations of individuals and organisations to participate could help to overcome some barriers to participation.

■ **Using various strategies to reach potential participants** – Researchers stressed the importance of using a range of recruitment strategies and offering different ways to participate. For example, using social media to avoid pre-selection by gatekeepers was recommended where appropriate and subject to appropriate ethical approval.

> A family member told us to advertise on social media, because [the organisation through which they received care] might cherry-pick who they told about the research.

In addition to face-to-face contact, conducting research via telephone, text messaging or Skype were seen as important for broadening participation.

■ **Financial compensation for participants** – Offering payments to individuals as compensation for their time, cost and travel was felt to be essential for recruitment of representative samples. Payments to organisations to incentivise them to release staff for research participation were also suggested, or payments directly to staff so that they could participate outside of working hours.

■ **Inclusion of user/carer organisations** – Including user/carer organisations as active collaborators or research leads was thought to be one way of improving recruitment. Two interviewees said that the inclusion of user organisations gave them credibility with the target group. However, it also involved passing some of the control over the project to the organisation, and some researchers found this difficult.

> Working with user organisations can help. In one case, we recruited via their Facebook page, although I wasn't allowed to join the Facebook group. The group gauged interest, then people were sent my email address, or their contact details were passed on to me. It was a very effective way. Some people said they were more likely to take part [because the first approach was from the user group].

Interviewees thought that involving users, carers and practitioners in projects from the early planning stages helped with recruitment.

> I have contacts in a few ADASS [Association of Directors of Adult Social Services] regional groups. I can attend their meetings. They will send out information to people for you. I found them useful for recruitment.

Two interviewees thought that users' and carers' capacity for involvement needed to be developed, and that more options for people to influence adult social care research should be on offer.

> [Researchers should] have users or carers leading research. There may be difficulties about where funders allow money to be held, but [we should] find ways of a far more influential role [for users and carers], for example, setting research questions, controlling the study more.

■ **Improving research registers** – Research registers were perceived as potentially very helpful, especially for accessing some groups (e.g. self-funders). However, it was emphasised that they needed continuous development.

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[3] https://enrich.nihr.ac.uk/

- **Advanced consent** – Three interviewees proposed securing advanced consent from potential participants, making future recruitment easier. Researchers could ask participants in current projects if they would consent to being contacted about future research.

One interviewee suggested that everyone entering the (state-funded) care system could be asked about the use of their data for research; this would increase data availability and access to participants.

> Currently, if people sign up to one study, they cannot [automatically] be approached for another. It is a GDPR [General Data Protection Regulation] problem, I don't think service users have a problem with that, to be approached again.

- **Collaborations with health organisations** – Three interviewees recommended collaboration with NHS trusts, as some have lists of participants from previous studies who had consented to be contacted about future research.

Populations harder to engage in research

Interviewees found it particularly difficult to recruit participants from some populations. The challenges and suggested strategies for overcoming barriers to recruitment vary according to the population group (Table 1).

It was thought some groups will remain challenging to recruit, for example, people with what were described as 'chaotic' lives, people with dementia who have no carers, or people unknown to adult social care. No specific strategies were suggested for improving recruitment of people in these groups.

Table 1. Specific groups reported as difficult to recruit

Population group	Challenges and barriers	Strategies and mitigating actions
Service user groups		
People who may lack mental capacity	Mental capacity issues may impact on their ability to provide informed consent. Gatekeepers may be concerned about the wellbeing of participants.	Adjust the consent process to facilitate those with capacity issues to provide informed consent. Provide easy-read materials. Use proxy consenters. Build rapport and trust with gatekeepers; demonstrate training in seeking informed consent from people with capacity issues.
Residents in care homes	Residents can be frail and often have dementia or are physically unwell.	
Personal budgets/Direct payments (PB/DP) recipients	LA lists may not be accurate; some PB/DP recipients do not use social care services, so cannot be recruited via those.	Recruit through local organisations (i.e. services for people with PB/DP or home care agencies) and community groups.
Self-funders	There are no central registers or lists of people who privately fund their own social care.	
Unpaid carer groups		
Family carers, dementia carers	Carers are often struggling and exhausted, although they are keen to give their views.	Offer flexible times, including evenings and weekends, and a variety of methods, such as telephone, text messaging and email. Offer incentives and provide substitute care (or childcare) during participation.
Young carers	Young carers often have multiple issues to manage which can change frequently.	

Table 1. Specific groups reported as difficult to recruit (continued)

Population group	Challenges and barriers	Strategies and mitigating actions
Social care professionals		
Formal paid carers	Paid carers' time is largely directed by their employers. They may have concerns about their work being criticised.	Offer flexible times and a variety of methods, such as telephone, text messaging and email. Offer incentives. Build rapport and trust with gatekeepers. Find ways of making staff comfortable to speak openly.
Care home workers	Care home workers may be too busy. Their responses are influenced by concerns about their employers' approval.	
Home care workers	They are not accessible at their place of work (they have just offices).	Offer flexible times and a variety of methods, such as telephone, text messaging and email. Offer incentives. Recruit through their employers (i.e. home care agencies or the disabled people they care for).
Personal assistants (PAs) for disabled people who work	There is no professional organisation for PAs and they are individually employed by their clients.	
LA workers, social workers	Willingness to participate depends on how busy they are and whether they consider research important.	Raise awareness of research benefit. Offer incentives. Offer flexible times and a variety of methods, such as telephone, text messaging and email.

3.5 Research funding bodies

Challenges

- **Focus on research impact** – Some interviewees expressed frustration about what they saw as research funders' unrealistically high expectations of what researchers could do in terms of recruitment with limited resources and capacity. One felt that there was too much focus on research impact, which may not always be possible to demonstrate, although the same person thought there was a reason to be positive about the landscape of funding for adult social care research.

> [social care researchers] like to go on about how bad it is, but we have never had it so good.

- **Lack of long-term planning** – Many researchers in adult social care have fixed-term contracts focused on current projects and therefore cannot dedicate sufficient time to planning and preparing future projects.

- **Contrast with health research** – One interviewee highlighted the contrast between adult social care and some healthcare, and thought that research funding bodies should take account of the extra challenges in the former.

> It works in [NHS] hospitals as they are drawing money, but not in social care. It's more complicated [in social care] than in health; it's not as clear-cut to reward organisations for helping recruit for a study. NIHR need to think about that, not just take the model from health.

Strategies

- **Increasing research capacity** – Some interviewees thought that funders could stimulate social care research by focussing on increasing capacity, for example, by funding more PhDs or incentivising professional groups to be involved in research.

- **Understand need for recruitment time** – Interviewees suggested that funders should recognise the need to allocate sufficient funding and time for recruitment of research partners and participants.

> My message to funders is: in some studies, researchers are asked to cut the preparation time, but they take longer than you expect. [Funders] need to accept it and allow if researchers need longer time, not to ask to cut it.

- **Funding for organisations** – Support and funding for user/carer groups or organisations and providers to undertake research would facilitate user and carer involvement and reach places researchers find difficult to access or seldom-heard groups.

> [Funding bodies should] financially support places, compensate places for helping to identify people, approaching people. Until LAs receive funding that is on the par with the NHS research, we will always try to do research with one hand tied.

- **Financial incentives for individuals** – It was suggested that individuals should be offered compensation for participation.

3.6 Research governance and ethics

Challenges

Several interviewees mentioned difficulties with research governance and ethics, potentially contributing to recruitment delays.

- **Delays in securing approvals** – Approvals from the Association of Directors of Adult Social Services (ADASS) were perceived as taking too long and the variation among LAs in research approval times hindered recruitment progress. The national, Health Research Authority Research Ethics Committee approval process was also perceived as inefficient by four interviewees.

- **Burdens imposed by ethical review** – Seven interviewees perceived ethical review processes to be putting excessive burdens on researchers, or promoting gatekeepers' restrictions on access to participants, thereby making recruitment more difficult.

> Ethics can make it difficult as well. They insist on gatekeepers that can make or break the study. If they insist, you have to go through someone who is not on board [with the research].

- **Unclear review policies** – Some interviewees mentioned occasions when organisations were afraid to make decisions and did not have guidance about who could provide assurance on correct procedures for sharing data.

> There are huge difficulties recruiting in care homes: they are subject to a lot of scrutiny through regulation. Managers don't feel empowered to make that decision and didn't know how to find out.

In addition, concerns about data protection made LAs excessively risk-averse about approaching potential participants.

Strategies

- **Time allocation for approvals** – Allowing sufficient time for ethical approvals was suggested, as was increasing research funders' awareness of time needed for approvals and of the difficulties of keeping to timescales (e.g. when dealing with organisations).

3.7 Research community

Challenges

- **Planning and preparation** – Some researchers were aware of their own shortcomings regarding planning recruitment.

> It always takes longer. It's time-consuming. I never had a project finish on time.

Eight interviewees thought they seldom allocated sufficient time for recruitment and consent. For example, more time is needed for consent with people with learning disabilities than with most other groups.

> None of it is easy. It is always more difficult and time consuming than one thinks.

One interviewee said researchers should take more personal responsibility for recruitment.

> If someone comes to me [with worries about recruitment], I say: Do your homework and work hard to make it as positive an experience for people as possible.

- **Study design** – Recruitment for experimental design studies was thought to be particularly difficult. Randomisation was thought to be exceptionally challenging in adult social care research because the methodology was often not sufficiently clear to potential participants. For example, it needs to be explained that participants might not directly benefit (or lose out) from taking part in research.

Some common methods of reaching individuals were criticised, such as using posters or newsletters and expecting potential participants to get in contact with researchers, as these approaches do not engage many potential research participants.

> There are things we know don’t work and we still do them.

Also, two interviewees thought that adult social care researchers have little experience of collecting primary data on a large scale, and, hence, of the recruitment issues involved.

- **Testing and validating research tools** – Three interviewees mentioned that some measurement tools, which can have an impact on recruitment and retention to studies, were often not suitable for some settings and that questionnaires were often too long or difficult to complete. Four interviewees said that pilot tests using measurement tools were often absent, insufficient or were carried out with a different group than the group being researched.

> Time gets in the way [of running pilot studies].

> You need to test [questionnaires] with actual respondents to spot problems.

> We’ve got to go to the people who will be concerned. In health research we would expect that.

- **Sharing knowledge** – It was also noted that exchange of knowledge about recruitment strategies among researchers was limited.

> Even in a small research unit, you don’t always hear what worked.

Strategies

- **Realistic research timetables** – Adequate time allocation to all stages of projects, allowing for flexibility and frequent contact with potential participants (e.g. organisations), was seen as crucial. One interviewee said they found it useful to pretend that their recruitment target was 20% higher.

> I have over-recruited effectively, by being really cautious, doing loads of work upfront. All was ok.

- **Building effective relationships** – Interviewees felt that building trusting relationships and partnerships with services and involving user/carer groups and practitioners in research would advance recruitment.

> I don’t think recruitment is a problem. It’s all about relationships.

> You can’t underestimate the importance of staying engaged with the service.

Three interviewees thought researchers should be more willing to share control and leadership of research with user/carer organisations.

> Researchers need to improve their skills for appropriately involving users, carers and practitioners in research and improve involvement, for example by user-led research or coproduced research.

Two interviewees had recruited peer-researchers and provided them with training and support to conduct interviews; both thought that having peer-researchers on their team improved recruitment.

- **Methodological expertise** – Researchers could improve their methodological rigour, which can impact on recruitment success and data availability. For example, by ensuring questionnaires are in an accessible format, potential participants are not discouraged by difficult materials. Another example could be securing advanced consent from service users, so that existing data could be utilised as much as possible, including health care data, which may help to answer some questions in care research, especially for people not known to services in that sector but who may use health services.

- **Sharing knowledge** – Sharing ideas and supporting relationships among researchers and practitioners were thought to be important, and could be supported, e.g. by NIHR SSCR.

4. DISCUSSION

Almost all interviewees had experienced difficulties in recruitment for adult social care research studies, and some described ways they had used to mitigate them. Our findings are consistent with healthcare studies that conclude that recruitment often takes longer and is more expensive than anticipated (e.g. Miller et al. 2003). Adult social care researchers have to deal with additional challenges, such as variations and frequent changes in the organisation and patterns of provision.

The senior researchers in this sample reported that because adult social care organisations lack their own infrastructure or external research support, research engagement was not a priority for them, so it was often difficult to secure their participation. As shown in healthcare research, providers may either facilitate or inhibit recruitment as they often control access to potential participants (Miller et al. 2003, Namageyo-Funa et al. 2014).

Face-to-face contact with organisational leaders and gatekeepers was recommended, consistent with the literature showing that 'less personal' recruitment methods such as newsletters or posters were usually less effective, especially in multi-cultural contexts (Eide and Allen 2005). Interviewees reported benefits of building relationships with gatekeeper organisations as partners, consistent with previous reports of positive recruitment outcomes from collaborative relationships with organisations in healthcare (Miller et al. 2003, Namageyo-Funa et al. 2014). However, long-term research plans, including investment, would be needed to support the development of lasting relationships with organisations.

Some of the issues concerning a better infrastructure to support adult social care research are the subject of action by the NIHR, notably CRN support. Very few respondents commented on the impact of the CRN in providing support for recruitment to adult social care research, but interviews were conducted in what were early days (formally speaking) in developing working relationships between adult social care researchers, providers, LAs and the CRN. Other aspects of the research support infrastructure remain to be developed, such as capacity in LAs and providers; contractual requirements; and financial incentives.

Interviewees reported persistent sample biases in adult social care research. One difficulty was that care practitioners, who are often gatekeepers, may not be fully cooperative in recruitment processes, and, for example, screen out potentially eligible participants who they judge to be 'unsuitable'. One researcher bypassed this selection bias by using social media, thus reaching a larger and more diverse population than when they tried to recruit via a care provider; however, this may also be problematic in terms of recruitment bias. Recently, social media have been promoted as efficient and cost-effective recruitment tools, although they have other limitations (Kurtzke et al. 2013, Arigo et al. 2018). Additionally, research registers such as JDR can facilitate effective recruitment and reduce recruitment barriers (Krysinska et al. 2017). This highlights the need for flexibility and the use of various recruitment pathways and methods and for care in planning recruitment strategies.

Recruiting specific groups of users, carers and professionals may present particular challenges.

For example, people from BAME groups have been under-represented in adult social care research and may require targeted recruitment methods; people with dementia and fluctuating levels of capacity need adjustment to the consent process; or groups with no clear access route, such as self-funders or personal assistants for working disabled people, require flexible and creative recruitment strategies. However, some interviewees demonstrated successful recruitment outcomes. There seems to be a need here, as in other aspects of recruitment to adult social care studies, to build a better evidence base to guide practice in future studies.

Some interviewees said that user/carer inclusion in research as active collaborators had led to increased participation and access to participants, including seldom-heard groups, as reported elsewhere (Staley 2009, Brett et al. 2014). They said that user/carer groups or organisations promoting their research added credibility to their projects and their participants confirmed that they were more likely to engage than if the research was promoted by a university. This result confirms previous reports of recruitment benefits when studies were accessed through trusted community agencies (Miller et al. 2003, Brett et al. 2014).

The comments about greater involvement of service users and carers in studies reflect continuing discussion about approaches to co-production of research in adult social care (e.g. Allen et al. 2019) and user-led research (Beresford and Croft 2012). It is an area that requires further empirical investigation as to its impact on research and improving research practice. We should also add the importance of involving practitioners in adult social care research, given the lack of a comparable group of professionals to the clinical academics in healthcare whose roles straddle the research and the practice worlds.

Interviewees thought that researchers should improve planning and preparation of recruitment, including setting realistic targets for time and resources needed, as suggested in health research (Gul et al. 2010, Archibald and Munce 2015). Interviewees suggested that funders should allow sufficient time and resources for recruitment and provide financial incentives and practical support for providers and user/carer organisations. Financial incentives for organisations have been shown to improve recruitment in health research (Miller et al. 2003, Rugkåsa and Canvin 2011).

Recruitment for some study designs was identified as particularly difficult. This is consistent with previous studies reporting recruitment for randomised trials in health research as challenging, as participants' preferences for particular interventions can play a role in recruitment (Miller et al. 2003, Walters et al. 2017). Better understanding amongst all stakeholders in adult social care research about randomised trials and different approaches to them may help improve recruitment to studies (Woods and Russell 2014).

Furthermore, interviewees suggested building research capacity, a need which has been recognised previously (Manthorpe and Moriarty 2016). As noted above, this is another area that has become the focus of improvement, namely work by the NIHR through its SSCR and Academy to develop support for more research capacity in adult social care. It is hoped that learning from this work can quickly cascade into more rapid and widespread research capacity development in the sector. Various comments about the arrangements for ethics and research governance were made by interviewees. Of course, these fall under the UK policy framework for health and social care research (Health Research Authority 2017) and here we only have the views of the researchers. However, this might be an area for closer scrutiny to see what changes might be made to help with recruitment to adult social care research.

5. LIMITATIONS

The main limitation of this review is that the individuals who participated may not be representative of the wider adult social care research field. We have to bear that in mind when interpreting the results of the interviews.

Also, it should be noted that the views presented here have not been triangulated with those of other stakeholders, such as provider organisations, and this could be helpful to do in future.

6. CONCLUSIONS

Interviewees were eager to share their experiences of recruitment challenges in adult social care research and to find strategies to overcome them. They were keen to see the existing knowledge drawn together, and to share successful approaches and build upon them. Strengthening the capabilities of the adult social care research community, influencing funding bodies and increasing public engagement were seen as opportunities for significant developments in adult social care research in the near future.

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