

Collecting self-report research data with people with dementia within care home clinical trials: Benefits, challenges, and best practice.

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### **Abstract**

One-third of people with dementia live in care home settings and in order to deliver better evidence-based care, robust research including clinical trials is required. Concerns have been raised by researchers about the capacity of care home residents with dementia to participate in clinical trials. This includes self-report measures, completion of which researchers have suggested may be unreliable or impossible and may cause distress for residents. Many trials, therefore, utilise only proxy completed outcome measures. This is despite evidence that individuals with mild through to advanced dementia can reliably report on outcomes, if appropriate measures and approaches to data collection are used. However, little has been written about best practice in data collection with this group. This study aimed to explore the experiences of researchers working on dementia trials in care homes and identify best practices to assist design of future trials. Thirty-three researchers completed an online, qualitative questionnaire outlining their experiences and the perceived benefits and challenges of data collection with people with dementia. We identified five main benefits; [1] improving the delivery of person-centred care, [2] hearing the voice of people with dementia, [3] residents spending time with researchers, [4] improving researcher understanding, and [5] having an evidence base from multiple sources. We also identified five main challenges; [1] effective communication, [2] fluctuating capacity, [3] causing distress to residents, [4] time pressures, and [5] staff availability. Researchers also made suggestions about how these can be overcome. We recommend that the challenges identified could be overcome using appropriate methods for collecting data. Thorough training for researchers on data collection with people with dementia was identified as important for ensuring successful data collection.

## **Collecting self-report research data with people with dementia living in care homes: benefits, challenges and best practices**

Globally over 46 million people are estimated to live with dementia; around 7% of the population over 60 years old (Prince et al., 2015). As dementia progresses, family members may be unable to support an individual's needs and care may be provided in a long-term care setting. At least 70% of care homes residents in the UK (Alzheimer's Society, 2014) and over 50% of nursing home residents in the USA have dementia (Harris-Kojetin et al., 2016). Providing high quality care for people living with dementia is complex (Dyer et al., 2018) and the poor quality of care currently being provided in care homes has been raised as a concern (e.g. Cadigan et al, 2012; Pot et al., 2013). For example, differences in quality of care have been found between nursing homes with and without specific units designed to provide care for people with dementia (Joyce et al., 2018). In the UK, the Government has established a programme of work to improve dementia awareness, care quality and increase research on dementia (Department of Health 2009, 2012, 2015). This has led to increased interest in research to improve the quality of dementia care in care homes including a growth in care home based clinical trials of psychosocial interventions, drug efficacy and studies focused on practice development initiatives. However, care homes represent a unique and often challenging environment in which to conduct research (Hall et al., 2009), and successful completion of randomized controlled trials (RCTs) requires careful consideration of the care home context when they are being designed (Luff et al., 2011). Collecting data from and about care home residents, and more specifically those with dementia for example, can present many complications and concerns for researchers (Murfield et al., 2011). Cognitive decline compounded by sensory impairments, physical comorbidities and communication difficulties and their impact on a resident's ability to consent and complete

outcome measures have previously caused researchers to question the validity of including people with dementia in research (Murphy et al., 2015), specifically when completing self-report measures (Brod et al., 1999).

Consequently, much RCT data collected about people with dementia in care homes is gathered from staff member(s) or family caregiver proxies, to mitigate some of these issues. However, the importance of including the direct perspective of people with dementia in research is increasingly recognised (Brooks et al., 2017). Additionally, the International Ethical Guidelines for Health-related Research Involving Humans (CIOMS and WHO 2016) stress the need to include adults who are not capable of giving informed consent in health related research. Despite this, people living with dementia or those without capacity to consent are often excluded from participating in research, particularly within clinical trials. However, not only can participating in research empower people living with dementia, allowing them to discuss their current and future needs and preferences (Reamy et al., 2011), generally people living with mild through to severe dementia are able to reliably rate their own quality of life (Hoe et al., 2005). People living with dementia have a unique perspective on their experiences, which cannot be captured by using only proxy responses. For example on quality of life measures, have been found to differ from those gained through self-report (e.g. Moyle et al., 2012; Orgeta et al., 2015). Furthermore, concerns have been raised that Alzheimer's disease clinical trials do not use any patient reported outcomes, meaning that they do not capture the needs and perspective of individuals (Saunders et al., 2018). Therefore, while there may be some care home residents with dementia who would be unable to complete self-report measures, evidence suggests that many are able and this is worthwhile.

Researchers therefore, need to consider optimal approaches to collecting self-report data from care home residents with dementia when designing clinical trials. However, there is

little information on best practice in this area. The aim of this study, therefore, was to explore the experiences of researchers who had collected self-report data from people with dementia in care home clinical trials to identify the benefits and challenges and provide best practice examples to inform the design and conduct of future clinical trials.

## Methods

### *Sample*

A cross-sectional survey was completed by researchers who were currently or had previously worked on one of the three UK care home RCTs with people with dementia (see Table 1 for demographic variables). Two trials were cluster RCTs investigating effectiveness of psychosocial interventions and one was a drug trial [references removed for peer review].

### *Procedure*

A total of 41 researchers were approached by e-mail, to complete an online qualitative questionnaire, via the institution who had employed them on the RCT. This asked participants about their experiences of collecting data with people with dementia, including questions around what they perceived to be beneficial and challenging about collecting data with this population.

### *Data analysis*

Anonymised survey data were downloaded (separately to demographic variables). The data were analysed using thematic analysis (Braun & Clarke, 2014). An inductive approach was taken, meaning that the research team did not enter into data analysis with preconceived theoretical frameworks, but identified themes from participants' responses. Analysis was carried out by two of the authors (DP and AG). A series of codes were used to assign a

conceptual label to sections of the transcripts and verbatim quotes were used to illustrate each code. To ensure a robust approach to theme identification, questionnaire responses were first analysed independently by DP and AG, before themes and coding were compared. The themes and sub-themes identified by each author were discussed and synthesised into an overall thematic framework. To minimise bias and ensure credibility of findings, where disagreements existed over thematic categorisation of a response, the wider research team discussed this until a consensus was reached.

### **Ethical considerations**

The Humanities, Social and Health Sciences Research Ethics Panel at [name of host institution] approved the study. Informed consent was obtained from all participants.

### **Results**

Thirty-three questionnaire responses (response rate = 80%) were received. Of these, 31 researchers had been involved in collecting data from individuals with dementia on between 1 and 4 clinical trials, for an average of 21.45 months, and were included in the analysis. Two participants were excluded as they had not collected data from people living with dementia.

Participants had been employed on one or more of five different dementia studies/RCTs. All RCTs involved direct participation of individuals' with dementia, either through observation, standardised self-report measures or medical tests.

Two overarching themes of benefits and challenges were identified with a number of sub-themes.

1. The benefits of collecting data from people with dementia:

Five themes were extracted related to the benefits of collecting data; improving the delivery of person-centred care, hearing the voice of people with dementia, residents spending time with researchers, improving researcher understanding, and having an evidence base from multiple sources.

Respondents described how collecting data from people with dementia modelled the use of person-centred care in care homes:

*“Furthering knowledge, care and treatment for those living within a care setting to provide gold standard care based on evidence” (Participant 2)*

Speaking to the residents living with dementia in care homes demonstrated that the person-centred approach being investigated in the RCT, was practised within the research.

*“To take a person centred approach in research you have to include people with dementia and their perspective.” (Participant 5)*

As well as the consideration of person-centred care, the majority of the respondents identified that collecting data with people with dementia allowed their voice to be heard and listened to in the research. This was seen as a rich source of information, which was ignored if relying solely on proxy informants:

*“I don't think it is possible to truly improve the quality of the lives of people living with dementia and people living in care homes without listening to the voices of the people living in those circumstances.” (Participant 8)*

They were also seen as providing a source of understanding about the research as well as supporting generation of new research ideas during data collection.

*“Gives residents an opportunity to have their say and be heard in the research community - could generate new areas of research which researchers wouldn't otherwise have thought about.” (Participant 28)*

In addition to this, the potential direct benefit to the well-being of the person with dementia due to the researcher spending time with them was highlighted.

*“Residents benefited from spending time with a researcher, it was 1:1 time and friendly and often resulted in chatting about other things than just the research.” (Participant 17)*

As residents often do not have the opportunity to meet new people, researchers provided social interaction opportunities. This suggests reciprocal benefits of collecting self-report data.

*“I think the residents enjoyed speaking to new people, feeling helpful, and the social interaction (in terms of collecting outcome measures data)” (Participant 24)*

There was also a positive effect on researchers, improving their understanding and knowledge around the impact of interventions for people living with dementia and increasing their understanding of how taking part in the research was affecting people in real terms.

*“The benefit to working with residents in care homes in research therefore is that we can understand the way that interventions impact on residents' wellbeing and why.” (Participant 8)*

A final benefit identified by respondents was that collecting data from people with dementia allowed the research to draw data from multiple sources, to permit comparisons to be assessed in the results.



*“Provides a first person point of view from someone living with dementia that can be used to compare with carer/family views.” (Participant 25)*

The unique perspective of people living with dementia was acknowledged, particularly when this was supported by information from various sources.

*“This enables residents to be involved and give their views. Residents are the individuals with experience of dementia.” (Participant 13)*

In summary, these themes reflected the range of benefits that researchers felt can arise from collecting data from people with dementia in care home clinical trials. These included potentially positive benefits for the participants in spending time with the researcher and ensuring the voice of the person with dementia is included in the research.

## 2. The challenges of collecting data from people with dementia:

Five themes were identified related to the challenges of collecting data; effective communication, fluctuating capacity, causing distress to residents, time pressures, and staff availability.

Researchers identified that people with dementia may have difficulties communicating and responding to questions due to sensory difficulties.

*“The main challenge for me was not being heard by residents and having to speak very loudly.” (Participant 5)*

The use of pictorial or print text aids could overcome these challenges, allowing data to be collected from individuals who struggled with verbal communication and sensory difficulties.

However, such aids were not available for all standardised measures and thus this degree of flexibility of administration was not always possible:

*“The challenges can be overcome by using cue cards to help a resident select an answer and overcome the sensory difficulties.” (Participant 13)*

The physical impairments residents experienced sometimes meant measure administration had to be conducted in ways that contradicted the training that researchers received, for example ensuring that a private space was available for conducting interviews.

*“Mobility difficulties can mean they don't want to move somewhere more confidential.” (Participant 6)*

This identified not only how sensory and physical impairments affected residents' ability to participate, but also impacted whether data could be collected in a confidential manner.

In addition to physical limitations, a resident's degree of dementia may impact their ability to comprehend the questions being asked when completing measures. This was raised as a common challenge among respondents, with researchers often questioning whether the person understood what they were being asked:

*“Residents with dementia in later stages may not be able to understand research questions or articulate/communicate their responses to researchers which will always be a challenge” (Participant 28)*

Given RCTs require use of standardised measures, there is often limited opportunity for researchers to adapt measures and questions within them, or use flexibility in how they are administered to meet individual resident needs. Likewise, assessing whether someone with dementia has the cognitive ability to comprehend and respond to the questions within a

standard measure is rarely straightforward as capacity may fluctuate.

*“Changes in capacity that can happen quickly.” (Participant 15)*

Researchers identified that care home staff may not be a reliable source of information to support their decision-making on this.

*“At times I have encountered staff who perhaps don't believe that residents are capable of contributing to research when they may actually have capacity, and be more than willing to participate.” (Participant 5)*

A further issue identified by researchers was that they felt the content of some measures (which may not be designed specifically for care home residents) or standardised processes for their completion sometimes caused distress for the person that they were collecting data from.

*“They could become distressed if they felt like they weren't doing it 'right' or giving the right answers.” (Participant 17)*

Researchers felt a responsibility for the well-being of participants, taking time to confirm that the research did not have a negative impact on them.

*“Judging the emotion of residents and the ensuring no negative impact from your interaction.” (Participant 10)*

*“Researchers need to be skilled to identify when a resident isn't able to reliably contribute to the research (and stop data collection) and ensure they feel comfortable and happy before the researcher leaves.” (Participant 17)*

Responding appropriately to these issues increased the amount of time that it took for researchers to gather data. Making assessments of capacity, determining informed consent

and completing the measures in a supportive manner at a time when the resident was able and willing to do so, all took a substantial amount of time, which was a challenge, particularly within the strict confines of time allocated for RCT data collection.

*“If a resident is having a particularly bad day and an interview would not be appropriate. Then the interview is put on hold, this causes challenges to the timescale.” (Participant 3)*

Patience, flexibility and the need for understanding of the complexities of collecting data with people with dementia in care homes, were identified as important qualities for researchers to have.

*“The key is to be patient and things will get done despite taking slightly more time. It is just the nature of care home research.” (Participant 3)*

Respondents highlighted the benefits of taking a flexible approach by making several attempts to complete measures. This might require the researcher to collect some data and then go back to collect the rest, or to try on one day but then re-try again at another time.

*“If residents do not wish to communicate, the conversation can be tried on another day.” (Participant 1)*

Furthermore, by building relationships with residents, researchers were able to identify the most appropriate times for completing data collection.

*“Taking your time with the resident and making sure that you have identified a time of day that perhaps the resident is most alert to do the measures” (Participant 16)*

Difficulties lay in finding the balance between completing measures efficiently, whilst being interested in having a more broad conversation with participants.

*“Trying to complete measures with residents without seeming disinterested in other things they have to tell you about or without cutting people off if they go off track.” (Participant 19)*

Finally, this time taken to collect data from people with dementia was further increased by the lack of care home staff time to support researchers. Care home staff members were often useful in determining which residents with dementia were more likely to be able to answer the questions and to introduce researchers to them as well as providing advice on the best way to approach the resident to avoid causing distress. Although, as outlined earlier, staff sometimes undervalued the participation of residents with dementia.

*“Checking with staff when the best time of day is and if the resident is ok on the day.”  
(Participant 6)*

To help staff better support decisions about capacity and communication approaches, it was suggested that training for them on using person-centred, inclusive research processes might be helpful when commencing a study.

*“Educating [staff] on importance and benefits of research, best care and practice when cared for people with dementia, educating about what living well with dementia may mean for the people with dementia.” (Participant 7)*

In summary, researchers face a range of challenges collecting data with people with dementia in care home trials, reflecting the difficulty of working with such a complex and potentially fluctuating condition.

## Discussion

The current study aimed to understand the benefits and challenges researchers perceive when collecting self-report data from people living with dementia and to provide insight into strategies that might be employed to do this effectively in future research.

A key message was the importance of collecting self-report data from people with dementia, despite the challenges this posed. Encouraging people with dementia to express their views allowed the voice of an often-marginalised group to be heard in research. Taking a relational approach that supports full inclusion of people with dementia demonstrates a person-centred approach to trials research and may reduce stigma associated with dementia (Kontos et al., 2018). While concerns about the lack of capacity of care home residents living with dementia to consent and reliably complete outcome measures often means they are excluded from research (Ries et al., 2017), researchers in this study asserted the important alternative perspective self-report measures gave. Including self-report measures where possible in RCTs, in addition to proxy-report measures is therefore recommended. As staff may not be aware of the individual abilities of residents in different contexts, such as the ability to report on their wellbeing and answer simple questions, they may be a distinct barrier to the individual having their voice heard within the research. As staff are often relied upon to inform the decision making on who may be able to participate, it may lead to a lack of inclusion of residents who are able to contribute. This means that a valuable voice may not be heard by the researcher and the residents' opinions are not seen as worthwhile.

Challenges around cognitive decline and ability of the residents to complete the measures were still highlighted. In some cases, the validity of the responses provided by some residents was called into question, whilst other residents were unable to complete measures at all. The challenges of day to day fluctuations in the capacity of individuals with dementia are known (e.g. Trachsel et al., 2015) and created difficulties in supporting completion of measures in the present study. This required flexibility from the researchers, as has been advocated by authors discussing qualitative research approaches (Murphy et al., 2014).

Collecting data from residents with dementia was perceived to have direct benefits to their wellbeing. Residents appeared to enjoy the opportunity for social interaction with the

researcher. This, if done well, was viewed as being beneficial, rather than a potentially distressing activity. While researchers identified that the content of measures or administration requirements could potentially be distressing, they also reported that building relationships with people with dementia negated some of these challenges, for example, residents feeling they were being tested or being suspicious about being asked questions. However, in line with existing evidence, questions within some measures have the potential to cause distress or emotional reactions for people with dementia (Brooks et al., 2017). This includes questions about aspects of quality of life, physical health problems or relationships. Cognitive measures can also be distressing for people to undertake as they highlight impairments. A range of researcher skills that could potentially mitigate distress such as flexibility, patience, good communication skills, and empathy, were identified. Taking time to build trust and relationships with participants with dementia in research studies has been highlighted as essential for effective communication (Stanyon et al., 2016).

However, the need for extended time to collect data from people with dementia is challenging, as the priorities and routines of the care home, such as avoiding meal times and activities, must also be accommodated (Brooks et al., 2017). This highlights the importance of building relationships with care homes, to streamline data collection processes (Murfield et al., 2011). When designing RCTs researchers must consider time required for data collection with people with dementia and allow researchers to manage this flexibly.

#### Overcoming identified challenges

Therefore, despite the identified challenges, this study indicates it is possible within RCTs to support people with dementia to contribute meaningful self-report data, providing the necessary timeframes, measures and researcher skills are considered at the study design stage. As the opportunity to participate in research should be offered to those both with and without

capacity to provide consent, with appropriate safeguarding in place where relevant (CIOMS and WHO 2016), a range of strategies that could be built into trials were identified. For individuals with sensory and communication impairments, pictorial or print text aids should be used alongside the written/oral questions to support communication (Jootun et al., 2011). However, currently many standard measures validated for use with people with dementia have strict administration protocols that do not permit deviance from the set verbally presented question and do not have validated pictorial or print text aides to supplement them. Further research is required to develop and validate such aides to support effective administration of measures with people who have communication or sensory impairments. Additionally, adaptations that may be beneficial when collecting other forms of data should be considered. Within qualitative interviews, researchers should develop short and simple topic guides to minimise participant burden, whilst being willing to be flexible on the questions asked. The interview should take a conversational and informal approach, to avoid people feeling like they are being tested or questioned. Researchers have suggested beginning with refreshments to set a positive tone for the experience (Innes et al., 2001). Pilot testing of topic guides with people with dementia is also recommended (Tilburgs et al., 2018), to ensure the appropriateness of questions. For those unable to participate in an interview, ethnographic methods may be more appropriate, allowing informal conversations to occur during periods of observation (e.g. Kelley et al., 2019).

The importance of quality training and supervision for researchers, not only prior to collecting data, but continuously throughout projects was highlighted. Training on the impact of dementia on people, effective communication techniques, how to effectively collect data, how to assess capacity outside of the initial consent process and provision of an understanding of what person-centred care in dementia is, was felt by respondents to potentially support researchers to address many of the challenge they may face. This may not



only support successful data collection but reduce the likelihood of resident distress.

Researchers with more experience working with people with dementia were often those who had strategies in place to negate challenges, therefore shadowing and peer supervision may be beneficial in this context.

Finally, creating and maintaining positive relationships with staff members in care homes is crucial. Staff frequently assist researchers to assess capacity, helping them to form a relationship with residents and increase the likelihood of a smooth data collection process.

This is particularly relevant where staff members have limited understanding of capacity and how this applies to research. Care home managers and staff members vary in their understanding of mental capacity, research recruitment and data collection processes, and their role within research studies (Goodman et al., 2011). Ensuring staff members are well educated about the research and understand the benefits that it might bring to their practice and residents could support this. Strategies to achieve this might include attendance of team meetings and immersion in the care home for a period of time in order to become familiar to staff. This would also help researchers to understand attitudes towards research in the care home and levels of engagement amongst staff members. Furthermore, researchers could also present research findings to the staff, to help them engage with the research process and implement findings into practice.

### Limitations

There are several limitations associated with the present study. Firstly, participants were recruited for this research via three research institutions and may not represent the views of all dementia researchers. However, participants had worked on a range of research projects for different organisations. Secondly, participants completed the questionnaire recollecting their past experiences as a researcher. These are subjective experiences and may not reflect the full range of benefits and challenges associated with collection of self-report data from

care home residents with dementia. However, as this research is exploratory, beginning to understand some of the issues and challenges raised will help researchers' in identifying key considerations when planning future research projects. Furthermore, throughout the questionnaire, participants generally focused on data collection with people who are able to communicate. Barriers to including people with more advanced dementia still exist and these were not as well discussed in the present study. Further work should explore experiences in collecting data with those less able to communicate and develop specific training for researchers in this area.

### Conclusions

Respondents highlighted benefits and challenges of collecting self-report data from people with dementia. The benefits of including people were felt to outweigh challenges in doing this and methods for overcoming these were suggested. Appropriate consideration of the needs of people with dementia during trial design and appropriate researcher training were considered fundamental to achieving best practice in successful data collection with people with dementia.

Table 1. Participant demographics

|   |  | N = 33   |
|---|--|----------|
| Age   |  |          |
|   | 21-25                                    | 8 (24%)  |
|   | 26-30                                    | 15 (45%) |
|   | 31-35                                    | 5 (15%)  |
|   | 36-40                                    | 4 (12%)  |
|   | 41-45                                    | -        |
|   | 46-50                                    | -        |
|   | 50+                                      | 1 (3%)   |
| Gender  |  |          |
|   | Male                                     | 4 (12%)  |
|   | Female                                   | 29 (88%) |
| Number of dementia research projects worked on    |  |          |
|   | 1  | 16 (48%) |
|   | 2  | 10 (30%) |
|   | 3  | 3 (9%)   |
|   | 4  | 4 (12%)  |
| Other dementia related experience (not exclusive) |  |          |
|   | Family carer/family member with dementia | 7 (21%)  |
|   | Care/support work based role             | 13 (39%) |
|   | Assistant Psychologist                   | 5 (15%)  |
|   | Volunteer                                | 2 (6%)   |
|   | Unspecified/none                         | 12 (36%) |

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