

# Facilitators and Barriers to Research Participation in Care Homes: Thematic Analysis of Interviews with Researchers, Staff, Residents and Residents' Families



JOURNAL OF  
LONG-TERM CARE

RESEARCH

EMMA LAW

ROSALIE ASHWORTH

*\*Author affiliations can be found in the back matter of this article*



## ABSTRACT

Following the global health pandemic of COVID-19, a spotlight has been placed on care homes in the UK and the disproportionate impact the virus has had, and continues to have (Hanratty *et al.*, 2020). There is an urgent need to widen our knowledge base about care homes and the inclusion of people living and working in care homes in research studies. This paper presents qualitative findings from a study exploring the facilitators and barriers to research participation in care homes. Semi-structured interviews were conducted with residents ( $n = 12$ ), staff ( $n = 15$ ), relatives ( $n = 6$ ) and researchers ( $n = 8$ ) across three care homes in Scotland between 2014 and 2015. The findings suggest that the key barriers and facilitators to research participation are best captured by three themes: relationships, knowledge about research, and structural challenges. The way these themes are navigated within the care home is expected to shape the willingness and ability of care homes to engage in research. Positive relationships, accessible information about research, and adequate time and space are all likely to increase research presence within care homes.

Conversely, poor relationships, alienating research communication, and limited time and space are all likely to result in care homes being unable or unwilling to participate. Overall, this paper demonstrates that care homes face several barriers to research participation, and efforts to improve relationships, raise awareness of the research process and provide flexible solutions for structural challenges are needed. Future research needs to be mindful of these challenges in order to facilitate research relating to COVID-19 and more generally in gerontology and dementia.

CORRESPONDING AUTHOR:

**Rosalie Ashworth**

NHS Tayside, GB

[rosalie.ashworth@nhs.scot](mailto:rosalie.ashworth@nhs.scot)

KEYWORDS:

Care Homes; Participation;  
Inclusion; Dementia;  
Gatekeeping

TO CITE THIS ARTICLE:

Law, E and Ashworth, R. 2022. Facilitators and Barriers to Research Participation in Care Homes: Thematic Analysis of Interviews with Researchers, Staff, Residents and Residents' Families. *Journal of Long-Term Care*, (2022), pp. 49–60. DOI: <https://doi.org/10.31389/jltc.87>

## INTRODUCTION

A global pandemic changed the lives of people across the world throughout 2020. As a consequence of COVID-19, many aspects of society were put into 'lockdown' in an attempt to minimise the viral spread. At this time we are continuing to live with and manage the consequences of the virus, while research into possible treatments and vaccines is an international priority (Doherty, 2021). There are a lot of unknowns in relation to COVID-19, however, thus far research has shown that people living with dementia (Greenberg *et al.*, 2020) and people living in care homes (Comas-Herrera and Zalakain, 2020), have been disproportionately affected by the virus. National Records of Scotland (2020b) figures suggest that the highest COVID-19 death rates of all those with pre-existing health conditions were among people living with dementia (31%).

In order to understand the wider impact of the virus on care homes, research is needed that focuses on this population. However, people living in care homes are less likely to be involved in research than those in the community (Ries *et al.*, 2019). Law *et al.* (2021) highlighted as few as 7% of care homes in Scotland were involved in research in 2014. Since this time, there is limited data available to suggest an improvement in these numbers (Department of Health and Social Care, 2019). Therefore, this paper will focus on care home interviews which explored the barriers and facilitators to research in this context, in order to support increased participation in the future.

## DEMENTIA AND CARE HOMES

In 2012, the 'Prime Minister's Challenge on Dementia' (Department of Health, 2012) sought to raise awareness of dementia and to increase the number of people living with dementia participating in research to at least 10%. Increasing participation would allow more evidence to understand dementia and the impact it has on people affected by the condition.

As Wortmann (2012) argue, the exclusion of people living with dementia has led to a dearth of evidence, which is a transdisciplinary issue for dementia research.

People living with dementia and their carers have expressed that not participating in dementia research was a form of deprivation and concurred the opportunity to participate in research must be offered to all people with dementia (Law *et al.*, 2013). Benefits of participation include feeling that a valuable contribution is being made to community and civic life (Dementia Action Alliance, 2010); as well as improved quality of life from interventions (Aguirre *et al.*, 2012); social benefits and the opportunity to challenge misconceptions about dementia (Tanner, 2012). Within this is the recognition that this does not mean the research options should be the same, rather that there should be equity of opportunities that account for safeguarding vulnerabilities and consent (West *et al.*,

2017), and allow for accessible information to support inclusion (Prusaczyk *et al.*, 2017). Law *et al.* (2014) found the UK target set out by the Prime Minister's Challenge (2012) was yet to be met, with around 4% of people living with dementia in England and 1% in Scotland participating in dementia research. The most recent review found that the target of 10% was still 'extremely unlikely' to be met for 2020, and that there needs to be a collective effort to increase participation in research for people living with dementia (Department of Health and Social Care, 2019).

The majority of people living with dementia reside in the community; however, the prevalence of dementia within care homes is high with an average of 70% of people in care homes living with dementia (Prince *et al.*, 2014). There is a clear incongruence between the drive for research participation, and the numbers of people living with dementia in care homes having access to research. Goodman *et al.* (2011) suggest that an infrastructure of support is needed within care homes to enable participation. In particular, researchers need to be sensitive to the disruption research can cause, and the need to negotiate relationships effectively to allow research alongside high quality care and support.

## CARE HOME ENVIRONMENT

The care home environment nationally and internationally can vary dramatically in relation to number of residents, type of funding, access to resources and training, use of medications, among other things (Katz, 2011; Kleijer *et al.*, 2013). In a survey of care homes in Scotland, Law *et al.* (2021) received responses from care homes sizes ranging from 8–180 beds; with the majority of residents living with a diagnosis of dementia or suspected dementia. Further the survey found as little as 7% of care homes had experience of past or present research (Law *et al.*, 2021). Within the UK, there are standards of care in which residential and nursing homes follow including, the Health and Social Care Standards (Scottish Government, 2017) and the recently launched 'Standards of Education and Practice for Nurses New to Care Home Nursing' (The Queen's Nursing Institute, 2021). Despite such frameworks, care homes have high staff turnover (Bostick *et al.*, 2006); high physical and psychosocial workloads (Zhang *et al.* 2016); and as the recent response to the pandemic has shown, they face limited resources which lead them ill-equipped for such incidences (Deeny and Dunn, 2020; Social Care Institute for Excellence, 2020).

Given the challenges care homes face, it is perhaps unsurprising that research levels are lower in care homes to other sectors; however, it is also recognised that people in care homes should have the opportunity to participate in research, with initiatives to create a network of 'research-ready care homes' (Goodman and Davies, 2012; Davies *et al.*, 2014; National Institute for Health Research, 2021). Research has reported how

research participation can improve wellbeing, through opportunities to socialise with researchers and peers (Perfect *et al.*, 2021); as well as offering a therapeutic activity in being listened to in a meaningful way (Lakeman *et al.*, 2012); access to information and resources, and pride in participation (Castillo *et al.*, 2012).

Shepherd *et al.* (2015) discuss, regulatory changes are needed to allow for more inclusive research to be conducted in a timely manner. More recently, Ellwood *et al.* (2018) compared methods of recruitment to care homes and found that a targeted approach, via a network of 'research ready' care home, was more effective than a time-consuming, resource-heavy systematic approach. There is a clear consensus across the literature that conducting research in a care home environment can be a challenge, and has led to a systemic exclusion of people living in care homes being included in research (Collingridge Moore *et al.*, 2019), limiting what we know and can learn about care homes and the experiences of residents and staff.

This paper explores the facilitators and barriers to care home research, expanding on the survey research of Law *et al.* (2021), in order to facilitate better uptake of research within care home settings.

## WHAT WE KNOW ABOUT RESEARCH IN CARE HOMES

The culture of a care home can be influenced externally by the corporate policies that are imposed on the care homes and this is particularly relevant in care home 'chains' (Cleary, 2004). As Jenkins *et al.* (2016) described, this could be a factor in the care homes participating in research as the chain management has to be consulted and agree to any research participation. Williams *et al.* (2016) found positive communication a significant facilitator to inclusion and participation of people living and working within a care home environment.

Scott-Cawiezell (2005) discusses the influence of good clear communication on participation in decision-making for all those living and working in a care home. Communication-based interventions were found to improve residents' ability to engage socially, which would have implications for participation (Burgio *et al.*, 2001). The links between enabling participation and enabling citizenship are clearer through the lens of communication and how positive communication can support inclusion, participation and social citizenship.

Finally, gatekeeping is also a factor of whether the care home and ergo their residents and staff are able to participate in research. Gatekeepers may be resistant to allowing the researcher access to the resident because of their interest in the person they are 'protecting' as found in Jenkins *et al.* (2016) paper in overcoming challenges to conducting research in care homes. This paper will explore whether these components are present in the context of enabling research in care homes in order to support recommendations for future research in this field.

## AIM

This paper explores the facilitators and barriers to people in care homes facilitating research.

## METHODS

The research was carried out in two phases - Phase one involved a survey of all care homes for older people in Scotland. It explored factors which influenced the care home staff and the residents, to participate in research and the perceived constraints to participation. The survey findings have been reported elsewhere [removed for peer review].

The focus of this paper is phase two involved using semi-structured interviews in the care home setting with researchers, residents, staff and relatives. Ethical permission was granted from the National Research Ethics Scotland A Committee (reference 14/SS/1076).

## CARE HOMES

The three care homes were identified through opportunistic sampling, based on staff availability and limited time and resources. Therefore, care homes invited to interview were situated in the NHS [removed for peer review] board area, in line with the lead author's location. The care home had to be registered for providing care for older people with the Care Inspectorate (Care Inspectorate, 2015), and could not be under special attention by the Care Inspectorate to ensure such homes were not put under undue pressure to also participate in research. Only one of the three care homes had been involved in research before, however, this was not dementia-related research and was at least five years prior to taking part in this study.

Two care homes had never been invited to participate in research, as far as the care home managers interviewed, could say. It may be due to an absence of an academic centre near the care homes, or a lack of engagement between the homes and researchers. The care home which had been involved had a very proactive manager who sought out interaction with clinicians and researchers and put them forward for a variety of research opportunities.

Care home 1 was situated in an urban area on a quiet residential street. This care home had provision for 47 residents split between two wings, one for people with nursing care needs and a wing for people with dementia. At the time of visiting the home it had a 'good' rating from the care inspectorate. It was owned by a large chain.

Care home 2 had provision for 34 residents in a semi-rural area and although did not have specialist care for people with dementia, there were a number of residents with dementia in the home at the time of the study. At the time of visiting the home had a 'very good' rating from the care inspectorate. It was privately owned.

Care home 3 was situated in an urban area but set in its own extensive grounds away from a busy road. It did not have facilities to care for people with dementia but did operate a 'home for life' policy. It had provision for 44 service users. At the time of visiting the home it had an 'excellent' rating from the care inspectorate. It was privately owned by a group of trustees.

## PARTICIPANTS

Opportunistic sampling was used within the three care home to recruit residents, staff and relatives for interview. All participants needed to be able to speak and understand English. Staff needed to be working at the care home for at least one month. Residents who were reported by the care staff as acutely ill, very frail or experiencing mental ill health, were excluded from participating. Residents who did not have capacity to consent had to have a representative who could provide proxy-consent. This related to one resident in each of the care homes. The determination of sample size within qualitative research is not as formulaic as that of quantitative research (Fusch and Ness, 2015). Feasibility, depth of analysis and diversity within the participant group are all important factors to consider; as Mason (2010) highlights, funded research often does not have the freedom to be open-ended to the point of data saturation. However, based on a review of sample size and saturation, a range of 20–40 sample size was found to be more common in qualitative research. A total of 41 interviews were conducted. *Table 1* summarises the participant's role and the care home in which residents ( $n = 12$ ), staff ( $n = 15$ ), and relatives ( $n = 6$ ) were recruited.

'Researchers' were defined as a person established in the field of care home research. They were identified through reading core care home research papers as part of the literature review and through the lead author's contact with people who were previously engaged in care home research. Eight researcher interviews were

conducted with researchers who have participated in care home research, within the United Kingdom.

## DESIGN

Semi-structured interviews were chosen in line with a qualitative approach of enquiry and an interpretivist view of knowledge (Bryman, 2008). Interviews were conducted sequentially to allow for data from the researcher interviews to shape the structure of the care home interviews. Researcher interviews were completed first, during June, July and August 2014. Care home interviews were conducted between January and June 2015. Of note, the interview data was collected several years ago, however, no equivalent data on UK care homes has been published in this time. Given the major impact of Covid-19 on care homes, it is important to have a clear frame of reference for before the pandemic, in order to support future research into the impact that Covid-19 may have had on research participation; as well as provide recommendations for conducting research in UK care homes.

Care home managers were interviewed first; this provided the opportunity to be shown around and meet with other people living and working in the care home. These were followed by interviews with residents, relatives and staff. Interviews ranged from 10 minutes to an hour in length, depending on the participants abilities and attention span.

## DATA ANALYSIS

A total of 41 interviews were conducted. All the interviews were recorded using a digital recorder and then transcribed for thematic analysis, as explored in more detail within Braun and Clarke (2006). Data was coded by the lead researcher; with transcripts read multiple times to allow for detailed commentary with each read through. The resultant codes were regularly reviewed with doctoral supervisors and refined over time based on emerging commonalities to create key themes (Creswell,

	CODE	CARE HOME 1	CARE HOME 2	CARE HOME 3	TOTAL NO. OF INTERVIEWS
<b>Staff</b>					
Manager	M	1	1	1	3
Registered nurse	RN	0	1	1	2
Junior care staff	JCS	0	0	4	4
Senior care staff	SCS	3	2	1	6
<b>Residents</b>					
Resident with no dementia	Res	6	3	0	9
Resident with dementia	ResD	1	1	1	3
<b>Relatives</b>					
Relative of Resident	Rel	4	1	1	6
<b>Key Informants</b>					
Researchers	KI				8
<b>Total</b>		15	9	9	<b>41</b>

**Table 1** An illustration of the staff, residents and relatives recruited from care homes 1–3, with identifier codes used for presenting the qualitative analysis.

2009). The final themes were reviewed externally as part of doctoral examination, and refined with co-authors for the purpose of publication.

## RESULTS

### FACILITATORS AND BARRIERS TO CARE HOME RESEARCH

Three themes emerged in relation to care homes involvement in research: Relationships; Knowledge about Research; and Structural Challenges. Each theme is discussed in turn, with anonymous extracts included for illustration purposes.

#### Relationships

Across participants, there was recognition that navigating relationships throughout the care home was fundamental to previous or future research participation. Interviews referred to the importance of having a positive relationship with the care home manager, as they act as the gatekeepers to research within the home:

‘A really helpful thing is the care home manager being on board and making sure their staff are informed.’ *KI-3*

Further, as a core member of the care home environment, the managers can, through positive communication, facilitate introductions and help a researcher to recruit participants and gain the trust of staff, residents and their families.

‘It helps if the care home manager introduces you, as you feel like you have validity in being there.’ *KI-4*

Conversely, a negative attitude can result in care homes missing out on research:

‘I feel the one thing we always walk away from is if the individual care home manager doesn’t want to take part because there’s just no point.’ *KI-5*

The researchers’ experiences of gatekeeping highlight how care home managers can be a barrier or a facilitator depending on their relationship with research. In addition, care home staff recognised that for research to take place, the managers needed to be supported to take on the additional work-load associated with research,

‘If you become involved in stuff like that, you do need to support your manager. You do perhaps need more time so your time on the floor would have to be considered and covered but that’s not our problem though.’ *SCS-11*

In order to take on additional responsibilities, it is unsurprising that a positive working environment would

be an advantage. The interviews draw attention to the ‘family like’ atmosphere care homes can have,

‘I think they feel part of a.... we’re like an extended family so they’ve come in and they’ll make new friends with other residents that are here so we end up with what we like to think of as one big, happy family.’ *RN-3*

The close relationship between people within a care home may also explain why managers were not seen to be the only gatekeepers to care home research.

‘You think you’ve done your gatekeeping with your top management but then you end up working or negotiating with a yet another set of people.’ *KI-7*

Researchers reflected on the potential for key workers to facilitate research based on their relationships with the residents. The key worker role enables a consistent point of contact for residents, who may be able to make more informed judgements about research opportunities and supporting participation.

Overall, the way in which relationships are experienced within the care home and between care homes and researchers plays an important role in how successful research can be in this environment. Whilst the majority of responses presented positive relationships, there remains gatekeeping in place that meant people are not being given the opportunity to consider research involvement. The second theme ‘knowledge about research’ may help to explain where the gatekeeping stems from and therefore how to address this for future relationships.

#### Knowledge about Research

The interviews presented a dissonance between wanting to support residents as much as possible, whilst gatekeeping their access to research opportunities. A lot of the hesitancy from staff was explained by misconceptions about research and the need to provide clear information as one of the key respondents highlighted:

‘A good piece of research would have all sorts of procedures for ongoing monitoring different kinds of resistance of avoidance to research and then stances for responding to that.’ *K-18*

Care home staff also discussed how family members did not always understand dementia which in itself creates a barrier to dementia research,

‘There are so many that really to this day don’t know what dementia is all about. We get it even with families coming in with their mothers and they find it very hard to cope with it. They just really don’t know, you know, what it’s all about.’ *SCS-22*



Similarly, there was acknowledgement that the process of research may be daunting if you have not participated before,

'I think with anything new, the interviews might be taped and might be scary for some of them but I know quite a few relatives here whose people have dementia and who would be quite keen to join in.'

MRN-2

'With residents it almost seemed like the kind of paperwork of the consent process was just a little bit overwhelming.'

KI-6

The importance of understanding research and eligibility is further highlighted by residents, who felt they were not suitable participants,

'I'm no' very clever right enough.'

Res-22

It is encouraging that residents and family members who felt more knowledgeable about research were positive about its potential impact:

'I think it's extremely important. If one is in a place like this, one must contribute oneself.'

Res-15

'All research is important because if some good comes out of it then, I don't have a problem being involved in it. You know what I mean? So, no, I think research is a good thing.'

Rel-2

Knowledge of research also includes familiarity with the processes within it. Of particular prominence in the field of dementia research is ethical concerns such as capacity of consent and informed decision making. Whilst ethical practice is an essential, necessary component of research, it is important that this is managed in a way that does not prevent choice and opportunity, as the researchers captured:

'I don't think there's an easy solution and I can see why we have now very thorough procedures for achieving ethical consent but I think for the level of risk involved in the sorts of research we are doing, it often feels like it's a bit of a sledgehammer to crack a nut.'

KI-7

Confidence in researchers and ethical practice may result in some staff feeling more able than others to support research. The more experienced researchers had built up a reservoir of knowledge and skill throughout the years in dealing with many of the different scenarios that can arise during this fraught and bureaucracy loaded process:

'In a very sensitive environment with lots of vulnerable people and often the staff are vulnerable just as much as the residents, one

has to be very, very processual and flexible and articulate in applying and re-applying consent.'

KI-8

The less experienced researchers verbalised the difficulties they experienced including: understanding and then applying capacity legislation; who to seek help from; talking to relatives about capacity; the difference of opinions between the junior researcher and care home staff about residents' capacity. For example:

'I think the capacity thing is definitely difficult. I'm very comfortable working out if someone has what I would discern to be mental capacity but I'm not as comfortable trusting someone else's judgement on it.'

KI-3

The potential reliance on staffs' knowledge about their residents in order to make informed decisions may result in care homes avoiding research involvement due to lack of time for staff to dedicate to research, as discussed in the final theme.

Some staff felt that their training was a type of research, with topics including dementia knowledge, health and safety, and person-centred care. It may be that more research-centred topics need to be covered to help distinguish education and research to provide tools to facilitate involvement, such as communication and consent. The interviews with care staff provide possible routes to targeting research education, by using examples of work already being undertaken within the care home.

'We do have letters that go out, you know, questionnaires for the residents that can be things like, you know, "what do you think of the food?" Good, bad, poor, excellent, you know. There's a list and they tick the boxes and then it's things like "what do you think of the cleanliness of the home?"...Things about the carers, "Are they nice and friendly?" You know, "are they nice and friendly?" you know, "are they good, poor, adequate?"'

SCS-12

The example of feedback and evaluation provided by care staff could be tailored to show different ways of asking questions and the benefit of involvement in such activities for the purpose of improving things.

### Structural challenges

The final theme explores structural challenges that present obstacles to research involvement. Arguably it is these challenges that do not give research the opportunity to get off the ground. The final theme explores how these challenges shape the barriers and facilitators to research in a care home environment.

## TIME

During the interviews, staff reflected on the need for more time to be able to participate in research. Some did not see how it could fit into the routine, despite being sure that it was an important aspect of life in a care home:

‘I’m not entirely sure of that because it depends really on whether we can fit that in to the routine of the home but provided there is a space to do the research, I think, yeah, there will be, yes.’ -SCS3

Given the busy schedule staff face, it is unsurprising that there were reservations about whether research could fit in. The findings showed that staff saw the benefits of having a researcher seeing their residents as this provided valuable one-to-one time with residents, which they could not always give them:

‘Someone to just sit with them and have a one-to-one because sometimes it is difficult to spend that one-to-one time. We do our best but it can be hard sometimes.’ -SCS11

Time for research needs to take account of both the procedural time within a research study, and the time needed around the research to build up relationships and allow for indirect benefits, such as increased social interaction (Higgins, 2013). Ethical processes such as assessing capacity to consent can be time consuming and fraught with intricacies and problems in interpreting, communicating and applying relevant legislation to others:

‘In a very sensitive environment with lots of vulnerable people and often the staff are vulnerable just as much as the residents, one has to be very, very processual and flexible and articulate in applying and re-applying consent.’ -KI8

Difficulties arose when the managers were not interested and this lack of interest was conveyed to the researchers by lack of respect for the researcher’s time, not enabling the researcher to contact relatives or not telling staff about the proposed study. Researchers expressed that they did not want to include these homes because of the cost implications due to the extra time it would take to engage with the home and therefore complete the research.

The negative side to this, as expressed by more than one researcher, is that the homes excluded, due to the manager’s negative attitudes, disregards all the people living and working within those homes who may have wanted to take part and have had interesting and valid perspectives to add to the research,

‘you’re not just a nice friendly visiting face, you are there for something that they have a right to be involved with or not be involved with.’ -KI6

The issue of time or lack of time, as viewed by the care home staff, can have a direct impact on the ability of researchers to enable people to be involved in research for the care home community.

## SPACE

The findings suggested that the physical environment of the care home could be both a possible facilitator and barrier to research. The availability of private, quiet areas to talk to people was discussed as an important facilitator, as was the physical layout of the care home. Having to interview people in busy, noisy, large public rooms with distractions of television, radio or other residents was a barrier.

‘There’s practical things like not having a quiet, private room to talk to a resident who’s hard of hearing and easily distracted and trying to do that whilst there’s other people who aren’t, who might be distressed or might be loud.’ -SCS22

At some point to varying degrees in all the study care homes there were uncontrollable noise levels due to other people shouting or being agitated, the television was left on and staff were noisy at times.

‘Because of the dementia they can’t interact so well. They find too much noise, too many people can be difficult and confusing for some of them... You can’t make the environment quiet or change the environment because then not everybody likes to be in the quiet.’ -SCS21

Some of the interviews were conducted in noisy communal areas, with the television on in the background. This was distracting and difficult to navigate for both the interviewer and interviewee.

One manager verbalised the difficulties of care home living:

‘I don’t think we’re there and I think, I mean, this isn’t a huge place...but large communal living has its limitations with people.’ -MRN3

This was echoed in other interviews with people remarking about the size and layout of the care home having an impact on which type of residents could live there, the need to be mindful of others due to communal living and the lack of privacy, which impacted on visits from relatives.

Research participation in resident’s rooms may add privacy from the communal areas, however, this is a very personal space and some people may not feel comfortable having an unknown person in their space.

‘I am very, very happy in my room. I’ve got my life around me.’ -RES1

As noted within relationships, having a presence within the care home was important to allow residents and staff to get to know the research, this relies on residents making use of these public spaces, which is not always the case,

‘He just sits in his room, dad, because he feels embarrassed of his frailties and he doesn’t want to be seen in the dining room because he’s got a shaky hand and he’s lost his vision mostly and he doesn’t want to be dependent on people, so he sits in his room.’- REL31

Consideration to physical environment, physical capabilities and emotional issues of residents and staff within the care home environment coupled with the qualities of the staff involved in research in care homes was seen as paramount to overcoming barriers and maximising facilitators.

## DISCUSSION

The findings of this paper suggest that the key barriers and facilitators to research participation are best captured by three themes: relationships, knowledge about research, and structural challenges. The way these three themes are navigated by researchers, care home staff, residents, and resident’s loved ones within the care home are expected to shape the willingness and ability of care homes to engage in research. Positive relationships, accessible information about research, and adequate time and space are all likely to increase the presence of research within care homes. Conversely, poor relationships, alienating research communication, and limited time and space are all likely to result in care homes being unable or unwilling to participate.

The research expands on findings of Smith *et al.* (2019) who looked at research in care homes for older adults. Our study included care homes which include people living with dementia, and interviews with staff, key informants, family and residents, adding a wider range of perspectives to research participation than if just care home managers had been consulted.

Further, the findings add more contextual facilitators and barriers to be considered alongside more study-specific challenges such as clinical trials of investigational medicinal product (Shepherd *et al.*, 2015). The obstacles to research participation mirror similar literature around the care home environment and the work places pressures people face. The importance of building positive relationships in order to overcome gate-keeping, and the need for flexible time and space have clear overarching effects out with the context of research (Scourfield, 2012; Garcia *et al.*, 2012). The interview findings add support to how these barriers can reinforce the exclusion of residents of care homes in research (Collingridge Moore *et al.*, 2019).

Findings in other contexts add further support for the themes we have identified for example: uncertainty around infringement of rights and the complex relationships between staff, families and patients in a hospice settings can be barriers to participation (Mackin *et al.*, 2009); structural challenges such as time and levels of commitment a study requires have been barriers in clinical trials for other disease areas such as diabetes (Robiner *et al.*, 2009); as well as stigma and trust in research practices leading to less willingness to participate in biomedical research in low and middle-income countries (Browne *et al.*, 2018).

Knowledge about research acts as a particularly interesting facilitator or barrier to research participation in the current health care climate. The interviews for our research took part before the onset of the Coronavirus-19 pandemic. The findings suggest that prior to the pandemic; knowledge about research was relatively low in care home setting, with examples of participants being unsure about the process and sharing concerns around consent, levels of involvement, benefits of participation etc. Whereas an indirect effect of COVID-19 is that it provides a very salient, tangible example of the research process, resulting in increased public health awareness (Fitzmorris Brisolara and Smith, 2020; Jun *et al.*, 2021; Provenzi and Barello, 2020). In the UK, by December 2020 over 600,000 people had taken part in public health research into the effects and treatment of COVID-19 (UK Government, 2020), with widespread vaccine rollout in 2021 (British Medical Journal, 2021). Comparatively, a typical clinical trial can take 12–15 years from study design through to the availability of a new licensed medication (Oxford, Stewart and Rohn, 2020). Clinical trials in care homes remain low, with no CTIMPS research within Scottish care homes, based on the Neuroprogressive and Dementia Network portfolio; and one clinical trial in set up exploring prophylaxis and COVID-19 that did not come to fruition. The findings of our paper suggest that this shift in knowledge may lead to increase in care home research participation, through addressing one of the barriers to research participation, ‘knowledge of research.’ However, the pandemic has also put unprecedented strain on care homes (White *et al.*, 2021) therefore, follow up research which explores whether the increased knowledge has a greater effect on participation than the decrease in time and space.

## LIMITATIONS

The interviews presented in this paper were conducted within a 16-week period between May and August, 2014, in Scottish care homes. As noted throughout the discussion, this research cannot ignore the significant impact that COVID-19 has had on health and social care.

However, the findings provide evidence of the facilitators and barriers to research participation before the pandemic and offer a useful baseline for comparisons in future research. Since the data was collected, there remained no research published that looked into the



facilitators and barriers to research participation in UK care homes, which reinforces the need for more research on this topic and the continued relevance of the findings. Another limitation is the use of opportunistic sampling of the care homes and the participants.

Although this was the most feasible approach given the time and resources available, findings may vary in other areas within and out of Scotland. Future research would be able to compare other areas against our findings.

## CONCLUSION

Overall, this paper demonstrates that care homes face several barriers to research participation, and that efforts to improve relationships, raise awareness of the research process and provide flexible solutions for structural challenges are needed. There is undeniably a spot light on care homes due to the coronavirus pandemic, and the findings from this paper encourage people to be mindful of the challenges care homes face in order to facilitate research relating to COVID-19 and more generally in gerontology and dementia.

## ADDITIONAL FILE

The additional file for this article can be found as follows:

- **Appendix 1.** Table 2. Topic guides used in the semi-structured interviews of key informants, residents, staff and relatives across 3 care homes in Scotland. DOI: <https://doi.org/10.31389/jltc.87.s1>

## ETHICS AND CONSENT

The research was approved for ethical review. Full details removed for peer review.

## COMPETING INTERESTS

The authors have no competing interests to declare.

## AUTHOR AFFILIATIONS

**Emma Law**  [orcid.org/0000-0001-6047-5030](https://orcid.org/0000-0001-6047-5030)  
NHS Tayside, GB

**Rosalie Ashworth**  [orcid.org/0000-0003-4378-1735](https://orcid.org/0000-0003-4378-1735)  
NHS Tayside, GB

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TO CITE THIS ARTICLE:

Law, E and Ashworth, R. 2022. Facilitators and Barriers to Research Participation in Care Homes: Thematic Analysis of Interviews with Researchers, Staff, Residents and Residents' Families. *Journal of Long-Term Care*, (2022), pp. 49–60. DOI: <https://doi.org/10.31389/jltc.87>

Submitted: 11 March 2021   Accepted: 07 September 2021   Published: 23 February 2022

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*Journal of Long-Term Care* is a peer-reviewed open access journal published by LSE Press.