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Widening research participation: a survey exploring stakeholders' views about opportunities for older adults living in UK care homes to participate in research

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Declaration of Conflicts of Interest

None

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Ethical approval

The study received a favourable opinion from the Research Ethics Committee at the School of Medicine, Cardiff University (reference: SMREC 22/50)

Abstract

Background. Older adults living in care homes are underrepresented in research resulting in a poorer evidence base for their care. Increasing opportunities and ability for care home residents to be included in research is urgently needed.

Aims. To explore the views and experiences of relevant stakeholders in the UK about opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement.

Methods. The survey was conducted from September to December 2022 using an online survey tool or paper-based format. Participants were recruited via multiple routes including social media and contact with care homes. Quantitative data were analysed using descriptive statistics and free-text responses were analysed using content analysis.

Findings. Eighty participants responded to the survey of which 46 were analysable from care home residents ($n = 6$), relatives ($n = 11$), care home staff ($n = 14$), other health and social care professionals who work with care homes ($n = 7$), and researchers ($n = 8$). The main barriers identified were the discordance between stakeholders' awareness of research opportunities, and difficulties with residents' communication needs. Facilitators include effective communication between stakeholders, positive staff engagement, and researchers' flexibility.

Conclusions. There are a number of barriers to the inclusion of care home residents in research. There is a need to develop strategies to improve communication and relationships between stakeholders, as well as training programmes to educate stakeholders about care home based research and its benefits.

Keywords: Care homes, Research participation, Stakeholders, Survey

Key Points:

- There is a discordance between stakeholders' views about research opportunities for care home residents and their relatives
- Care home staff play an important role in sharing research information and recruiting care home residents to participate in research
- Future strategies should focus on improving how opportunities and preferences about research are communicated

Abstract

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Introduction

There is a paucity of research evidence regarding the health and social care needs of care home residents despite this growing population often having complex needs, with an estimated 80% suffering from cognitive impairment or dementia (O'Neill et al., 2020; Bollig et al., 2016; Alzheimer's Association, 2019).

Less research is conducted in care homes compared to other healthcare settings in the UK (National Institute for Health and Care Research [NIHR], 2017) and the lack of care home research including residents limits our understanding of their care needs and quality of life, preventing advances in practice. The Nuffield Council on Bioethics has reported the potential impact of historical systematic exclusion of older adults from research, including care home residents (Nuffield Council on Bioethics, 2023). In order for research to be successful in furthering knowledge, informing practice, and improving quality of life, it is imperative that study participants reflect those whom the research is intended to benefit (Kuchel, 2019). Researchers have suggested that the exclusion of care home residents in research may be due to practical and ethical concerns (NIHR School for Social Care Research, 2020).

The barriers and facilitators to the inclusion of UK care home residents in research have been investigated through a recent scoping review (Nocivelli et al., 2023). Complex factors were identified, including research design; understanding and beliefs about research; communication; relationships; eligibility criteria; preference-based decisions; and care home staff and environment. These findings validated findings of previous research identifying challenges of conducting research in long-term care facilities across geographical locations (Lam et al., 2018). Importantly, this review found a lack of research exploring the views and experiences of relevant stakeholders (i.e., care home residents, relatives, care home staff) about the opportunities for older adults living in care homes to get involved in research and the barriers they believe residents face (Nocivelli et al., 2023).

In this study we aim to explore the views of UK care home residents, relatives, care home staff, other health and social care professionals who work with care homes (HSCP), and researchers about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their involvement.

The term care home used in this paper relates to long-term care facilities for older adults, including residential and nursing homes.

Methods

Participants

Individuals who identified as one of the stakeholder groups, living and/or working in the UK, were eligible to participate in the survey. Participants were also required to be able to consent to completing the survey.

Participants were recruited via multiple routes including direct contact with care homes; academic conferences; existing networks including ENRICH (Enabling Research in Care Homes); the British Society of Gerontology Special Interest Group; contacting researchers of ongoing care home studies; direct contact with GPs; research centres (see acknowledgements section); and social media.

Data collection

The cross-sectional survey was conducted using an online survey tool (Qualtrics). The survey included fixed-choice and ranking questions with free-text boxes throughout for participants to include additional information. Fixed-choice answers were developed using the findings of a previous scoping review (Nocivelli et al., 2023).

A small pilot was conducted with participants who met the inclusion criteria ($n=3$) to test survey acceptability, comprehensibility, and content. Small amendments to design and content were made following the pilot.

Participants were invited to complete the survey online through a link, or a researcher was available to go into the care home to support residents to complete the survey either on an iPad or paper version if required.

The survey was divided into four sections: (1) demographic data ('About You'); (2) views about current opportunities for residents to take part in research; (3) views about what helps or prevents residents being included in research; (4) views about how to support decisions about taking part in research. Participants were also given the option of providing contact details if willing to be contacted about taking part in an interview for the next stage of the study. See supplementary materials.

Due to the objectives and design of this exploratory study, conducting a formal sample size calculation was not appropriate. A target size of around 100 participants was estimated from similar studies, for example Hemsley et al. (2010). Participants were provided with information about the study (either on the homepage of the Qualtrics survey or in paper format) and were asked to tick a box at the start of the survey to confirm they consented to participate.

Data analysis

Paper-based survey responses were entered into the online questionnaire by a member of the research team to support data management and analysis.

All survey data were exported to Excel from the online survey tool. Data cleaning was conducted, removing responses that contained only minimal responses (e.g., started the survey but did not answer any questions).

A conventional content analysis was performed on free-text responses to individual questions and common themes were identified. Codes were developed using the emerging themes, as is typical for content analysis (Hsieh and Shannon, 2005) and responses were coded in Microsoft Excel.

A weighted scoring method was used, where factors were given a higher value or 'weight', to analyse responses to questions which involved ranking factors based on previous literature (both questions in Part 4). Answers ranked in first and second places were weighted and totalled to present what stakeholders deemed the greatest barrier/enabler (first place x10, second place x5). Answers ranked in fourth and fifth places were weighted and totalled to present what stakeholders deemed the least important barrier/enabler (fifth place x10, fourth place x5).

Results

There was a total of 80 responses to the survey (74 online and 6 paper). Responses were excluded from analysis if they: provided minimal or no demographic data (n=18); started the survey but did not answer any questions (n=16). A total of 46 responses (57.5%) were included in analysis. Demographic characteristics of participants are shown in Table 1.

Table 1. Demographic characteristics of participants ($n = 46$)

	No. (%)
Stakeholder	
Care home resident	6 (13)
Relative/friend of resident	11 (24)
Care home staff	14 (31)

Other health and social care professional who works with care homes	7 (15)
Researcher	8 (17)
Location of care home	
Wales	20 (44)
England	24 (52)
Scotland	2 (4)
Northern Ireland	0 (0)
Length (duration) of experience, mean (range), months	
Living in/working with care homes	92.2 (1-564)
Age	
18-35	6 (13)
36-55	20 (44)
56-75	16 (35)
76-95	3 (7)
Missing data	1 (2)

Care home staff members and HSCP were asked to state their role in a free-text box.

Responses from care home staff (13/14) included: Care assistant ($n=2$), Administrator ($n=1$), Trainee advanced clinical practitioner ($n=1$), head of dementia care ($n=1$), manager ($n=7$), responsible individual ($n=1$). Responses from HSCP (6/7) included: social worker ($n=2$), nurse ($n=1$), GP ($n=1$), clinical nurse ($n=1$), clinical studies officer ($n=1$).

Sharing research opportunities

Participants were asked how opportunities to take part in research were currently shared with care home residents and their families. 'Care home staff' was the most selected

answer, followed closely by 'posters or information sheets'. The answer least selected was 'social media'. See Table 2.

Free-text responses to this question ($n=16$) related to issues such as lack of opportunities and sharing opportunities.

Responses from residents and relatives highlighted a lack of research opportunities. For example, one care home resident stated that "*they're not*" when asked how opportunities to take part in research were currently shared with them, and one relative's response was that they had "*never been approached*".

Answers relating to the methods of sharing research opportunities, were reported by either care home managers, researchers, or HSCP, not by residents or relatives, and related to ways in which research is shared with residents and relatives. For example, one researcher stated that "*Clinical studies officers visit their local 'research ready' care homes to discuss opportunities*".

Making decisions about resident participation

Participants were asked how decisions about residents taking part in research are usually made. The most selected answer was 'resident makes their own decision', with 'proxy/personal consultee or representative make decisions' the answer least selected. See Table 2.

Free-text responses to this question ($n=8$) related to a lack of knowledge, and that care home staff controlled residents' access to research.

Some relatives and HSCP reported a lack of knowledge about how decisions about research participation are made. One relative reported “*never [having] received a request*”, and a HSCP expressed their lack of knowledge, stating “*I don’t know*”.

Comments relating to the perceived control of care home staff came solely from researchers, one example being “*Care home staff may control access (gatekeeper role)*”.

Other responses related to residents’ capacity to make decisions about participation, discussed by a member of care home staff, and opportunities from outside networks which were mentioned by a HSCP.

Improving opportunities to take part in research

Participants were asked how opportunities to take part in research could be improved for residents. All answers were popular (chosen between 21 and 36 times), with the most selected answer ‘researchers visit care homes and share opportunities’. The least selected option was ‘care home staff share opportunities regularly’. See Table 2.

All free-text responses to this question ($n=7$) related to finding optimal methods to improve opportunities for participation. One resident reported that it is “*Better if someone comes in*”, for example.

Other responses included the role of research ethics committees in “*allowing*” residents with dementia to participate in research.

Barriers to resident research participation

Participants were asked to rank statements in order of which they considered the greatest barrier to residents taking part in research.

The statement that was considered the most impactful barrier to residents taking part in research was 'lack of awareness about research opportunities' (n=29), followed by 'difficulties with residents' communication needs' (n=18). The statement ranked as the least impactful barrier was 'residents' feelings of not being heard or valued' (n=28), followed by 'understanding or attitudes about research' (n=13).

Enabling resident research participation

Participants were asked to rank statements in order of which they considered most enabling for residents to take part in research.

The statement that was considered the most impactful enabler to residents taking part in research was 'positive staff engagement' (n=23), followed by 'flexibility of researchers within the care home around organisation and routines' (n=15). The statement ranked as the least impactful enabler to residents taking part in research was 'being part of a care home that has previously been involved in research and is registered as 'research ready'' (n=23). This was followed by 'flexibility of researchers within the care home around organisation and routines' and 'better understanding and positive attitudes about research' (n=15).

Communicating information about research to residents and families

Participants were asked how information about research could be better communicated to residents and their families to help decide about participating in research. The most selected answer to this question was 'developing relationships between researchers, care home

residents, family members and staff' and the least chosen was 'provide a personalised decision-making process to the needs of each potential participant'. See Table 2.

Free-text responses to this question ($n=5$) related to issues such as recruitment and research methods, and communication and relationships.

A suggestion on how to improve communication by researchers was shared by one member of care home staff, suggesting that "*more publicity*" may help. Responses relating to communication and relationships were made by residents, staff and researchers and related to researcher flexibility and accommodating individual needs. For example, "*Explain what you're doing*" was expressed by one resident, and a care home staff participant stated that "*Residents are generally willing participants in voicing views. The format, communication and simplicity is required to encourage them to complete in their own time*".

Supporting residents to express their views about taking part in research

Participants were asked how they believed residents could be supported to express their views about taking part in research in the future, should they not be able to make their own decisions about taking part at that time. The most selected answer was 'Talking to residents about what their preferences would be about taking part in future research' followed closely by 'Using tools such as communication aids (e.g., picture cards) to help residents express their views'. See Table 2.

Free-text responses to this question ($n=9$) related to barriers to resident research participation such as resident disinterest; method of consent; inclusion; and support not being possible.

Residents were ambivalent about expressing their views about taking part in future research, for example one resident stated they would be *“Happy for family to decide”*.

Practical suggestions, including novel methods of consent, were offered by researchers, and one relative commented that their involvement was a gesture of support for resident inclusion in research.

One care home staff member was cautious of supporting residents to express views on research participation stating that *“Very often communication is not possible with residents”*.

Table 2. Responses to survey questions

	No. (%)
How are opportunities to take part in research currently shared with residents and their families? (n = 45 responses)	
Care home staff	25 (56)
Other health and social care professionals	13 (29)
Social media	7 (16)
Posters or information sheets	21 (47)
Researchers	12 (27)
Other	17 (16)
How are decisions about residents taking part in research usually made? (n = 44 responses)	
Resident makes their own decision	34 (77)
Care home staff make decisions	14 (32)
Family/friends make decision on residents' behalf	19 (43)
Proxy/personal consultee or representative make decisions	9 (20)
Other	8 (18)

How do you think opportunities to take part in research could be improved for residents? (*n* = 46 responses)

Researchers visit care homes and share opportunities	36 (78)
Care home staff share opportunities regularly	21 (46)
Multiple formats of sharing opportunities (such as posters, leaflets, talks)	28 (61)
The care home actively seeking to take part in research	22 (48)
Other	7 (15)

How can information about research be better communicated to residents and families to help make a decision about participating in research? (*n* = 41 responses)

Present information in a way that is personalised and relevant to each resident or family member	25 (61)
Clear, concise format – provide choice of information type	28 (68)
Developing relationships between researchers, care home resident, family members and staff	34 (83)
Staff engagement and support	25 (61)
Care home becoming a ‘research ready’ care home	21 (51)
Give residents time and encouragement to make decisions	28 (68)
Include family members from the very start	30 (73)
Flexibility and understanding of researchers	24 (59)
Provide a personalised decision-making process to the needs of each potential participant	19 (46)
Other	5 (12)

How can residents be supported to express their views about taking part in research in the future should they not be able to make their own decisions about taking part at that time? (*n* = 41 responses)

Talking to residents about what their preferences would be about taking part in future research	28 (68)
Using tools such as communication aids (e.g., picture cards) to help residents express their views	24 (59)
Other	9 (22)

Discussion

This is the first survey to explore the views of UK care home residents, relatives, care home staff, HSCP who work with care homes, and researchers about current opportunities for residents to participate in research, decisions about participation, and the barriers and facilitators to their inclusion.

Most stakeholders shared the view that current opportunities for resident research participation are primarily shared by care home staff. This view highlights the important role care home staff can play in sharing research information and recruiting as previously reported (Shepherd, 2020). However, due to the impact of research on care home staff, including time pressures and workload (Jenkins et al., 2016), and research burden (Donnelly et al., 2018), this role is not something that all care home staff are willing or able to engage with.

The findings highlighted contradictions between care home residents' and relatives' views about research opportunities in comparison to the professional stakeholders' views. Whilst care home residents and relatives expressed the view that opportunities are lacking, other stakeholders reported that research opportunities were shared. This discordance between

views has also been reported in studies about residents' quality of life in a care home (Usman et al., 2019). This finding also suggests a lack of communication between stakeholders, consistent with other research findings that present this as a barrier to recruitment in care homes (Elwood et al., 2018; Smith et al., 2019; Perfect et al., 2019).

Differences in stakeholder group views about how decisions are made about research participation were found. Relatives seemed to be less informed about the decision-making process, which is consistent with reports of sub-optimal communication between care home staff, researchers, and relatives (Hall et al., 2011; Wood et al., 2013). Further, researchers' comments surrounding decision-making referred to the ways in which care home staff can be a barrier to resident participation in research, which is consistent with much of the literature (Fossey et al., 2020; Gine-Garriga et al., 2020; Law and Ashworth, 2022).

Most stakeholders viewed a lack of awareness about research opportunities and difficulties with resident communication as the greatest barriers to residents taking part in research. These findings are consistent with research suggesting that residents are unaware of research opportunities and are often overlooked with regards to being suitable for participation (Bartlett et al., 2019; Law, 2016; NIHR, 2019), as well as a suggestion that an act as simple as directly asking residents if they wish to participate would be beneficial (Law, 2016).

Interestingly, stakeholders viewed residents' feelings of not being heard or valued as the least impactful barrier to inclusion in research. Frequent reporting of residents' worries about research participation, perceptions of disempowerment and lack of autonomy (Donnelly et al., 2018; Hall et al., 2009; Goodman et al., 2011; Goodman et al., 2013; Clarke et al., 2019) contradict the views reported by stakeholders in this study, suggesting that they may be unaware of residents' true feelings. Perceptions of a lack of autonomy and disinterest were also highlighted in residents' comments about how they could be supported to express their

views about future research participation should they no longer be able to make their own decision.

Stakeholders viewed positive staff engagement, and the flexibility of researchers around the organisation and routines in care homes, as the greatest facilitators to resident inclusion in research which is consistent with the literature. Fossey et al. (2020) suggest that positive staff engagement, including seeing staff as 'part of the research team', can be invaluable in both recruitment and delivery of research studies in care homes. Further, recommendations from experienced care home researchers include the importance of researcher flexibility in facilitating inclusion (Wood et al., 2013; Fossey et al., 2020; Bartlett et al., 2019; NIHR, 2015).

Stakeholders viewed being part of a care home that has previously been involved in research and is registered as 'research ready' as the least impactful facilitator to resident inclusion in research. This may be due to a lack of understanding about what a 'research ready' care home is or being unaware of the successes of organisations aiming to improve research in care homes, such as ENRICH.

Strengths and limitations

This is the first study to explore stakeholders' views on care home resident research participation and is able to provide insight into a wide range of views on research opportunities, decision-making, and the barriers and facilitators to research participation for UK care home residents. A strength is the use of conventional content analysis on free-text responses to allow further expression of views. Knowledge generated from the analysis is based on all stakeholder participants' unique perspectives (Hsieh and Shannon, 2005).

The study was limited by the modest sample size and the small number of participants who were care home residents. The recruitment approach meant we were unable to track non-responders which may have resulted in participation bias. Difficulties were encountered gaining access to care homes and, due to the small size of this stakeholder group it is likely that their views captured in this study may not be representative of all care home residents in the UK. It should be noted that resident and relative stakeholder groups may only have been able to provide limited experiences based on a particular care home, which may not be research active, whereas other stakeholder groups may have wider experience across the care home sector. Furthermore, recruiting only care home residents with the capacity to consent to participation limits the generalisability of these findings to residents who may be unable to consent to participate in research.

Implications

The findings broaden our understanding of what stakeholders deem to be the barriers and facilitators to resident inclusion in care home research and how opportunities for inclusion can be improved. These findings can support the development of strategies to improve communication and relationships between stakeholders, as well as training programmes to educate stakeholders about care home research and its benefits, and targeted interventions to improve research inclusion for UK care home residents.

Conclusion

Care home residents are currently under-served by research. In this study, a range of stakeholders identified the most important barriers to the inclusion of care home residents in research and suggested ways to address them. Discordance between stakeholders' views was apparent, particularly between residents and other stakeholders, suggesting that communication between stakeholders is not effective and would benefit from strategies or

interventions to improve how opportunities and preferences about research are communicated.

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