

Introduction and background

Older adults, who often experience the greatest prevalence of disease and require the most complex care needs, are generally underrepresented in research resulting in evidence that may not be generalisable to those who may require it the most [1-2]. A lack of research exists identifying addressing appropriate research methodology and strategies for recruiting the older adult population [3], evident in the underrepresentation and exclusion of older adults in facilities dedicated to the care of older adults, such as care homes [4].

The exclusion of care home residents in research has been suggested to be partly due to practical difficulties and ethical concerns about including this 'vulnerable' group in research [5]. The resulting underrepresentation of care home residents in research has resulted in a poorer evidence base for the care provided for older people living in care homes.

Increasing the opportunities and ability for care home residents to be included in research, including greater inclusivity of residents with cognitive impairment, is urgently needed. In health and social care research, adequate representation of the population who are likely to benefit from the research is important in order to support the generalisability and application of research findings in practice. Representation is needed in care home research to allow for generalisable evidence-based findings to inform and increase the quality of person-centred care for older adults living in these facilities. To better understand why older adults living in care homes are often excluded, and therefore underrepresented, in care home research

Research aim: to identify resident-related barriers and facilitators to including older people living in UK care homes in research and identify potential interventions to appropriately modify identified barriers and facilitators.

Methods

Design. Arksey and O'Malley's (2005, [6]) scoping review methodological framework was followed, comprising of six stages: identifying the research question; identifying relevant studies; selecting studies; charting the data; collating, summarising, and reporting the results; and consultation.

Eligibility. The identification of relevant studies followed the Population, Concept, Context (PCC) framework, as recommended by the JBI [7]. Studies and other information sources were included in the review if they: (1) included care home residents, residents' family members, care home staff, or researchers; (2) mentioned barriers or facilitators to inclusion, or suggestions/advice for modifying barriers or facilitators; (3) took place in UK care home settings; (4) were published between 2005 and the commencement of the review; (5) were published in English.

Search Strategy. Electronic database searches of: MedLine, Web of Science, Scopus, CINAHL and PsychINFO, were conducted. A combination of terminologies, separated by key concepts, were tailored to each database with the help of a subject specific librarian. Grey literature was investigated through unpublished literature (EthOS), whole site searches of relevant organisations (ENRICH, AlzheimersUK, British Society of Gerontology) as well as existing networks.

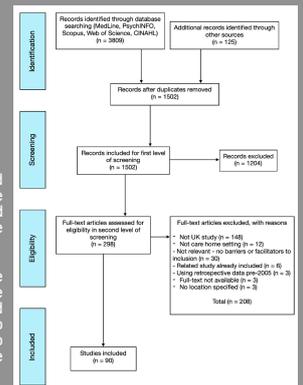
Key Concepts	Search terms
Care homes (titles and abstracts)	"care home", "nursing home", "residential home", "long-term care facility"
Research (titles and abstracts)	"research", "study", "trial", "investig", "explor", "observ"
Participation (titles and abstracts)	"research subject", "research participant", "particip", "research", "recruit", "involve"
Barriers and facilitators (titles and abstracts)	"barrier", "challenge", "factor", "facilitator", "perception", "perceive", "view", "attitude", "experience"

Table 1. Search terminologies input into each database, as appropriate, separated by key concept.

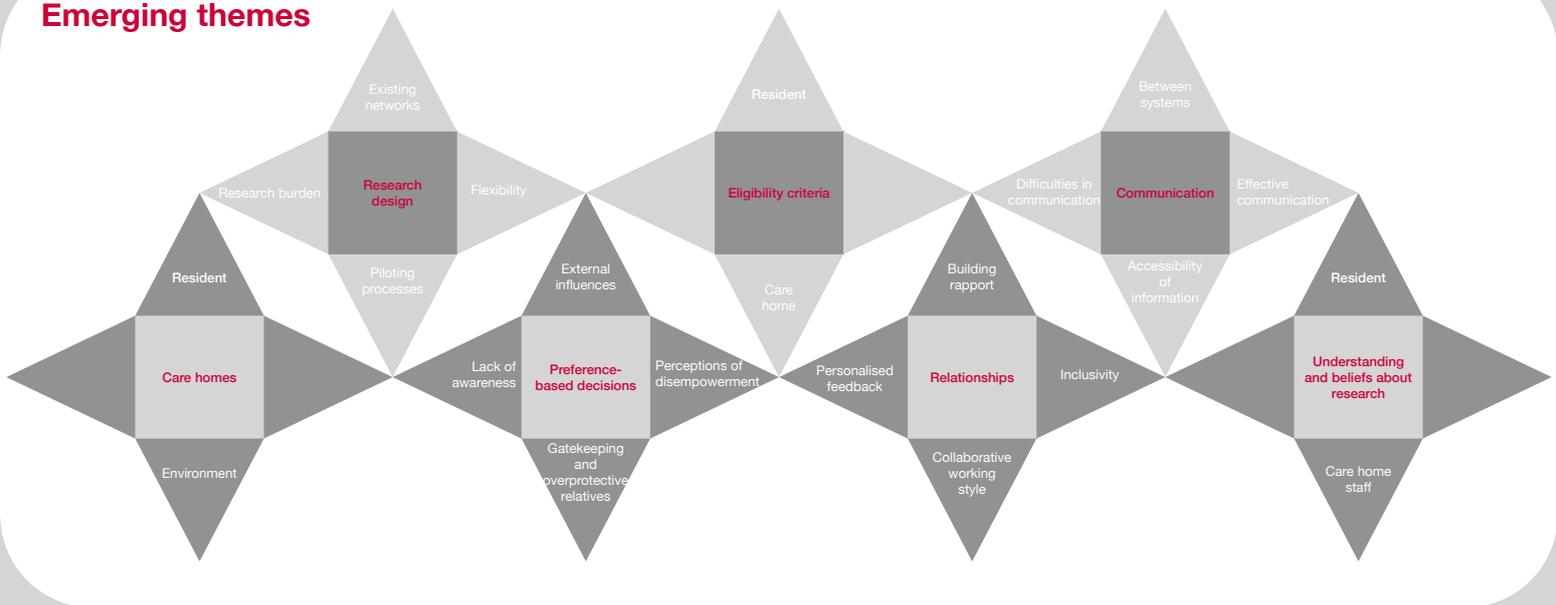
Results

Of the 90 papers identified, 84 reported potential barriers and 75 reported potential facilitators of inclusion of UK care home residents in research. 30 of the included records also included advice or suggestions for improving the inclusion of care home residents in research.

Alongside factors that directly affected the inclusion of care home residents, identified whilst undertaking analysis of the records included, a number of indirect factors were identified which were viewed as important and influential and so warranted inclusion. These complex barriers and facilitators to the inclusion of UK care home residents in research were organised into seven thematic categories.



Emerging themes



Emerging themes

The emerging themes encompass a range of barriers and facilitators to the inclusion of UK care home residents. These include factors surrounding general research design and specified eligibility criteria for both participants and for care homes. Communication in terms of the presentation and accessibility of information, and communication between care homes residents, care home staff members, and the research team, as well as the relationships between these systems are discussed. Factors surrounding the understanding and beliefs about research of both residents and care home staff make up another theme, as do care home factors surrounding both the care home staff and the care home environment.

Conclusions

In order to understand why UK care home residents are often excluded from research and, as a result, are underrepresented in research, it is important to consider the potential resident-related barriers and facilitators to their inclusion. This scoping review has identified and synthesised resident-related barriers and facilitators to the inclusion of UK care home residents in research, available in the existing literature, using a narrative approach. Isolating resident-related barriers was more complex than originally thought as both direct and indirect factors needed to be considered as influential. Further research is required in order to explore the interaction between the direct and indirect barriers and facilitators to UK care home resident inclusion in research.

How can you help?

The next stage of the project aims to explore the views of care home residents, families, care home staff and other health care professionals who work with care homes, and researchers about:

- (1) current opportunities for residents to participate in research
- (2) decisions about participation
- (3) the barriers and facilitators to resident involvement

There will be a particular focus on issues related to equality, diversity, and inclusion.

If you identify as one of the stakeholders listed above, we would be very interested to hear your views. Please consider completing the survey to help with the next stage of this project. You can access the survey by scanning the QR code. Alternatively, please ask for a link or a paper copy of the survey, as preferred.



References

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