Understanding meaningful PPI in research with older people living in residential settings

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Research in care homes – redefining relationships and expertise

This presentation will use an ongoing research project

Consider the process and the results of attempting this redefinition
What’s in a name?

Considering starting points for relationships and ideas of expertise

From EMPIRE to RReACH

Starting points – institutional activities – bidding, proposal, staff recruitment

Starting point – context of the research activity
  - Collaboration for academic health research and care – aiming to change relationships between research and health care delivery
Starting points

Starting point – context of the research activity (continued)

- Patient and Public Involvement – NIHR aiming for change in relationships between researchers and the public

![Diagram](image-url)
Scope of the project

Funded for 18 months

Research associate funding – appointment process resulted in 3 individuals, each working part time.

Aims of the project

◦ What are key research messages from successful collaborative research involving older care-home residents?
◦ What has been successful in achieving PPI in residential settings
◦ What skills, resources and planning are needed?
◦ Who are the ‘patients and public’ when carrying out research in care homes?
◦ What are residents’ priorities for involvement in research?
◦ What concerns do residents have about involvement in research and how can these be addressed?
Initial proposal

‘Active involvement of older people with experience of residential care settings is central’

How to achieve active involvement

◦ Through membership of an advisory group that meets regularly throughout the project
◦ Through direct supported work alongside researchers

Research design and methods

◦ **Systematic review** of literature of research involving PPI in care homes
◦ **Focus groups with older residents** to discuss findings of systematic review, and other ways and priorities for involving residents in research
Developing an engaged process

**Defining relationships** between faculty staff (Anne, Bridget, Fiona) and fixed term contract researchers (Andrea, Kathleen, Tamara)

**Processes** – discussion in team meetings and through email, of principles and practices, shared reflections on processes, ‘What kind of team are we?’

**Results** – changing the name of the project, extending the reach – engaging with people who may not have been approached before – going beyond existing networks – negotiating the possible ways to relate with the project, process evaluation of project
Reaching out – and staying safe

Relationships – both rewarding and risky, managed in accepted practices in the context of research, how do these accepted practices afford/constrain redefinitions of relationships?

Ethical advice – about reaching out to people to collaborate on refining detailed aims and plans, defining roles as members or participants.

FOR IMMEDIATE RELEASE

Care home residents invited to shape University of East Anglia research

Researchers at the University of East Anglia are looking for older residents in care homes and their families to help shape new research projects.

A team from UEA’s School of Health Sciences are exploring ways to involve residents and members of the public better in research projects on care homes.
Literature review

Decision taken to start on this work at the same time as seeking ethical advice and preparing to make contact with possible PPI’ research team members

‘What are the key research practice messages from successful collaborative research involving older care home residents and other members of care home communities?’

English language, age over 65 (WHO and AgeUK), Timeframe 1990-2014 (National Health Service and Community Care Act 1990, NHS PPI)
# Search Terms

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<tr>
<th>Patient and public involvement</th>
<th>Care homes</th>
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<td>Advis<em>r</em></td>
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<td>Residential home</td>
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Inclusion of literature

No restriction on the methodology or types of study designs included as long as there was a PPI element in the studies and research took place with care homes, defined as ‘where residents have relocated to shared living, residential settings for older adults’

Primary outcomes
- Scope of PPI in care home research
- Nature of PPI
- Successful criteria to achieve PPI with care home residents
- The skills, resources and planning needed for successful PPI in care homes

Secondary outcomes
- PPI demographics
- Nature of reporting PPI
Process of collaboration on literature review

Extraction of relevant details of each study into a data extraction form using Access

Structured summary of each paper will be produced

Extracted data will be put in tabled for comparison between studies

PPI and research project team members will, together, discuss and determine the methods and processes for data synthesis – recording reasons for the decisions.

Results of searches and removal of duplicates – 3812 abstracts, now to be assessed for inclusion/exclusion
Summing up

Valued principles:
- Idea of equal partnership and shared decision making
- Idea of inclusiveness
- Idea of flexibility

Challenges:
- Accountabilities
- Timely recruitment of PPI members
- Fixed timeframe and resources
Conclusions

Need for evolving and reflective processes for redefinition of research relationships and working through tensions with varied accountabilities and fixed parameters

Changes along the way in this project:
- Process evaluation added in
- Reach out to build new relationships in addition to existing networks
- Offer choice to potential PPI team members about nature and extent of their activity
Acknowledgement

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References


References


