Understanding meaningful PPI in research with older people living in residential settings
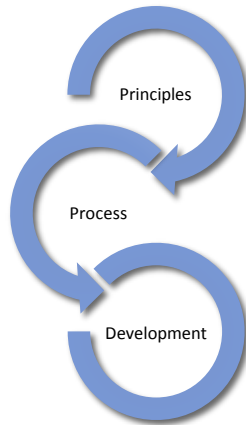
ANNE KILLETT, BRIDGET PENHALE, FIONA POLAND, TAMARA BACKHOUSE, ANDREA KENKMANN, KATHLEEN LANE

SCHOOL OF HEALTH SCIENCES, UNIVERSITY OF EAST ANGLIA

Research in care homes – redefining relationships and expertise

This presentation will use an ongoing research project

Principles

Process

Development

Members of the public

People in care homes

UEA research team

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

CLAHRC
East of England

Research Themes
patient safety
health economics
patient and public involvement
dementia, frailty and end-of-life care
enduring disabilities and disadvantage
innovation and evaluation for population health

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

◦Ongoing debates and developments in 'participation' and 'involvement', Arnstein 1968, Cornwall 2008, Tritter and McCallum 2006, Burns et al 2012, Killett et al 2012, Goodman et al 2011

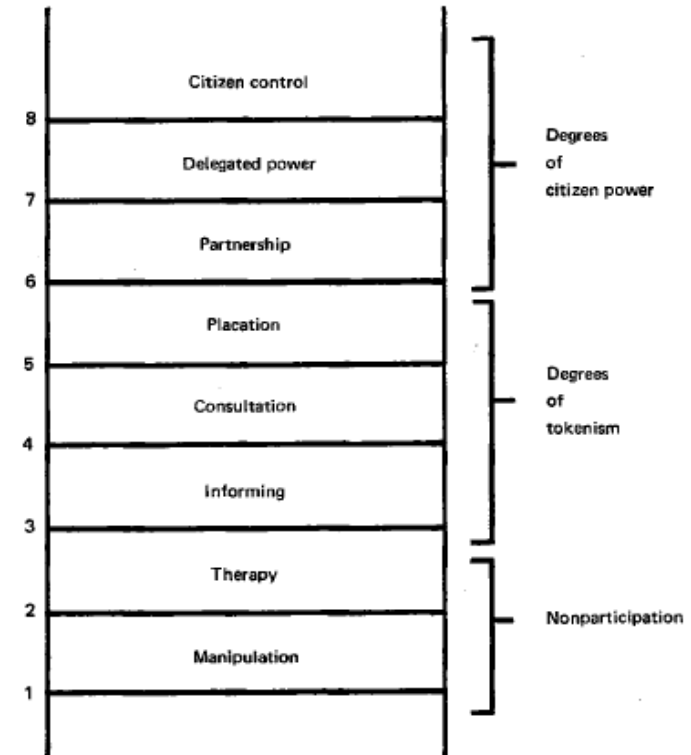FIGURE 2   Eight Rungs on a Ladder of Citizen Participation

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?

CLAHRC East of England
translating applied health research through
collaboration
University of Cambridge
University of East Anglia
East of England Academic Health Science Network
Cambridge University Hospital NHS Foundation Trust
Public Health England Knowledge and Intelligence East
Norfolk and Suffolk Dementia Alliance
Norfolk and Suffolk NHS Foundation Trust
University of Hertfordshire
Cambridgeshire and Peterborough NHS Foundation Trust
Cambridgeshire County Council
Health Education East of England
Norfolk Clinical Academy for Dementia
Rescon Ltd

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

Research in care homes for older adults often does not involve those people with real knowledge or experience of care homes. I would like to participate and

□ share in decision-making
□ give the project team advice

I would like to attend

□ regular meetings (every 4-6 weeks)
□ just a few meetings (two or three)

I can attend meetings (travel cost will be paid)

□ at the university
□ only in my own (care) home
□ somewhere near where I live
□ by telephone (at our expense)

I would be comfortable about attending

□ short meetings (1 hour or less)
□ longer meetings (up to 2 hours)
□ small groups (up to six people)
□ larger groups (no more than 12 people)

□ I will need extra support in order to attend a meeting

Please specify: _____

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

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

Patient and public involvement	Care homes
Advis*r*	Assisted living
Client	Elder care
Consumer	Homes for the aged
Engagement	Long term care
Participatory	Nursing homes
Participatory research	Old People's home
Patient and public involvement	Residential home
PPI	
Stakeholder	

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
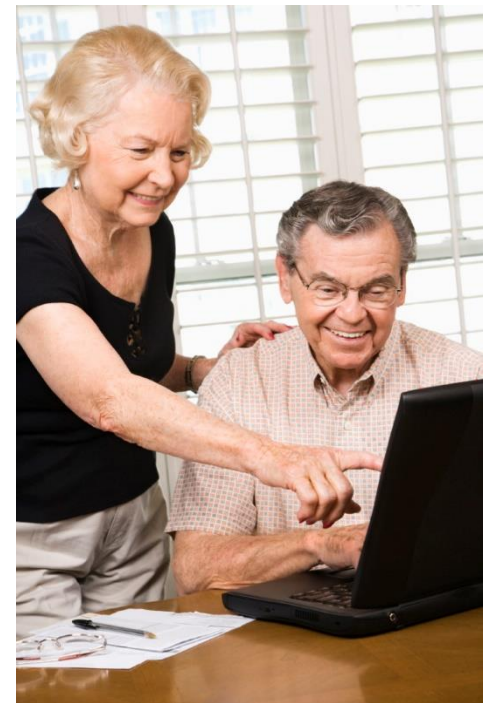
Process of collaboration on literature review

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

DIALOGUE

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

EXPLORATION

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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