



Involving older people in community-based research

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Why involve older people?

- i Involvement will improve quality and applicability of research
- i Rhetoric of participation – many demanding a say
- i Study of participants in 50+ Research Registry showed older people seeking to be involved & informed (Warburton & Dyer 2005)
- i Partnership approach part of external funding arrangements



Consistent with broader user involvement in health

- i Seen as must-do, virtuous activity (Beresford 2003)
- i Continuum of involvement from sources of data to partners to independent researchers
- i Pose different challenges and opportunities



Dilemmas of involving older people

- Older people can be seen as a marginalised group and excluded through ethical concerns
 - Vulnerability and frailty
- But does this lead to them being excluded from research?
- As well as self-excluding as a result of ageism?



Involving older people in research

What do you think are the 3 most important things for the researcher to consider when seeking to involve older people in research?



What is good community-based research in ageing?

- i Provides genuine and useful outcomes – makes a difference – used in policy and practice
- i Research should be ethical, representative and valid
- i Mutual respect = essential principle. Use strengths of all stakeholders.
- i Recognise and value diverse views throughout the process



A guiding framework

1. Acknowledge research as a process
2. Clarify roles and determine levels of involvement
3. Communicate effectively
4. Recognise different expectations
5. Recognise difference
6. Ensure representativeness and diversity



1. Acknowledge research as a process

- i Research involves different stages – from developing RQs & priorities to deciding methods, interpreting findings, promoting outcomes
- i Involvement can be across any of these stages – older people can be far more than passive research subjects
- i Remember that skills may be needed or else unequal partners. Participatory research can be empowering



2. Clarify roles and determine levels of involvement

- i Appropriate involvement needs to be determined and agreed
- i Avoid tokenistic involvement
- i Can include consultative processes eg advisory committees
- i Needs to be communicated among parties



3. Communicate effectively

- i Use of clear and appropriate terminology
- i Be age sensitive & avoid terms with negative connotations
- i Interpret research process clearly & avoid jargon
- i Look at appropriate modes of communication eg Internet?
- i Provide clear summary of findings



4. Recognise different expectations

- i Recognise different knowledges – eg research expertise
- i Community / researchers may have different priorities - organisations can help disseminate findings
- i If student project, say so.
- i Timelines should be declared – can be a source of frustration – balance between speed and quality



5. Recognise difference

- i Researchers need to ensure processes are ethical and non-ageist – frustrations of research that appears inappropriate, misleading or patronising
- i Community needs to recognise that there are diverse methods and that reliability and validity are critical
- i Also need to consider power differences & recognise different experiences / understandings



6. Ensure representativeness and diversity

- i Avoid a narrow, stereotypical view of ageing population
- i Build in diversity – there is a wide range of capacities within all age ranges
- i Most older people in community settings are willing and able to contribute to research
- i Also remember that no one is representative of all older people – experience is socially and culturally determined – no one view is “right”



Conclusions

- i Need to consider these 6 issues if seeking to undertake research with community samples of older people
- i Is there anything else that should be included??