



Social
Policy and
Ageing
Research
Centre



Safeguarding against the tokenistic involvement of older people in the participatory research process

Martha Doyle

**Social Policy and Ageing Research Centre, Trinity College Dublin,
Ireland**

4th Living Knowledge conference

**Engaged Communities, Engaged Universities: Developing policy and
practice in participatory research**

Queen's University Belfast 27-29 August 2009.

Gold Standard?

- Continuum from service-user informant to research analyst (Walker, 2007)
'A window dressing for decisions that have already been made to give an artificial appearance of involvement' (Carter and Beresford, 2000:12)
- More important the distribution of power and empowerment of research participants
- Absence of evaluations of how method altered the process or outcomes (Fudge et al, 2007)



An Account of a Participatory Project and the Lessons Learnt

Objective

Using a participatory research approach:

To identify ways of improving the delivery of social services to older people in a Dublin suburb and make practical and feasible recommendations on how these changes can be achieved.

Presentation based on article by:

Doyle, M. & Timonen, V. (2010) Lessons from a Community-Based Participatory Research Project: Older People's and Researchers' Reflections, *Research on Aging*, 32 (2)p.244-263.

Background and Design

Background:

9 month project

- 8 community members (ownership and direction of project lay ultimately in hands of the committee)
- 26 older volunteers (core group 15-20)
- A total of 26 research meetings (1-2 hours each)

Design:

- Administered questionnaire to 205 local community dwelling persons aged 60 years (Volunteers, Committee, Researcher)
- Completed seven focus groups (33 people) with service providers, family members and volunteers who delivered informal social care and support to older people in the community (Researcher – assistance of committee & volunteers)
- Analysis and write up (Researcher and Committee)

How process assessed

Volunteers' perceptions

- Non-hierarchical reflexive group meetings which sought to discuss volunteers' continued and changing impressions of the process (N=18).
- Group discussion on project facilitated by third party mid-way through project.
- One-to-one interviews (using time-line charts) with 5 volunteers at conclusion of the project.

Researchers' perceptions

- Research diary and detailed fieldwork notes after each of the 26 meetings.

Older people's perceptions of process

Motives for Involvement

Altruistic desire to help. *Giving* rather than *receiving* (Dewar, 2005). Perceived the research as being of immediate practical value to them & their neighbours.

'I meant well, I thought it was a good idea, that's why I got involved, and I'd be into all that, active, doing things... If you could do an act of charity at the end wouldn't that be good too, make some crater happy too'

Personal benefits – acquire information on entitlements and age-specific services and improve services in the area

'I suppose I was thinking maybe being selfish myself you think down the line, what might be handy to have in the area, so far so good, health wise I've been good, so I guess it was a little bit selfish about myself, getting older [why I got involved]'

Social reasons and possibility of forming new friendships

'Because I want to be mixing with people so I was glad to hear there was something on. Well I said to myself, it was nice seeing all the old folk there, people that you never even knew their faces around the area or that, like it would give you new contacts.'

Devising the Questionnaire

- Questionnaire compiled with the volunteers over 6 sessions.
- Enjoyable experience.
- Informal process. Volunteers intimated that they felt comfortable discussing ideas.
- Noticeable opening up of group by 3rd or 4th meeting.

However

- Discordance between the volunteers' and research committees' opinions on number and length of questions.

'I think the questionnaire was a compilation of everyone's views, ye [that is committee and academic researchers] might have stuck in a few of your own.....I think if you were doing it again, if you set out first of all, what do we want to find out and then the minimum number of questions to get that answer'.

Data Gathering

- Most believed it was 'exciting' and 'different'
'It's an attitude more than training you'd want, how you approach people, really I would say, open, chat to them and let them talk to you.'
- Many wanted to only approach people they were already acquainted with.
- All thought it was important to exercise discretion and were pleased that people could self-complete the questionnaire (n=160).
- Most enjoyed the social contact – with some spending over an hour talking with survey respondents.

Data Gathering (continued)

- Many potential survey respondents refused to answer the questionnaire.
- Volunteers believed the motives for refusal included pride, suspicion, scepticism, secrecy, sensitivity about issues relating to social participation and health deficits or some believing they were too young and questionnaire not of relevance of them.
- Led to extension of fieldwork by 6 weeks.

Data Analysis

- Volunteers only given opportunity to comment on complete draft of report.

Subsequent meeting with volunteers suggested:

- Some believed they had contributed enough time already to the project:

'The like of us feel now, what we have done, the next crowd is coming in and should be doing more work, we did the ground work, and we'll see what comes out of it now'.

- It may have proved unwieldy to have been more involved in analysis:

'If you have five or six people talking about how to do it you'll never get it done, the thing is one person goes off and does it, and the others make the comments on it, if you had them all in a room, you'd never get it done, 'cause people feel they must make their contribution even though they'd be saying the same thing'.

- Some would have liked the meetings to continue to maintain friendships between the volunteers.

Researchers' Reflections

Principle 1:

To recognise community as a shared unit

- Elusive concept
- Volunteers a proxy to this population?
- Many who fulfilled age criteria did not believe the research was applicable to them
- Should we have limited the target population – socially isolated, disempowered – but would this group be willing and capable to participate in data collection
- Representativeness of community within quantitative strand problematic, qualitative deemed time consuming.
- Raises questions validity and reliability concerns but is this important in CBPR?

Principle 2: Build on strengths & resources within community

- Involvement of over 40 volunteers
- Members of the clergy participated as volunteers and provided office space
- Service providers identified difficult to reach older people, disseminated questionnaires and took part in focus groups

Principle 3: Facilitate collaborative, equitable involvement in all phrases of the research

- Always assumption researcher would chair and steer meetings
- Use of innovative participatory group techniques used in other disciplines (eg Chamebers, 1994 or Becker, Israel and Allen 2006)
- Democratically elect committee
- Greater emphasis on sharing of knowledge instead of sharing of tasks?

Principle 4: Integrate knowledge and action for mutual benefit of all partners

- Unanticipated result was that many volunteers became more active in their local area, a number revisited survey respondents believed to be isolated
- Roll out of new community initiatives on completion of study:
 - Creation of a visitation team
 - Roll-out of Friendly call service
 - Age ActionCare and Repair Services
 - Book club
 - Preliminary talks on the establishment of a community day care centre

Would this mobilisation have occurred in conventional research?

Principle 6

Facilitate a cyclical and iterative process

- An aspiration towards the adoption of a reflective and iterative process at volunteers meetings.
- Suggestions on how meetings could be restructured
- Information evening.
- Did not go far enough to promote equitable involvement but fostered a sense of partnership - More group meeting between committee members and volunteers required to devolve power and foster more equitable working relationships

Principle 7

Address health from both positive and ecological perspectives

- Need to focus on interaction and importance of community, environment and personal networks.
- Research focused in equal measure on social and physical well-being.
- However, given the research design and lack of a random sample, not in a position to make any substantive claims on how health and economic factors impacted on people different or disentangle the factors that led to social isolation of some older people (eg 10% of respondents)

Principle 8

Disseminate findings and knowledge gained to all partners

- Report launched in the local area to audience of circa 150 people (mainly older people and local service providers)
- Using personal networks committee arranged for Minister for Health to launch report and other prominent politicians to attend

Principle 9

Foster a long-term commitment by all partners

- Need to work within the constraints and timetables of the community
- What are realistic cost estimations
- Time intensiveness of the process needs to be appreciated by policy-makers and funding agencies who propound the advantages of CBPR but in many cases not prepared to invest the funds required to permit an extended working relationship between the 'community and researchers.
- How is it compatible with the timetables and obligations of academics
- Will university departments recognize that in the absence of a long-term commitment, the utility and lasting effectiveness of CBPR is compromised.

Conclusion

- Danger that the moral argument for participation may obscure the practical implications and realities of involvement.

Need to question:

- How much and what type of involvement do older people want?
- How do we show adequate recognition of participants' involvement?
- Should participants who work as co-researchers be offered monetary rewards – if not are we perpetuating ageist stereotypes?
- Do older people and academics place similar importance on level of participation with CBPR – in current study preference for mid-point on continuum.

Conclusion II

- Important that weaknesses and potential short-comings be considered (engage in critical reflection)
- When control of the project resides with a small group, there is a danger that the term 'participatory' can be manipulated. It can obscure the location of power and control and lead to ageist treatment of older people whose involvement is used as a publicity tool, whose opinions are not granted equal status and whose empowerment is not pursued throughout the entire process.
- Need to stipulate transparent decision-making structures from the outset of the project
- Basing an assessment on nine principles of CBPR may be useful— need to question whether the 9 principles need to be adjusted to the priorities of older people

References

- Barnes, M. and G. Bennett. 1998. "Frail Bodies Courageous voices: older people influencing community care." *Health & Social Care in the Community* 6(2): 102-111.
- Becker, A.B., B. A Israel, and A. J. Allen. 2005. "Strategies and Techniques for Effective Group Process in CBPR Partnerships." in *Methods in Community-Based Participatory Research for Health*, edited by B. Israel, E. Eng, A. Schultz and E.A. Parker. San Francisco, CA: Jossey-Bass.
- Cornwall, A. and R. Jewkes. 1995. "What Is Participatory Research?" *Social Science & Medicine* 41: 1667-1676.
- Freire, P. 1970. *Pedagogy of the oppressed*. New York: Continuum.
- Dewar, B. 2005. "Beyond tokenistic involvement of older people in research- a framework for future development and understanding." *International Journal of Older People Nursing* 14 (3a): 48-53
- Walker, A and Barnes, M. (1996) Consumerism versus empowerment: a principled approach to the involvement of older service users, *Policy and Practice*, 24, (4) , 375-393.
- Walker, A. 2007 Why involve older people in research? *Age and Ageing* 36(5):481-483

Thank you for your attention

- **Contact Details:**

**Martha Doyle
Social Policy and Ageing Research
Centre
School of Social Work and Social
Policy
Trinity College Dublin
Dublin 2
Ireland**

E-mail: martha.doyle@tcd.ie