

Involving older service consumers in health research: action research as a strategy for promoting involvement

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Abstract

This paper considers the extent of older service consumer involvement in health-related research and, through a critical consideration of the literature, explores the levels and ways in which older service consumers are involved. Having considered the context of consumer involvement in health research we differentiate that involvement in previous studies along a continuum from passive participation to active, independent participation, and consider the strategies that support the differing levels of involvement. The experiences of research involvement from the perspectives of both older service consumers and professional researchers are explored, and the benefits of, and difficulties facing, such partnerships are considered. The importance of education and training for both older service consumers and professional researchers for such partnership working is highlighted, and strategies for enhancing effective involvement in planning, designing and managing research are suggested. The benefits of utilising an action research approach to promote and support consumer involvement are considered and the processes for developing this approach as a key strategy for promoting older service consumer involvement explored.

Keywords: Older people, research involvement, action research

Introduction

The move away from a paternalistic model of health care provision towards one where decision-making is shared between service consumer and service provider has taken place across different healthcare settings. This includes the care of the older person where maximising the participation of older people in active decision-making concerning their treatment continues to be an important policy driver (Department of Health, 2006). Alongside the increased involvement of service consumers in determining the care they receive is a parallel move towards their increased participation and partnership in research designed to develop the services they use. In this model of research, service consumers are no longer consigned to the passive role of subject where research is conducted upon them. Rather, they are able to participate in

a more active way, as part of the research team.

Reed *et al.* (2004) note that there are a number of degrees or levels of involvement ranging from service consumers as data sources, through service consumers as partners in research, to service consumers as independent researchers. The latter two levels of participation may involve service consumers developing research guidelines, developing methodology and research tools, collecting and analysing data, interpreting findings and writing up.

This paper examines the extent to which older service consumers are included in healthcare research as active participants and considers how an action research approach can be utilised as a strategy to promote involvement of older service consumers in health research. The term 'consumer' rather than 'user' has been

chosen as the preferred terminology as it encompasses a broader concept of both current and potential 'user' (Ross *et al.*, 2005). The term 'professional researcher' is used to identify those employed as researchers and distinguish them from consumers who are undertaking research.

Involvement of older people in health research: the background

The Involve library and the National Institute of Health library were searched for relevant published and unpublished literature. In addition, the following electronic databases were searched: CINAHL (1982 to June week 1 2007), AMED (1985 to June 2007), British Nursing Index and Archive (1985 to May 2007), OVID MEDLINE (R) (1950 to May week 5 2007), PsycINFO (1985 to June week 1 2007). The search terms used were: older person; elderly; geriatric and consumer involvement; consumer participation; patient involvement; patient participation; action research; research methods; research methodology.

A number of authors have considered the impact of older consumer involvement in health research, and, whilst such involvement has been identified as beneficial (Davies & Nolan, 2003; Tetley *et al.*, 2003; Barnard *et al.*, 2005; Dewar, 2005; Paterson *et al.*, 2005; Ross *et al.*, 2005), a number of important issues that need to be addressed have been identified. These include challenges to notions of power, status and accountability (Ross *et al.*, 2005), the need to clarify the role of the consumer (Barnard *et al.*, 2005; Dewar, 2005), and the need to acknowledge negative experiences of involved consumers. Studies involving older service consumers in health research have been carried out in England (Reed *et al.*, 2002; Tetley *et al.*, 2003; Greenhalgh *et al.*, 2005; Ross *et al.*, 2005), Scotland (Tolson *et al.*, 2006), Canada (Gallagher & Scott, 1997; Moyer *et al.*, 1999), and Australia

(Chenoweth & Kilstoff, 1998; Ritchie *et al.*, 2003; Richardson & Reid, 2006). Clinical settings included diabetic care (Greenhalgh *et al.*, 2005), dementia day care (Chenoweth & Kilstoff, 1998), primary care (Moyer *et al.*, 1999; Ross *et al.*, 2005) psychology (Richardson & Reid, 2006), and in-patient hospital care (Reed *et al.*, 2002). Other studies focused on general care provision and nursing care (Ritchie *et al.*, 2003; Tetley *et al.*, 2003; Tolson *et al.*, 2006).

In addition to involving older people in the research process, other stakeholders were involved by researchers. These included nurses (Moyer *et al.*, 1999; Tolson *et al.*, 2006), healthcare practitioners (Gallagher & Scott, 1997; Chenoweth & Kilstoff, 1998), 'local experts' (Richardson & Reid, 2006), bilingual health advocates and their managers (Greenhalgh *et al.*, 2005), people with disabilities (Gallagher & Scott, 1997), health and social care practitioners (Ross *et al.*, 2005) and family carers (Chenoweth & Kilstoff, 1998). The degrees to which these older people participated, echo those discussed by Reed *et al.* (2004), ranging from a relatively passive role to an active role as a fully independent researcher. These studies can be differentiated along a continuum from passive participation to active, independent participation, and the strategies that supported the differing levels of involvement identified.

Older people have participated in research in a more passive way in the studies by Moyer *et al.* (1999), Richardson and Reid (2006) and Greenhalgh *et al.* (2005). Moyer *et al.* (1999) report on a study that was undertaken with the aim of developing approaches to gain access to older adults at risk of losing their independence. The approach taken was to make contact through community networks in order to develop an understanding of their situation. The authors describe a cyclical approach to defining the problem, initiating action and evaluating change, although the level of involvement of the older people at risk did

not appear to move beyond the research participant level. Richardson and Reid (2006) describe an action research project to develop and evaluate a group cognitive-behavioural therapy (CBT) programme for older adults experiencing depression. They describe the participants in the action research process as “service consumers and service providers” (p.62). However, service consumers only participated by completing the pilot CBT programme and providing data concerning its effectiveness through completing quantitative and qualitative assessment tools. Greenhalgh *et al.* (2005) report on an action research project to develop group education and support for bilingual health advocates and elderly South Asian patients with diabetes. The authors worked with local health care staff and service consumers to assess need, train staff, set up and evaluate the education and support groups. Service consumers were involved to a lesser extent than staff and appear to have contributed to the research at the evaluation stage only by participating in focus groups and being observed by the researchers. Whilst the authors of these two papers describe this involvement as action research, arguably it does not differ from a traditional model of research in which patients and service consumers act as subjects.

Older people took more active roles in the projects described by Tolson *et al.* (2006), Chenoweth and Kilstoff (1998), Gallagher and Scott (1997), Ross *et al.* (2005) and Ritchie *et al.* (2003). Tolson *et al.* (2006) report on the first five years of a participatory research project to develop approaches to promote the attainment of evidence-based nursing care for older people in Scotland. The authors adopted an action research methodology that included older service consumers, although neither the number of older people nor the exact nature of their involvement throughout the project were clearly stated. Areas of the research where older people were involved include testing the feasibility of creating an

online community of older people and carers to collaborate on the development of resources for older people. In this phase of the project, older people were actively involved in developing resources designed to be used by older people and their carers to make their expectations and aspirations known when care is required.

Chenoweth and Kilstoff (1998) report on a participatory action research project undertaken in Australia to design, implement and evaluate a new therapy programme in a multicultural day-care centre for people with dementia. The research participants included the researchers, who acted as facilitators for the study participants, the day-care staff, family carers and day-care clients. Although the day-care clients were involved in the research to a lesser extent than were day-care staff and family carers (for example, staff and carers participated in focus groups and in-depth interviews whilst day-care clients did not), day-care clients did contribute to the research process by helping to develop an outcome measurement tool. Given the difficulties the authors experienced working with day-care clients suffering from dementia - many of whom did not speak English as their first language - these efforts to include service consumers are to be applauded.

Gallagher and Scott (1997) report on an action research project, undertaken in Canada, to identify and rectify factors contributing to slips, trips and falls in public places by older people and by people with disabilities. Research partners in the project included older people, people with disabilities, health practitioners and professional researchers. These stakeholders were consulted in order to establish project goals, develop methods and prepare for the dissemination of findings. However, the authors do not describe the exact tasks that research partners undertook nor whether different stakeholder groups participated in the research in different ways. Older people

were also involved in data collection, being both the study participants from whom data were collected, via a telephone-administered questionnaire, and data collectors who administered the questionnaire.

Ross *et al.* (2005) report on their experiences of older consumer involvement within a project carried out in a primary care setting that aimed to explore older people's expectations, priorities and need for information in relation to the risk of falls. Older service consumers were involved on a number of levels, including project design and management, analysis and dissemination of findings. A key component of the project was the establishment of a consumer panel that worked in partnership with the research team. The need for carefully constructed, regular and individualised communication was highlighted, as was the level of commitment required from the research team. Whilst both service consumers and the involved consumers generated a number of 'top tips' for improving the experience of involvement, the strategies for implementing these were not explored in depth.

Ritchie *et al.* (2003) report on an Australian pilot study to explore whether retirement village residents could be empowered to address issues of concern regarding their health and well-being. Participatory action research methods were used and the residents of three urban retirement villages were invited to be co-researchers. Residents were aged between 65 and 91 years and were living in self-care accommodation. The authors report that residents became actively involved in identifying major concerns and went on to participate in groups that addressed the issues identified, although they do not state how many residents became involved. The activities these groups undertook included negotiating with the local council, setting up a newsletter and liaising with village managers. In some cases, residents

undertook these activities alone, in others they were assisted by a professional member of the research team.

Older people adopt a very active role in some research projects (Reed *et al.*, 2002; Tetley *et al.*, 2003; Reed *et al.*, 2004; Ross *et al.*, 2005). Reed *et al.* (2004) discuss two studies where older people were greatly involved in the research process. The first investigated recent developments in discharge planning in Newcastle Health Authority (Reed *et al.*, 2002). In this study, older people were involved in a range of roles as interviewers, data analysers, report writers, editors and as co-author of a journal article. The second study (as yet unpublished) examined the issues that older people felt most affected their quality of life after retirement. In this study, the older person acted as an independent researcher, initiating the study and obtaining the training and resources needed to undertake the research.

Tetley *et al.* (2003) describe the experience of establishing and working in a research partnership exploring people's involvement in decision-making processes when using care services in later life. The authors, who include some of the older people from the partnership, describe the circumstances leading up to the establishment of the research partnership when the lead author initiated a research project to explore older people's involvement in decision-making processes when using care services. A total of seven older people became involved in the research and undertook tasks including advising and supporting the lead author on the project, attending and participating in meetings held by the regional National Health Service Executive and presenting at regional conferences. Specifically, the older people advised the lead author about the participant consent forms and participant information sheet, liaised with potential participants and assisted in obtaining consent.

In Chenoweth and Kilstoff's (1998) study, the benefits of participation that day-care clients reported included being empowered to make changes and providing companionship. These findings are echoed by Ritchie *et al.* (2003) and Tetley *et al.* (2003). Ritchie *et al.* (2003) report that residents valued the opportunity to clarify mutual concerns and to make collective decisions on changes that could enhance their own health and well-being. Tetley *et al.* (2003) report that the research resulted in personal gains for the older people who participated, including companionship and support. The study reported by Ross *et al.* (2005) highlighted the very positive way in which service consumers reported on their involvement, in terms of both the personal benefit they received (e.g. gaining an opportunity to learn about falls) and the input they gave to the study. The members of the consumer panel were subsequently able to realise their aspirations to make a contribution to on-going, local policy development, through engagement in key decision-making groups within the PCT. The degree to which the consumers' experience of involvement in research is addressed in the research reports is somewhat limited. There appears to be a tendency to focus on how the professional researchers experienced this involvement, both positive and negative. Where the consumers' experience is reported, this is, in the main, reported positively but whether this signifies that such involvement is always positive or whether negative experiences are under-reported is unclear.

Action research: an approach to maximising participation

There appears to be a stronger body of evidence for involving older users in studies that have used an action research approach (Gallagher & Scott, 1997; Chenoweth & Kilstoff, 1998; Ritchie *et al.*, 2003; Greenhalgh *et al.*, 2005; Richardson & Reid, 2006; Tolson *et al.*, 2006) than for any other research approach. Although, as

discussed above, the claims of some studies to have used an action research approach are not always fully substantiated, there have been significant developments in terms of the models of participatory research that promote older service consumer involvement (Hanson *et al.*, 2006). Action research is a method arising out of critical social theory, the aims of which are for group members to gain authentic insight into their problems and to make decisions about future goals that are both useful and empowering. In truth, action research refers less to a specific research technique and more to a set of principles underlying the conduct of an inquiry (Reason, 1988). The principles intrinsic to this approach are participation and collaboration in creating knowledge from experience, application of this knowledge as action for change and collective reflection towards ownership of what has been learned. Hence, participation by all group members is written into action research and present at all stages. Indeed, recent developments have emphasized the participatory nature of action research and its potential for democratising knowledge. Thus, Gergen (2003) discusses the relationship between action research and 'orders of democracy' noting that action research can contribute to a 'first-order democracy', by bringing people together in action and discussion, and to a 'second-order democracy', by providing a process of action, analysis and reflection through which conflict can be resolved.

King (1995) discusses four areas of benefit stemming from the participatory nature of action research that provide support for the method:

1. Benefits to the individuals who participate in the process, including trained researchers who will be challenged to justify their actions and interpretations;
2. Improved practice: those who work to create change will be more committed to bringing these changes to fruition;

3. Improved theory: a theory that incorporates the knowledge of, and is constructed by, those to whom it will apply will be of greater practical relevance;
4. Improved opportunities for meaningful social change.

Action research operates within a different paradigm to more traditional forms and King (1995) argues that new concepts of validity and reliability are required. Waterman (1998) concurs, arguing that the validity of action research does not rest on the generation of generalisable knowledge. The author suggests three forms of validity appropriate to action research relating to the principles of participation, contextual relevance and the aim of democratising knowledge. It is suggested that it is on the basis of the following that the validity of an action research study should be judged:

1. Dialectical validity: relates to the way in which an action research study engages with debates about problems and solutions with a range of participants in an attempt to improve a situation;
2. Reflexive validity: relates to the extent to which the project has considered the limitations of the study and the strengths of what has been achieved;
3. Critical validity: relates to the moral responsibilities to promote inclusivity and emancipation.

Whilst the action research model would seem to encourage the involvement of service consumers, as well as healthcare providers and trained researchers, Dewar (2005) notes that, when it comes to older service consumers, a number of assumptions work against their full participation. For example, assumptions are often made that growing old inevitably results in reduced capacity for involvement in decision-making, that older people are not sufficiently prepared to be able to articulate their opinions, and that they lack the

confidence to express themselves. Dewar argues that these ageist attitudes mean that older people are often excluded from participation in research. Reed (2005) highlights that communication and ownership of research at the practice level can sometimes come into conflict with funding and project management processes and procedures.

Using an action research approach to promote older service consumer involvement

Both theory and research strongly suggest that the involvement of older service consumers in research is beneficial, offering pragmatic and ethical benefits to both the process and the outcome of a research project. However, the extent to which older service consumers have been involved can be seen to be variable and, in relation to the more passive level of involvement (for example, Richardson & Reid, 2006), it is not easy to distinguish clearly how this differs significantly from the more traditional role played by service consumers as the 'subjects' of research.

When individuals from different backgrounds, with different experiences, skills and different access to resources come to work together, there is a risk that such differences will translate into an unequal distribution of power. Reed *et al.* (2004) stress that professional researchers need to question both their motivations for, and the likely outcomes of, involving older people in research, to examine whether involvement will be empowering or exploitative. Will their involvement see a true partnership where lay people participate fully and equally, or will an inequitable distribution of power frustrate this aim? Evidence from research reflects this concern, suggesting that this method of working presents challenges that need to be overcome if older people are to participate effectively and make a real contribution to research.

Firstly, prejudice on the part of professional researchers needs to be overcome. Whilst this may echo the ageist attitudes present in wider society (Dewar, 2005), Reed *et al.* (2004) note that such prejudice may feature in all attempts to involve service consumers in research, particularly if researchers seek to apply traditional scientific notions of objectivity and rigor. Hence, efforts to provide education to professional researchers to encourage them to re-think their conceptions of older people should be accompanied by education concerning the value and possibilities offered by other research paradigms, in particular the benefits offered through a more participatory action research approach. Hubbard (2004) identifies how a number of user-led organisations have been taking a lead in developing capacity in participatory and emancipatory research. Encouraging professional researchers to engage in a more thoughtful consideration of what methods might be appropriate to the types of research question being addressed in areas that are significant to older people could generate work in which older people are centralised as initiators and managers of research, rather than being somewhat marginalised in the more passive role as research subjects. Such education should provide concrete examples of successful projects and the benefits that are associated with a different way of working, in order to enable professional researchers to appreciate fully the important role that older service consumers can play in strengthening the validity and credibility of research.

Secondly, there are resource issues involved in the inclusion of older people as partners in research. The successful engagement of older people entails both time and material resources, including the training of both the involved service consumer and the professional researchers. Whilst, with the increasing awareness of the importance of involving service consumers in research, such training could be argued to be core to the basic training of all researchers, the

training required by service consumers – both as individuals and groups – will inevitably require costing as part of the core research project budget (Ross *et al.*, 2005) and the time required for such activity may not always be easy to estimate. In addition, service consumers should be paid and have all their expenses met, in accordance with the principles of good practice outlined in the guidance from INVOLVE (2006).

Thirdly, the specific skills that older people need to participate fully in the research process have to be clearly identified. Dewar (2005) describes developments at the Royal Bank of Scotland Centre for the Older Person's Agenda, initiated to support the involvement of older people in research. The core of the Centre's programme has been the development, implementation and evaluation of education that enables older people to participate in partnership working with a greater degree of confidence. The content of this education has included learning specific skills related to the research and policy process, as well as learning that relates to building confidence and working in partnership. Evaluation of the course revealed that participants felt they had achieved several things. These included developing a more critical approach, increased confidence, increased awareness of social and political issues, increased ability to confront situations and enhanced communication skills. 'Graduates' of the programme have gone on to participate in a variety of projects, including research and writing for publication. Although the benefits resulting from this programme are evident, it should be noted that the minimum age for participation is 50 years and while it can be argued that those aged 50 years and above are, indeed, 'older', individuals in their 50s are not 'older service consumers' in the sense understood in the literature relating to the care of the older person. Although the authors do not provide any information concerning the ages of those who have, to date, participated in the programme, they

note that recruiting participants to the programme from 'hard to reach' groups, including older people in care homes, frail older people, and people from ethnic minorities remains a challenge. However, the provision of any such education to older service consumers may undermine the aim of democratising knowledge by reinforcing the belief that only those who have received the requisite training can participate in research.

Conclusion

In this article, we have considered a range of models and strategies used to engage older service consumers in research, across a range of health care settings. However, it can be seen that there are some core structures and processes that could be usefully adopted by research teams and their service consumer partners:

Project planning

In order to present to commissioners of research a comprehensive proposal, research teams need to work in partnership with service consumers from the earliest stages of planning. This will enable strategies for developing and sustaining the required level and cost of involvement throughout the life of the project to be clearly identified. This planning stage must consider fully not only the methodology and methods of the project but also the project management strategy. A key component at this stage is to identify who will be involved, how they will be involved and what training they need in order to be effectively involved. Such training will need to be funded and it is possible that this could limit funding opportunities - in that applications would only be made to those commissioners willing to consider proposals that included training costs. However, even when such costs are fully met, what is not built into funding bids is the development of the funding bid itself and, if service consumers are to partner professional researchers in this development, it needs to be recognised

that funding such involvement is part of the core cost for organisations which undertake research. This is an obvious limitation to the inclusion of service consumers in developing funding bids, as only those organisations with existing resources are able to budget for such involvement.

Project design

The process of developing the methodology and methods of the study can be an area where tensions arise between the 'expertise' of the professional researchers and the experience of the consumer. Participatory working arrangements that build the confidence of the consumer, whilst demonstrating the value of the consumer perspective, are an important strategy to address this potential tension. Creative ways of developing consumer involvement need to be sought and this, in itself, may be an important factor in project design, perhaps requiring an eclectic rather than purist approach to the selection of methods to be employed in the collection and analysis of data. Where necessary, training for both the professional researchers and consumer researchers that enhances their skills in new ways of working should be beneficial.

Project management

There is a risk that the perceived 'expertise' of the professional researchers and the stringent requirements of research governance structures and processes will diminish the potential for effective consumer involvement in the management of the project. The skills that older consumers bring with them to the project need to be identified and utilised. Similarly, the skills developed in the course of the project should be recognised and built on. Project management structures that are non-hierarchical, yet with clear lines of communication, responsibility and accountability may well offer the best option for enhancing consumer involvement in the management of research projects.

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