

How does the rhetoric of 'user participation' in research apply to older people?

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Abstract

In recent years there has been a government emphasis on the involvement of service users and carers in the planning and shaping of services. The rhetoric and, to a lesser extent, the practice of user participation in research, is very much embedded in current health and social care policies and practices. Yet there remains an assumption that older people are less involved in this process in comparison to other user groups. In response, this discussion paper highlights the different research initiatives older people have been involved in and suggests that training in research skills for older people is crucial to further advance their active and meaningful participation. Older people's involvement in research occurs along a continuum of participation, although research that is fully led or controlled by older people remains a rarity. The narrow range of involvement by older people in research is considered in relation to both policy and practice.

Keywords: User involvement, older people, user research

Introduction

During the early 1990s, service user consultation and involvement became high on the political agenda in the UK, with the advent of key documents like Working for Patients (Department of Health, 1989) and The Patient's Charter (Department of Health, 1991). More recently, there has been a government emphasis on the involvement of service users and carers in the planning and shaping of services (NHS Executive, 1999; Department of Health, 2001, 2002). Early initiatives largely involved consultative models of involvement, whereby views were primarily sought on individual care or service developments. Since then, more democratic models of involvement have emerged that have been influenced by disabled groups and social care services (Beresford, 2002). In light of this, Peace (2002) suggests there is now a 'rhetoric of participation', which actively encourages people to take part in service development and knowledge production. However, not all user groups have had the

same opportunities for participation (Hubbard *et al.*, 2004).

Ageist stereotypes which assume that ageing leads inevitably to a reduced capacity have been identified as hindering older people's involvement in research (Reed *et al.*, 2004; Dewar, 2005). Additional ethical concerns have been raised when involving older people particularly those who are frail and those who have dementia (Warburton & Dyer, 2004). Some professionals have also raised concerns about the additional time and costs that are perceived to be incurred when meaningfully involving older people in the research process (Dewar *et al.*, 2004). These reasons and rationales may go some way in explaining why older people appear to have a less established tradition of involvement in research in comparison with other user groups. For instance, mental health service users have very much led the way in user research and have established national research networks, such as SURGE (Service User Research Group for England) and SURE (Service User Research Enterprise) at

the Institute of Psychiatry, King's College, London. However, there is a danger that somehow presuming older people are less likely to get involved in research activities may perpetuate an assumption that they are less active and interested, thereby potentially denying this group of service users any benefits that might occur through involvement.

To what extent are older people actively involved in research?

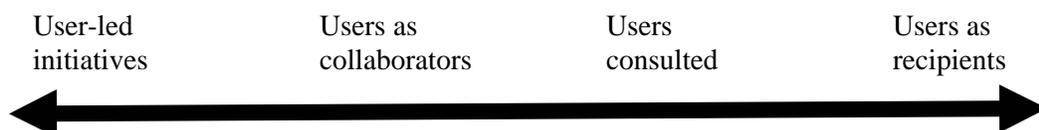
Until recently, service user involvement in research has been mainly as 'subjects', a passive position on the right-hand side of the continuum of participation, as illustrated by Lathlean *et al.* (2006) in Figure 1 below. In recent years, there has been a shift towards meaningful and active user involvement in research. On the continuum of participation, this has meant a move towards the more active end, where service users are involved as collaborators or directly leading initiatives or research projects. Active participation is assumed to be both beneficial and necessary in developing better quality services that are more relevant to the priorities and needs of those who use them (Thornton, 2000; Ross *et al.*, 2005).

As with user group participation in research more generally, older people's involvement occurs along a continuum of participation. For example Dewar *et al.* (2004) were commissioned by the Scottish Executive and Convention of Scottish Local Authorities to provide information in relation to how older people are involved in the planning, delivery, monitoring and evaluation of public services in Scotland.

The older people were not involved as researchers but as data sources in focus groups, indicating their typical involvement along the passive element of the continuum. Likewise Ross *et al.* (2005) recruited a small group of older people to form a panel working alongside the research team disseminating findings about a local falls prevention scheme as part of the Department of Health London Primary Care Studies Programme. The panel's role, the authors concede, was similar to an advisory group by ensuring that the way the research was undertaken was relevant to older people using health and social care services. The older people were not directly involved in the study, but they did participate in the development of the interview agenda, provided guidance, validated methods and worked on the analysis. Such participation indicates a shift towards the middle of the continuum, as it is at this point that involvement becomes more active.

At the middle of the continuum of participation, service users are likely to be involved in the designing of an interview schedule or questionnaire, conducting interviews or participating in the analysis of data and the writing of papers or other dissemination activities. The study by Prager (1995) is illustrative of the sorts of user involvement at the middle of the continuum. Here, 11 older people averaging 73 years were trained in survey techniques to conduct a pilot study of frail elderly living in Tel Aviv. The older people were not involved at the early stages of designing the study nor at the latter stages with the dissemination of the findings, but they were involved in the refining of the research instruments.

Figure 1 Continuum of participation (Lathlean *et al.*, 2006)



It is at the opposite end to passive involvement on the continuum of participation (Figure 1) where the research becomes fully user-led in the conception, design, execution and dissemination of research projects. Fudge *et al.* (2007) reviewed the literature on active involvement by older people at any stage of the research process other than as research subjects. They found no published research that was led entirely by older people. However, since 2000, the Joseph Rowntree Foundation has been supporting a programme of research concerning the lives of older people. The programme was developed by an Older People's Steering Group whose members were older people, researchers and policy advisors. This programme of research remains unique, as it focuses on the priorities defined by older people, rather than those traditionally set by professional researchers and planners. The steering group has completed 18 projects in relation to 'searching out the issues', and a further 9 which aim to bring about service changes informed by the programme's findings (Older People's Steering Group, 2004).

As part of this programme, the Joseph Rowntree Foundation funded the *Housing Decisions in Old Age* (HDOA) study that explored people's housing pathways in later life (Clough *et al.*, 2006). A group of older people was recruited to carry out 189 in-depth interviews and, although the older people were not fully involved in the study at all stages, 10 members have since set themselves up as the co-operative *Older People Researching Social Issues* (OPRSI). Having recently completed a one-year project on 'Older People as Researchers: Potential, Practicalities and Pitfalls', funded by the Joseph Rowntree Foundation, the group is now offering its services as qualified and experienced social interviewers. With support from 2 members of the HDOA research team, OPRSI has also undertaken smaller research contracts, been asked to participate in training

activities, written research proposals and is taking part in a larger two-year Department of Health funded project on user-professional relationships in health and social care (Leamy, 2005).

What is the value of research skills training?

In order to empower older people to better understand the research process and undertake their own research, some training in research skills is essential (Davies & James, 1999). In order to promote the active involvement of older people in the research process, some projects have incorporated training in research skills for older people. For instance, HelpAge International is a community-based, research and development organisation working to improve the lives of disadvantaged older people. The organisation values the full participation of older people as crucial to ownership of the process of community development and advocates the training of older people in participatory research methods (Heslop, 2002).

In the UK, Clough *et al.* (2006) delivered research training (awarding a certificate in social research methods), for the older people involved in the HDOA study. The authors also highlighted the role of Staffordshire University who collaborated with Staffordshire Health Authority to develop a research training course for older people and those with disabilities. The idea underpinning the project was not about directly influencing particular structures or services, but to engage service users with the idea that they should be more involved in the services that they use. Dewar (2005) further reports on a training programme provided by the Royal Bank of Scotland Older People's Agenda, which was devised to facilitate older people in becoming more involved in partnership working. The course intended to build upon the expertise and knowledge that older people possess. The only entry criterion for participants was to

be a minimum of 50 years old. Following this programme, the older people could then progress to a further course on developing participatory appraisal skills. The author reports that 35 people underwent all or some of the units of this programme and many have since utilised their new skills with the writing of articles, co-facilitating courses and taking on the role of co-researchers.

A number of the research training programmes identified were based on formal accreditation. For example, the training programme developed by Leamy and Clough (2006) at Lancaster University ran over two terms and was a 40 credit unit requiring the completion of four assignments. High demand for the Lancaster programme led Bournemouth University (in collaboration with Bournemouth and Poole College) to develop an accredited training course in Community Survey Research for older people, equivalent to NVQ1 or GNVQ Foundation (Fenge, 2006).

By contrast, Taylor (2006), who undertook a study to identify the research training, support and information needs of 10 UK-based Older People's forums and groups, found that most wished to avoid any form of accredited research training. The benefit of accredited research skills training for older people is further questioned by Reed *et al.* (2004), who suggested that, although it has the potential to increase confidence, it may reinforce the traditional view of research being an expert activity that lay people cannot undertake in a meaningful way. Instead, the authors suggest training should not become tied up with technicalities whereby the value of involving older people in research becomes lost in abstruse debates about applied and conceptual complexities.

Why involve older people in research?

At the University of Massachusetts, the Manning Certificate Programme in Gerontology developed 2 models for older

people researchers (Bass & Caro, 1995). In the first model, the older people researchers participated in an action research project, which was part of the certificate award. In the second model, the graduates of the course became researchers in a 12-month research project. The authors suggest that participation in the models has the potential to impact positively upon the older people's lives, as they learn about particular social and policy issues. In addition, they suggest that when older people are equipped with specific policy and research information, they can play a significant role in the shaping of public policy. Being involved in research thereby has the potential to bring about self-empowerment, as communities and individuals come together to identify and solve their own problems and bring about change (Macauley *et al.*, 1999; Dewar, 2005). Leamy and Clough (2006) suggest that the learning of research skills also has value if older people are interested in attaining voluntary and community employment. Additionally, having opinions and views listened to - sometimes for the first time - has been identified as positively impacting on the lives of older people (Heslop, 2002).

Involving older people in research can also benefit and strengthen the research, as Bass and Caro (1995) found when older people were involved in undertaking interviews. The similarities in age led to higher levels of rapport, which meant that the older people researchers were often very successful in obtaining rich responses from respondents. Similarly, Ross *et al.* (2005) found that involving an older person as an independent observer in a focus group added another layer of insight to the analysis and interpretation of the data. Peace (1999) suggests that, by involving older people in research, a new analytical seam can be brought to the process, as older people often bring their own experiences and sensitivities to topics.

What are some of the issues and tensions?

Involving older people in the research process has the potential to impact positively on the lives of older participants and can strengthen the research. However, Reed *et al.* (2004) suggest that actively involving older people in the research process can also raise different challenges, depending upon where their involvement occurs along the continuum of participation. Reflecting upon their experience of involving older people in research, the authors point out that in one study there was a difference between the academic researchers' and older people's views of what constituted 'good research'. The older people had extensive experience of services and the improvement of these services was their priority. Similarly, although the academic researchers wanted to contribute to service development, they acknowledged the additional criterion of meeting academic rigour, which was compromised when the older people departed from the interview schedule, leading to inconsistencies in the data. The authors' response was to reject a 'purist' research stance and adopt a model of user participation, which involved taking into account the views of the older people, particularly around data analysis and action planning.

Negotiating and agreeing levels of involvement were also raised as a tension in the Lewisham Older Women's Network, which was commissioned to undertake a health survey (Peace, 1999). Some members of the committee did not want to take part in the data collection process and, in response, the older people were allowed to choose which part of the process they wanted to be involved in. The varied levels of member involvement illustrate that older people cannot be assumed to constitute nor be treated as a homogenous group. Research also shows that ageing varies between different communities and societies (Heslop, 2002). There are also distinctions,

in relation to gender and different minority groups, lifestyles, beliefs and also in attitudes and approaches to old age, as well as fitness and income levels (Blake, 1998). Retired people have reported that they desire the space to enjoy family and leisure activities (Thornton, 2000). If their involvement is not focused, there is the potential that the older people will become frustrated, leading to disillusionment and fatigue (Peace, 1999).

When considering self-organised groups of older people, it appears for the most part that they tend to focus their attention towards issues directly affecting retired people, such as social problems around ageism, pensions and other related issues. Thornton (2000) suggests that older people might not necessarily want to be involved in researching these matters, but focus on them as they believe they are easier to influence. The author provides the example of the Northern Ireland Help the Aged Senior Panel, where the older people decided to focus on free public transport as they considered they had the best chance to influence policy-makers in this area.

The end of collaboration can also raise a number of issues, as Tozer and Thornton from the Social Policy Research Unit at the University of York found (Peace, 1999). The authors established an Older People's Advisory Group to guide their study, which was concerned with identifying opportunities for older people to have their say in the planning and evaluation of community care services. At the start of the project, the older people were informed that the work and collaboration was time limited. Nonetheless, many of the older people, who had gained confidence and new skills through participating, felt bereft when it came to an end. The authors concede that they found this aspect particularly challenging, especially if the older people did not have any other commitments at the end of the project.

Discussion

The above outline review challenges any assumption that older people are less active and interested in research. There are examples of research initiatives taking place across the UK that older people are actively involved in. However, when it comes to research that is fully led by older people, this appears to be scarce, if non-existent. The Older People's Steering Group (2004) at the Joseph Rowntree Foundation report that, organisations which are responsible for developing policy and service strategies for older people and who fund research, often fail to sufficiently involve older people in defining the questions, undertaking the work or negotiating the meaning of the findings. The group concludes that, until there is more effective involvement, policies and services are unlikely to reflect accurately what older people need and want.

Older people's lives and interests are, of course, wider than health and social care issues. A great diversity of experience exists in the lives of older people, which has often been ignored or overlooked in those areas that older people may be asked to focus upon. It is crucial that older people are involved in broader issues and not only those matters relating to health and social care (Dewar *et al.*, 2004). Furthermore, a number of practical issues need to be considered if older people are to be actively involved in all stages of the research process. The additional time, costs and commitment it can take to meaningfully involve older people in a truly participatory way, whether leading or collaborating in the research, cannot be underestimated. Research commissioners specifying the need for public involvement should grant a budget that recognises the costs of authentic and effective participation (see INVOLVE, 2006). Training in research skills is crucial for older people if they are to participate in and/or adopt a leadership role in research. Whether the programme of study is accredited or not is likely to be influenced

by the funder. However, as Taylor (2006) suggests, accreditation is not necessarily seen as a priority by older people themselves. Heterogeneity amongst the older population suggests that the decision on accredited research skills programmes should be made in collaboration with those who are likely to attend the training (see also Peace, 1999).

Planning the involvement of older people in research is an activity that should occur before a study begins, as well as during the life course of a project. However, the ending of involvement is not always fully considered or prepared for. Very often friendships are formed during the course of a project that provide emotional and social support. Older people may acquire new confidence and skills and may feel disappointment and disillusionment when their competences and new capacities are no longer required – hence the end of involvement needs to be suitably planned for.

Additionally, working within a conventional deductive research stance that favours objective, value-free knowledge may not be wholly compatible with a more participatory form of research that seeks the active involvement of participants in the research process and emphasizes the need to do research 'with' rather than, traditionally, 'on' participants (see Northway, 2000). Such a shift requires moving away from the conventional hierarchical relationship of researcher/researched, and entails a reconceptualisation of the research act with regard to a fair and open use of power, if those who are marginalized and vulnerable are to have their voices heard (Winter & Munn-Giddings, 2001; O'Brien & Moules, 2007). Until such a shift takes place, policies and services are likely to be developed that do not reflect the needs and priorities of those who use them.

Conclusion

The rhetoric of user participation in research has not led to all user groups being involved as equal partners in the research process. Older people have been assumed to be less active and interested in research than other service user groups. This paper indicates that such an assumption is not accurate or appropriate, albeit research that is fully led and controlled by older people appears to be some way off. If we are to advance older people's active involvement in research then older people, professionals and researchers need to possess the skills and resources to make this happen. Older people need to have greater access to research skills training and funding needs to be more realistic about the costs of meaningfully involving older people in research. Finally, we need to see more assertive organisational and government guidelines that promote the active involvement of older people in research if we are to develop policies and services that reflect the realities of what older people want and need.

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Notes on Contributors

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In 2007 Andy and Carol were funded by Skills for Care, in collaboration with Essex County Council, to run a 12-week training course in research skills for older people. The course was co-facilitated by all 4 authors and as a direct outcome of the course 9 of the older people who

participated on the programme formed an Older People's Research Group 'WhyNot'. Further funding has recently been attained from Essex County Council to support the development of WhyNot for a further 3 years.

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