Why involve older people in research?

While some scientists will reject the premise of this question, seeing older people as the subjects or objects of their investigations and no more, the majority in the broad field of ageing must, from time to time, ponder it (among many others of course). There are three main reasons for this current dilemma in ageing research.

First the social and cultural transition in all postindustrial societies—usually labelled from modernity to post-modernity or late modernity [1]—entails far reaching changes in the nature of social relations, including those between the individual and the state. The most obvious manifestations of this cultural change are the rise of consumerism and individualism which, amplified for political reasons by neo-liberal globalisation [2], has spread from the market to the state. Therefore, in an ever widening array of public and quasi-public services, including the NHS, a ‘consumer’ perspective is sought in order to make services more ‘responsive’ [3]. Those conducting research in conjunction with these services—older people are the major user group of health and social care—find themselves having to reflect this new ethos in their work as a condition for research funding. Some do so willingly or enthusiastically, others less so.

Secondly, this consumer perspective is also reflected by other funding agencies including those charged with supporting scientific research. Therefore, the UK’s research councils have over the past 10 years stressed increasingly the importance of ‘user’ engagement and, in particular, the roles of non-academic users. For those in the field of ageing research this necessarily means the involvement of older people; hence the question at the top of the page. It creates a dilemma for many gerontologists because of their varying levels of sympathy for the principle of involvement and because, until very recently, there has been very little published on this topic and very few models of good practice to draw on.

Thirdly, these institutional, top-down, perspectives are mirrored at the grassroots level by the growth of social movements representing a wide range of groups; but they have a fundamentally different agenda, which expresses not simply a desire for involvement but, rather, a demand for control over their own lives [4]. This self-advocacy movement is represented most powerfully in the disability field and, specifically, in the social model of disability but is becoming increasingly relevant in the ageing one [5]. Therefore, older people themselves, albeit a minority, are asserting their right to be active participants not only in policy making and service provision but in research too.

For these reasons the systematic stock-taking by Fudge, Wolfe and McKevitt [6] is very timely, even if its findings will raise no eyebrows. The period covered by the review excludes many of the outputs from the ESRC Growing Older (GO) Programme which represented the most substantial boost to the involvement of older people in scientific research, across a wide range of approaches (see below), that ageing research in the UK has seen (GO Programme http://www.growingolder.group.shef.ac.uk/index.htm). Also, as the authors note, their study is limited by the fact that it searched only peer-reviewed journals. This is likely to exclude a great deal of relevant literature because, on the one hand, the idea of user engagement is relatively new to social research let alone to the biological and physical sciences and, therefore, it has yet to be subjected to sustained scrutiny. More importantly, on the other hand, some journals reflect a rigid positivistic scientific paradigm that finds alien the subjective, uncontrollable features of involvement. Therefore, not surprisingly, there is considerable variation in the current practice of engaging older people in research by different disciplines and in the expectations of their respective research funders. Undoubtedly social research led the way and the name of one of the pioneers of older people’s involvement, Averil Osborne, is kept alive by the British Society of Gerontology fund aimed at encouraging this endeavour [7]. Again, not surprisingly, there is variation in practice within social gerontological research. While most funders look for convincing evidence of engagement the Joseph Rowntree Foundation (JRF) has sponsored a long series of projects that have enlarged substantially the scope and meaning of older people’s involvement in research [8–11].

What the current involvement of older people in research means in practice can be characterised as a continuum between two ideal types: consumerism and empowerment [12, 13]. The consumerist model consists of relatively small incursions by older people into the research process, most commonly as a relatively passive reference point among several to be ‘consulted’ for example through focus groups or membership of project advisory committees. At the other pole, much less frequently, older people are more closely involved as active research participants. This active engagement ranges from making contributions to various stages of the research process, from taking a leading role in problem definition and conceptual development [14, 15], to commissioning (through representative organisations), to formal training as researchers or co-researchers [11, 16, 17]. In between is a range of different practices and statuses in the relationship between researchers and older people. As Fudge et al. found the most common forms of involvement...
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are skewed towards the consumerist end of the continuum. This is certainly the least challenging approach and one that may satisfy the research funders (though not some such as JRF) but, again, until very recently, there have been very few more thoroughgoing examples of involvement to learn from and they are all consistently challenging, time-consuming and, invariably under-funded.

So why bother? There are two main reasons why older people should be involved in ageing research. First of all, as a matter of human rights, like any human research subjects, older people have a right to be consulted about research that is being conducted on them. Arguably this imperative is particularly strong with regard to older people because of their experiences of age discrimination and other forms of social exclusion. The only question, therefore, should be how much consultation/involvement? The answers will differ between and among disciplines. Access to the meaning of old age, however, cannot legitimately be attempted scientifically without the active engagement of older people as participants of various kinds in the research process rather than ‘objects’. Needless to say the results of research conducted within this participative framework will be enriched by a dialogue based on older people’s interpretations of their own lives and experiences and the researcher’s. Secondly, if researchers want to produce findings that might contribute to the quality of life of older people or the quality of the services or products they use, then it is essential to involve them so that they can contribute their own understandings about ageing and service use which can often be far removed from those of scientists and service professionals [18]. The well documented partial and precarious take-up of assistive technologies [18, 19] is just one example of the inadequacy of attempts to involve older people in identifying needs and appropriate solutions [20].

Beyond these essential ontological and epistemological reasons for the involvement of older people there may also be political ones, such as to further or respond to their experiences of age discrimination and other forms of social exclusion. The only question, therefore, should be how much consultation/involvement? The answers will differ between and among disciplines. Access to the meaning of old age, however, cannot legitimately be attempted scientifically without the active engagement of older people as participants of various kinds in the research process rather than ‘objects’. Needless to say the results of research conducted within this participative framework will be enriched by a dialogue based on older people’s interpretations of their own lives and experiences and the researcher’s. Secondly, if researchers want to produce findings that might contribute to the quality of life of older people or the quality of the services or products they use, then it is essential to involve them so that they can contribute their own understandings about ageing and service use which can often be far removed from those of scientists and service professionals [18]. The well documented partial and precarious take-up of assistive technologies [18, 19] is just one example of the inadequacy of attempts to involve older people in identifying needs and appropriate solutions [20].

Beyond these essential ontological and epistemological reasons for the involvement of older people there may also be political ones, such as to further or respond to their self-identification and emancipation, to challenge ageism or to produce data for campaigns [4, 13]. Linked to the socio-cultural transformation referred to earlier is a new multi-layered politics of ageing, which includes an emphasis on self-representation by older people [21].

These reasons for involvement suggest forms of engagement that move beyond the often tokenistic approach of consumerism towards the empowerment end of the continuum. Is there any evidence that this involvement benefits either research or older people themselves? Fudge et al. found that very few studies performed any formal evaluation and that these were focused on only one side of the equation. On this basis they draw a justifiably cautious conclusion. In the wider literature, there are more examples of such evaluations although these are still in the minority. What they reveal, however, is that the huge efforts entailed are usually considered worthwhile not only for the older people but also for the research questions and, indeed, the researchers [8, 9, 22, 23].

The current New Dynamics of Ageing Research Programme funded by five UK Research Councils (ESRC, EPSRC, BBSRC, MRC and AHRC) has picked-up the baton from the GO Programme and placed the involvement of older people high on its agenda (NDA Research Programme http://www.newdynamics.group.shef.ac.uk/). This includes the creation of the first Older People’s Reference Group in a Research Council Programme. The European Research Area in Ageing (ERA-AGE http://era-age.group.shef.ac.uk/) has also made this topic a priority and will shortly publish a guide to good practice [24] to supplement those cited earlier and others such as the excellent HelpAge International source book on participatory research with older people (with particular reference to development) [25]. On the basis of these resources, the growing commitment of researchers in this field to involve older people and the parallel desire of older people to take an active role in research, it is expected that the next systematic review will be based on a substantially increased level of scientific outputs.

References


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Evaluating the impact of the National Service Framework for Older People; qualitative science or populist propaganda?

The 'evidence-base' for policy in United Kingdom healthcare is often conspicuous by its absence.

But can we assemble evidence on the effectiveness of policy? If policy is about ways of organising services to deliver interventions of proven value, then evaluation could look at implementation, and crude outcomes. A policy to change stroke services to deliver thrombolysis, could be evaluated by the proportion of cases thrombolysed, safety data, and survival rates. Similarly, we might quantify the activity of falls services, or the rates of people going into care homes. Health policy is more than this, however, promoting structures, systems and procedures, which, whilst often attractive at face value, lack any rigorous empirical support. Moreover, policy is implemented within a social and political context of ideology, commercial interests, resource constraints, media reports, pressure groups, lobbyists and public expectations, all of which skew its effects.

The National Service Framework for Older People (NSFOP) was published in 2001 as a broad service specification for the way older people should be managed in health and social care. It included specific guidelines on stroke, falls and mental health, which were more or less uncontentious. However, there were also aspirational system-wide standards on avoiding age-based discrimination, promoting dignity and person-centred care, a Single Assessment Process, and rehabilitation in the form of intermediate care. This came without tightly defined operational targets, or additional funding. Professional ownership was uncertain; the policy was for older people in the health service everywhere, not just geriatric medicine or old age psychiatry.

In this issue we publish an evaluation of the impact of the NSFOP, commissioned by the UK healthcare regulator, the Healthcare Commission [1]. The paper sharply divided our reviewers.

The study reports qualitative methods — public meetings, focus groups, and individual interviews, involving a total of 3,500 older people from around the country. Older people were largely ignorant of the NSFOP, but perceived changes over time in health and social care, some positive, some negative, some in keeping with the NSFOP, others not. Expectations were generally low. However, many with