

Exploring Innovative Ways of Seeking the Views of Older People in Health and Social Care Research

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Editorial

This edition of the journal is a product of a conference that was held in London in June 2002 to explore innovative ways of seeking the views of older people in health and social care research. The speakers were addressing some of the issues and dilemmas that they had experienced in attempting to privilege the voice of so called 'hard to reach' groups such as people with dementia and people from minority ethnic groups. The primary objective of the conference was to explore ways in which health and social care researchers seek the views of older people. Some of the discussion focused on *values* by emphasising the importance of adopting inclusive and emancipatory approaches. Such values provide a framework for understanding and exploring the reasons why researchers wish to adopt more inclusive approaches. Other participants addressed the *practicalities* of including older people, especially those who may have a cognitive impairment such as dementia. We applied the term 'innovative' to the methods discussed in the sense that they are not a common part of most researchers' repertoire of skills, for example, use of a video camera to gather data or the application of counselling skills during interview.

A major reason for the conference was the growing interest and literature concerned with hearing the views of older people in health and social care research. This body of work may be categorised in the following way and includes literature focusing on: facilitators and barriers to involvement (Oliver, 2001); methods (Bennett, 2000); impact on research (Entwistle et al, 1998); and impact on services (Chalmers, 1995). Within health and social care research there is encouraging evidence that the opinions and experiences of older people (Barnes and Bennett, 1998), older people with dementia (Wilkinson, 2002), older people from minority ethnic groups (Nazroo, 1999; Bowes and Wilkinson, 2003) are being sought. Yet, as researchers we are still at the very early stages of understanding processes that lead to inclusion and exclusion in the research process and we have much to learn from each other about good practice (Thornton, 2000).

A key context and impetus for the conference and one that may be of particular interest to readers of this journal were policy directives promoting the involvement of service users in research and also service planning, monitoring and development. One group of health and social care service users who are being encouraged to become involved in research and service planning, monitoring and development is older people (Department of Health, 2000, 2001; Scottish Executive Health Department, 2001, 2002). Underpinning this policy direction is the assumption that actually listening to those who use services will lead to the development of more responsive and effective services and thereby improve quality of life and care (NHS Executive, 1999). Likewise, researchers assume that user involvement has the potential to improve the ways that research is commissioned, designed, conducted and disseminated, thereby improving the relevance and quality of the research.

If this policy trajectory continues it is likely that the role of older people in research will become more than that of 'respondents' and 'subjects'. The Research Governance Frameworks for Health and Social Care (Department of Health, 2002), Consumers in NHS Support Unit (Hanley et al, 2000) and the Scottish Executive (2002) all encourage the active involvement of users at all stages of the research process. Whilst this growth in policy emphasis on increasing involvement is to be encouraged, we cannot lose sight of some groups whose views are still not actively or consistently sought. In particular, people with dementia are often overlooked or excluded, often due to a perception that their cognitive impairment acts as a barrier to their views being communicated (Cohen and Eisdorfer, 1986). It is only in recent years that attempts have been made to privilege the views of people with dementia (see the edited collection of projects Wilkinson, 2002; also Hubbard et al, 2002) and the papers in this edited collection build on these earlier attempts to address issues of method and methodology.

However, including older people, especially those with dementia, in research is not a straightforward task and there is no consensus on which methods are most effective. We have little understanding

about the psycho-social effects upon those who engage in health and social care research, nor whether their participation improves the quality of the research. Moreover, there is no evidence base about the extent to which user involvement influences the quality and effectiveness of services.

This special edition contributes towards this growing body of work on involving users in health and social care research in two ways. Whilst the authors each have a different focus and emphasis, collectively they address the question *why include older people in research?* Secondly, they present and assess *methods* that they have used to privilege the opinions and experiences of older people, especially those with dementia, in research.

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The paper by Stephen Sabat opens the collection with an overview of the fundamental importance of elucidating the subjective experience of excluded individuals. This is followed by a selection of papers beginning with Lee Berney and David Blane's description of the lifegrid method where they consider its benefits in enhancing long-term recall and being sensitive to the individual circumstances of participants, ending with a discussion of its applicability for research involving people with dementia. The next paper by Ailsa Cook focuses on the use of video as both a tool for data collection and as a method for engaging people with dementia in a research study on their communicative experiences. The importance of engaging with people with dementia taking part in research is also a theme of the paper by Marie Mills who discusses the importance of counselling skills for gathering data. Mills highlights the importance of the relationship between the researcher and participant and suggests a range of ways that this can be supported throughout a research project. The final full length paper in the collection is by Heather Wilkinson and Alison Bowes and describes the difficulties encountered in a study that aimed to make contact with and gain access to people from South Asian communities with a diagnosis of dementia in order to explore their experiences of service provision.

At the end of this collection Joyce Cormie presents a short paper that summarises the key methods and themes raised in each of the earlier papers to draw on and highlight the issues that emerge for practice.

Ending in this way ensures that we do not lose sight of the importance of involving older people across policy, research and practice.

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