



ERA-AGE
European Research Area in Ageing Research

GOOD PRACTICE GUIDE

Involving Older People in Research:
examples, purposes and good practice



Marian Barnes
Professor of Social Policy

Dr Sam L Taylor
Senior Research Manager

Foreword

This ERA-AGE Guide is intended to encourage those engaged in various aspects of research to consider and endorse appropriate approaches to involving older people in research. The guide seeks to encourage older people's involvement in research processes in order to produce relevant outcomes for older people themselves. The good practice guide provides several European-based examples of older people playing successful significant and different roles in research in a variety of contexts. In addition, some general recommendations are made which are drawn from the collective experience of researchers from across Europe.

I would like to thank the authors, on behalf of the ERA-AGE partners, for their clear and succinct analysis and all those who have informed the development of the guide. I entrust this guide to you as a contribution to the future development of the involvement of older people in research. A supplement ERA-AGE document 'European Examples of Good Practice in End User Involvement in Research' provides brief details on European approaches which can be accessed via the ERA-AGE website (www.shef.ac.uk/era-age). It does not claim to be definitive but it is offered as a working document that can be augmented and improved as new information comes to light. Indeed readers of this document are actively invited to contribute new information to the data base and, especially, examples of good practice. This can be done by contacting ERA-AGE, Rita Saddler email r.n.saddler@sheffield.ac.uk

Alan Walker

Director

ERA-AGE

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INTRODUCTION

1.1 Background

The European Area in Ageing Research (ERA-AGE) has further developed the recommendations of the European Forum on Population Ageing Research (Walker and Cook, 2004) and subsequently endorse the need to extend and deepen older people's involvement in research as a priority for development. This objective is located within a broader emphasis on the need for better engagement with research users and for research into ageing to become more policy and system oriented. Older people are both research users and the subjects of research into ageing and thus their relationship with such research is potentially more complex than that of other research users such as policy makers and service deliverers. This guide specifically focuses on older people's involvement in ageing research, addressing them as stakeholders with multiple interests and identities with respect to ageing research.

The summary recommendations coming from ERA-AGE Forum and good practice meetings and the European Forum on Population Ageing Research (hereafter FORUM) concerning priorities in the field of ageing research highlights the diversity of topics, concepts, approaches and methodologies encompassed within this field. Recommendations derive from broadly based discussions addressing three topic areas in the ageing research field:

1. Genetics, longevity and demography.
2. Quality of life.
3. Health and social care.

There were some potential areas of ageing research that were not identified within the research priorities, including topics relating to specifically political or cultural aspects of ageing. Such topics might include older people as political actors and as subjects of political debate, the representation of ageing in cultural productions and artefacts, older people as transmitters of cultural values and the impact on older people of cultural change. There was little emphasis on the psychological aspects of ageing, nor on what old age means to older people themselves. But even without these areas the field of ageing research identified from the ERA-AGE and FORUM recommendations is huge.

It encompasses the diversity of experiences of older people whose lives are shaped by inequalities across the life course, those whose lives have been lived in one place, and those who have migrated between places and countries. It also covers the policy, economic, domestic and geographical environments which provide the resources and constraints within which older people live their lives and seek support when they have need of this. Ageing research addresses older people as:

- social actors,
- knowledgeable experts on the experience of ageing,
- recipients of health and welfare interventions,
- care givers, and
- paid workers.

It also looks at the ageing body, what causes this to decline and in what circumstances older people remain healthy or succumb to illness.

Because the ERA-AGE and FORUM recommendations address ageing research across Europe there is much emphasis on the need for methods, measurements and concepts to enable comparison across nation states and groups within them. The temporal dimension of ageing research is inherent to the topic and the report also highlights the need for longitudinal comparisons. Structural supports are advocated that will enable multidisciplinary and multi state collaborations to produce such comparative evidence at a European level. Whilst advocating a new 'discipline of ageing' in universities, the report emphasises the value of synergies between disciplines and notes the importance of not studying ageing in isolation from other relevant topics – such as the nature of civil society. At this point the report acknowledges the significance of cultural and psychological factors in ageing although no specific priority topics are identified.

The involvement of research users is emphasised not only to ensure the relevance of the topics and approaches adopted, but also to maximise the likelihood that research findings will have an impact. It suggests that 'user groups' should have a role in translating findings into more understandable and policy relevant recommendations and that they should be funded to enable them to play this role.

At a European level networks need to bring together researchers, user groups and older people on a long-term basis to enable collaboration and more effective dissemination of research findings. The report suggests that funding for European wide NGOs is necessary to support this and that there is also a need for specific support for users to become involved in research. However, research is commissioned and takes place at very different levels: from the very local to the national and international level and older people's involvement needs to be supported at every level.

It is in this context that this guide considers the learning that is already available concerning older people's involvement in research. This derives both from direct experience of older people's involvement and from broader work on participative methodologies and practices. The focus here is specifically on older people's involvement in *research*. There are many other contexts in which older people can play a part in influencing policy, practice and public perceptions of older people: via Senior Citizens' Forums, older people's advisory groups, user panels and Pensioners Conventions. Older people also can and do take part in the context of broader opportunities for citizen participation: neighbourhood forums, membership of boards of governance of health and other public services and issue specific activities such as sustainability forums, for example. In some cases research is one aspect of the strategies used by such initiatives and examples of this are cited in this guide.

But this is not a guide to older people's involvement within these participatory spaces (for a discussion of such examples see e.g Barnes, 2005, Vergeris and Campbell-Barr, 2007 and Viriot-Durandal, 2002). Whilst there are some similar issues that affect the success of engagement in policy and service delivery contexts and in research contexts, there are also issues that are specific to the research context. Thus the examples included here are exclusively examples of participation in research.

The examples have an undeniably UK bias for which we apologise!. Hopefully this guide may prompt responses from colleagues in other European countries to offer learning from their experiences in different contexts.

1.2 How to use this guide

There are 6 sections in this guide which address various aspects of older people's involvement in research. Each section has headings and subheadings for ease of reading. The main content of Sections 1-5 is followed by a set of general good practice recommendations for implementing good practice. Recommendations are highlighted in blue. Section 6 provides a summary of good practice recommendations.

Each section heading is colour-coded and towards the bottom of associated pages you will find a matching colour-coded box. The contents page has page numbers which also facilitates readers to obtain specific information rather than reading the whole guide.

SECTION 2

PURPOSES AND TYPES OF INVOLVEMENT

2.1 Why involve older people?

It is important to consider *why* a greater involvement of older people in research is considered beneficial and worth investing in skills and capacity development in order to support. There are different reasons for involving older people and these affect both the nature and extent of involvement that might be sought in different contexts.

- a. Producing research that is considered relevant and important by older people.** Younger experts may identify issues that they think are of importance to older people, and/or necessary to understand the ageing process, but if they do not discuss these ideas with older people they may miss the point or define the research in ways that do not reflect aspects of the ageing experience that are considered most important to older people. Research resources may be invested unwisely or projects badly designed as a result.
- b. Understanding what ageing means to older people.** Ageing is not a phenomenon that can be understood solely by observing from the outside. Access to the subjective experience of ageing requires research that is designed to enable older people to make an active contribution in generating knowledge and understanding through reflecting on, exploring and communicating aspects of their lives and experiences in a dialogic process with researchers.
- c. Ensuring that research has a bigger impact.** One of the reasons older people and others who have been considered 'objects' of research have started to resist this identity and claim a more active role within the research process is because they feel exploited by research that is carried out without any noticeable impact on their lives. A key difference between research which enables researchers to access older people's own understandings and interpretations of their lives and experiences, and research which is identified as participatory or emancipatory is that the latter has explicit liberatory change objectives. Whilst the research methods adopted may be similar to those used in other research, the actors and the purposes are different. From this perspective older people's involvement in research has a political as well as an epistemological dimension.
- d. Developing skills amongst older people.** Taking part in research is an opportunity for older people to draw on and develop skills. It may enable older people to apply skills they have developed in different contexts during their lives (such as organisational or interpersonal skills) and thus experience the value of recognition for the contribution they can make, and/or may enable them to develop new skills that are valuable in various contexts.

- e. **Challenging ageist assumptions.** Taking part in research offers an opportunity for older people to occupy an active role that challenges dominant perceptions of older people as passive and solely subject to others' interventions. It places older people in the role of knowledgeable experts from whom others can usefully learn.
- f. **Generating data to be used as a campaigning resource by older people.** Research findings are an important campaigning resource: whether it be to secure public investment in clinical treatments or services demonstrated to enable good support for older people, to demonstrate the impact of pensions policies on the lives of older people, or to highlight the impact of broader policies (such as transport policies, or UK plans to reduce the number of post offices) which have particular consequences for older people. Involving older people can ensure not only that research has relevance for such purposes, but also can increase familiarity with and understanding of the implications of research findings.

Different purposes will apply in different research contexts and these purposes have implications for the nature of the involvement older people might have within the research process. Researchers and research commissioners need to consider why they want to involve older people and what types of involvement might be most appropriate in different contexts. Older people themselves will have different motivations and priorities for taking part and will want to negotiate the nature and purpose of their involvement with researchers.

2.2 How to involve older people?

Four broad types of involvement are suggested by this analysis:

- Firstly, older people may be involved as **active subjects** in the research – contributing knowledge, experience, understanding through the way in which data are generated. They may be involved both individually and collectively in this context.
- Secondly, they may act as **advisors** to researchers, research commissioners, practitioners and policy makers seeking to make use of research. They may advise on research priorities, research design, on research methods and ethical issues associated with these, on the way in which research data might be interpreted and understood, and on the policy and practice implications that might flow from this.
- Thirdly, older people can undertake research on their own behalf, acting as **research practitioners** working on their own or in collaboration with academic and other colleagues. They can undertake any or all aspects of research, including design, data collection, analysis and dissemination.
- Older people's organisations can also act as direct **commissioners** of research and make use of it in campaigning, policy work and direct service delivery.

Examples of older people's involvement in research in each of these four categories are considered in the next section. These examples also illustrate the way in which research addresses older people in the different identities listed above: as social actors, experts, recipients of health and social care, carers and paid workers.

RECOMMENDATIONS

- From the outset it is important for key stakeholders to consider the focus of research studies and why it is, or it is not, important to involve older people
- Consider how older people may be involved in research processes and identify appropriate approaches to enrich research development and the production of relevant outcomes for end users

SECTION 3

OLDER PEOPLE'S INVOLVEMENT IN PRACTICE

3.1 Examples of older people's involvement in practice

The examples discussed here illustrate in practice some of the ways in which older people have been involved in research concerned with ageing and older people, and attempts to secure engagement which had limited success. They are not necessarily to be considered 'good practice' examples (although nor are they included as 'bad practice') rather they are illustrative of the different contexts and means of involvement and of the difficulties which can be experienced in some circumstances. They also form the basis of an analysis of the issues that need to be addressed to ensure effective involvement which are discussed in section 4. This section does not attempt to be a comprehensive listing of projects that have involved older people in some active way. References to other such projects on websites have been identified, but not identified published reports of them. Other reports and articles refer to older people's involvement but provide limited information about this or do not add any further learning to the examples cited here.

Although the four categories of involvement are used in order to structure discussion, these examples also reveal the extent to which such categories are blurred and that older people can be involved in more than one way in any particular project; involvement in one way may also lead on to involvement in others.

a. Older people as active subjects of research

Developments which have emphasised the importance of ensuring health and welfare services are responsive to the needs of those who use them have resulted in research which has sought to understand older peoples' experiences of such services. 'Consumerist' research that simply regards service users as recipients and respondents to a predefined series of questions cannot really be understood as involving older people in research. However, projects such as that undertaken by Norma Raynes in Manchester go well beyond this (Raynes, 1998). This project aimed to enable older people to define quality criteria for residential homes to be used in determining contract specifications. Older residents in such homes were brought together in focus groups in order to highlight issues that were important to them. This was prompted by an open question asking them to say what they thought made a good home. Responses were recorded on a flip chart and then explored in more detail during discussions. The outcomes of discussions were used to help shape contracting specifications and some homes responded immediately to what older people had said on receipt of the research report outlining results of the study. In this instance older people who were current users of services were able to take part collectively to generate a better understanding about what is important to older people about residential care and to influence the way in which both commissioners and providers acted as a result.

In a rather different way a Finnish project sought to involve older people in designing the interventions that were then the focus for a randomised control trial to assess the effectiveness of psychosocial group rehabilitation (Pitkala et al, 2005, Routasalo et al, 2004). The intention of this study was to examine effective ways to reduce loneliness amongst older people. Since the intention was to develop interventions that responded directly to older people's own interests the older people who were part of this project were themselves involved in the design of activities and the valuing of older people's contributions to this process was identified as one factor in the success of the groups.

But it is not only in relation to their identities as users of welfare services that older people can be involved in this way. Pat Chambers and Jill Pickard (2001) evaluated a project designed to increase the participation of younger older people (50 and above) in education and other activities such as gardening, local history, photography and other activities identified as a result of public meetings with older people. They wanted to ensure that older people were involved in the process of evaluation and secured funding from the Averil Osborn Fund to enable this (see below for a discussion of this fund). The researchers used focus groups involving older people who were participants in what was known as the Lifetime project in order to generate a questionnaire which could be used to collect data from all project participants. The project aimed to increase the extent to which older people are social actors engaged in a range of educational, cultural, sporting and leisure activities and the opportunity to play an active part in the research process was seen as another such opportunity.

The above example is included under the heading of older people as active subjects of research because the focus groups generated insights from the 80 older people involved in this way as well as contributing to the design of questionnaires to be used more widely. They could also be considered as 'advisors' contributing to the details of research design and this type of involvement is evident in a number of projects, including projects undertaken as part of the 'Growing Older' programme, supported by the Economic and Social Research Council in the UK (<http://www.growingolder.group.shef.ac.uk/>). The following are examples of this.

Lennart Magnusson and Elizabeth Hanson examined approaches to improve the quality of life of frail older and disabled people and family carers by information and communication technology (Magnusson & Hanson 2003; 2005). Older people and their carers helped to shape the development of the programme by providing feedback and comments on various aspects of research during group discussions.

Sheila Peace and her colleagues at the Open University set out to explore the relationship between environment and identity in later life (Peace et al, 2003). The research started with focus groups to identify what older people thought were the most significant aspects of the places in which they lived and the results of these discussions were used to design interview schedules and an innovative research tool – a 'wheel of life'. Participants also went on to produce a video about aspects of the environment and identity.

Haleh Afshar and her colleagues studied older women from different ethnic groups in order to understand their priorities in terms of quality of life and successful ageing (Afshar et al, 2002). Older women contributed via their participation in focus groups and interviews, but also acted as advisors at the point at which preliminary findings were available in order to discuss the significance of the issues that had emerged from the study.

Research that addresses experiences of ageing is not only concerned with the experience of old age. Pat Chambers has also worked with colleagues in Cork, Ireland in a life history project with older women (Leane, Duggan and Chambers, 2002). They describe adopting feminist research methodology in order to explore Irish women's experiences of sexuality and reproduction in the period 1920-1960, in particular focusing on the impact of the Roman Catholic faith in shaping such experiences.

They used a combination of individual and group interviews, meeting the older women on a second occasion after the research interviews to explore their experiences of the research process. Thus not only did they seek to ensure the women could construct the narratives of their experiences in their own way, they were also concerned to understand the extent to which the women felt able to determine what they talked about, and to consider how this affected 'silences' within the interviews: that is issues that the women did not want to disclose.

Marian Barnes has also sought to work in ways that enables older people to generate their own stories in ways that make sense to them. Marian researched what care giving means to family carers, including older people who are caregivers, and also used narrative life history interviews as a means of enabling carers to identify what was important to them and to shape their story in the way they wanted to (Barnes, 2006). Her aims here were both to understand caring relationships in the context of individual and shared biographies and to explore the relationship between 'care' and 'rights' from the perspective of care givers. Once again this involved inviting older people to reflect back on their lives as well as talking about current experiences of caring in old age. Interviews were long – in one instance taking place over two sessions and in another resulting in informal follow up contacts to review documentary material the woman had collected relating to her experiences of health and social care services. Like Leane and her colleagues, Marian returned the narratives she had constructed from the interviews to those she had interviewed for them to review and tell her if there was anything they did not want her to use publicly when reporting the results of this study. This resulted in one woman making a number of detailed further comments.

b. As research practitioners

In the examples discussed above older people were not directly involved in undertaking research, although they were able to influence the substance of the research through methods designed to enable them to shape the interview process and, in some instances, to contribute to the interpretation of results. But increasingly older people are active participants in carrying out research and it is this that is the main focus of this guide.

In some cases there are direct connections between initiatives designed to enable older people to have a say and opportunities for them to take part in research. The Fife User Panels Project, led by a development officer working for Age Concern, Scotland, enabled older people who made substantial use of community based health and social care services to meet together to talk about their experiences of using services and to identify areas for change. Like the Raynes project discussed above its focus was on older people as users of services, but identified them as experts and active participants in determining an agenda for change, rather than as respondents to a consumer survey.

Unlike the Raynes project it was not designed as a research project but as a development initiative and the Panels were established as ongoing opportunities for older people to meet, talk amongst themselves and meet with service providers they wanted to influence. An evaluation of this project was commissioned and this aimed to reflect the participatory nature of the project itself by involving older people as research colleagues in the evaluation process (Barnes, 1999).

The older people who were members of the panels, were, by definition, people who needed assistance to meet together, who were frail and/or experiencing substantial health problems. In view of this it was decided to recruit more active older people to take part in the evaluation. Their contribution was to interview panel members about their experiences and to contribute to the process of analysing interview responses. Six volunteers aged from late 60s to 80s met with the researcher responsible for the evaluation and the development officer who led the project on three occasions in order to take part in the detailed design of interviews and develop skills in research interviewing. After the interviews had been carried they met again to talk about their experiences of conducting the interviews and to consider key issues arising from them.

Lorna Warren, Tony Maltby and Joe Cook explored the experiences of a multi ethnic group of older women in another project undertaken as part of the Growing Older Programme. This project aimed to increase knowledge and understanding of factors that affect the quality of life of older women in diverse circumstances and their desire and ability to have a say about the services available to them (Cook, Maltby and Warren, 2004; Warren and Cook, 2005). In the first phase of the research older women were active subjects talking about their lives and experiences in discussion groups. Ten women who took part in these discussion groups (reducing to 8 as a result of illness and death) went on to join the research team and carry out one to one interviews to explore in more detail the 'inner' side of ageing in life history interviews. They took part in a series of research training workshops that were extended when it became clear that they wanted to be more fully involved in the dissemination of research findings. They went on to take part in a number of conferences, produce a video (Older Women's Lives and Voices, n.d.), and one was involved in research led teaching at the university.

Research conducted by Tony Maltby and his colleagues at the University of Birmingham addressed the situation of older people as workers (Admasachew et al, 2005). The research was 'committed' research in the sense that it was designed to encourage access, retention and progression of older workers and once again sought to model these principles in the way it involved older people in the research process. It built upon the Older Women's Lives and Voices (OWLTV) project mentioned above and adopted the lessons learned in that project. An early stage of the project comprised discussion groups of older people (50+) to explore their employment experiences. From these discussion groups a team of four volunteer researchers were recruited who undertook an accredited research training programme and worked with the university research team to carry out unstructured interviews with a sample of discussion group participants. The older volunteer researchers were also involved in analysis and dissemination of research findings. Subsequently two of the volunteers received a small grant from the Averil Osborn Fund in order to carry out their own review of older people's involvement in research (Gough, Afzal and Bagnall, 2006).

A more specifically action research approach was adopted in a study involving Chinese older people (Chau, 2007). In this case Chinese older people living in different cities in England took part in a project designed to enable them to determine which aspect of local policy or

service delivery they wanted to try to influence, to support them in carrying forward their project and then to reflect on their experiences. 207 people from eight cities took part in projects focussing on, for example, lifelong learning services, a club run by and for Chinese older people and experiences of care giving.

A study carried out at the University of Lancaster with Counsel and Care and two voluntary housing agencies aimed to develop a model of housing and care to bridge the gap between "very special housing" and "residential/nursing" care. The study explored how older people make decisions about housing and what consequences these decisions have on their well-being. Older people conducted interviews as well as providing advice and opinions about the research process throughout the course of the study.

A training programme for people aged 60 and over was developed and delivered in both Lancaster and London. The practical element of this course comprised conducting interviews for the research project (<http://www.lancs.ac.uk/fss/apsocsci/decisions/home.htm>).

Finally, the 'OPPS' project, which was led by Sam Taylor formerly at the University of Teesside, trained 5 older people's forums in research methods. These Forums then went on to develop their self-led research projects. Each Forum identified their own research question and planned, designed, developed and disseminated their own research findings in order to influence local government and the development of appropriate community services. The results were submitted in a formal report to the funders of the project, Help the Aged (Taylor 2004). Substantial practical benefits resulted from these studies in terms of changes to policy in the local communities. Three of the Forums went on to participate in further studies.

These examples emphasise the importance of some form of training to enable older people to take part in research on their own behalf or working with research colleagues. The Royal Bank of Scotland Centre for the Older Person's Agenda has developed a substantial programme of training and development opportunities to enable older people to do just this (Dewar, 2005). The content of this programme is designed not only to build specific research skills, but also to offer learning opportunities that will enable older people to take part confidently in other contexts. Older people undertake basic training units:

- Building confidence and making changes.
- Drama for democracy.
- Reviewing documents to enable the older person's voice to be heard.
- Having a voice in formal arenas.
- Helping older people to tell their stories.
- Getting hold of information via the Internet.

They can then progress to a course in participatory appraisal and thus develop skills in an approach that links research to action and which enables communities to develop their own solutions to problems.

The programme was evaluated and older people were concerned to ensure that they would have opportunities to apply the skills they had learnt. They have been able to do this in a number of contexts including:

- Acting as co-researchers in a project on eating well for older people who live alone and have difficulty leaving home.
- Working with policy makers and researchers to prioritise the mental health and well-being agenda.
- Joining a European team to explore active citizenship in four countries.

c. As advisors

In a number of the projects outlined above older people acted in advisory roles as well as taking part in the delivery of research. In other cases such an advisory role is the main focus for involvement.

Researchers working at the Social Policy Research Unit at York University (SPRU) undertook research to find out in what ways older people may be able to have a say to influence community care services (Thornton and Tozer, 1995, Tozer and Thornton, 1995). Thus the subject matter of their research was the involvement of older people and the researchers sought to reflect this in the way in which they carried out the research. In addition to an advisory group comprising other researchers, policy makers and practitioners with knowledge of the subject, a separate advisory group comprising eight older people was convened and met separately for a year whilst project fieldwork was carried out.

Two members of the older people's advisory group also attended the other advisory group following an initial period of uncertainty about their relative roles and relationships between the two groups. The group questioned and commented on methods used by researchers and carried out specific tasks, such as devising topic guides and questionnaires to be used in fieldwork, and writing summaries of early research findings. They also spent time discussing issues of importance to older people and this both enabled researchers to ensure they reflected such issues within the research, and influenced the way in which data was analysed. The older people who made up the advisory group were in their 60s and 70s and not themselves users of community care services. Thus they were seen as people who could talk knowledgeably about general issues of importance to older people, but not as experts with experiential knowledge of using services. They were considered to have learnt about the research process as a result of their involvement.

The 'older people as advisors' model has been used in the context of a number health related research initiatives. For example, In Holland the Dutch Burns Foundation used interviews, focus groups and a dialogue meeting involving people with burns and professionals, to explore older people's ideas about priorities for burns research (Broerse, 2006).

One of the reasons for involving older people in research is to ensure that the impact of research in ageing is of benefit to older people and one way of achieving this is working with older people's organisations. Representatives of such organisations were members of the programme advisory group for the UK Economic and Social Research Council 'Growing Older' programme and one of these organisations, Help the Aged, brought together 14 older people to review project findings and produce a summary of key findings from the programme (Owen and Bell, 2004). This summary focused on findings the editorial board members thought would be most important to older people.

But in doing so they also produced a highly accessible summary of a large and complex research programme that has been widely distributed and used by policy makers. This illustrates the value of older people's involvement as research advisors at all stages of the research process.

d. As commissioners, direct users, campaigners

There are many organisations both 'of' and 'for' older people that are involved in campaigning and policy development as well as service delivery. Research is one aspect of the strategies that they can and do use to pursue their objectives. For example, the Alzheimers Society in the UK has a Quality Research in Dementia programme that is an active partnership between carers, people with dementia and the research community (<http://www.alzheimers.org.uk/Research/index.htm>.) At the heart of this is the QRD Advisory network comprising 150 carers, former carers and people with dementia who play a full role in:

- * Setting the priorities for research.
- * Providing comments and prioritisation of grant applications.
- * Selecting applications for funding.
- * Monitoring on-going projects being funded by the Alzheimer's Society.
- * Telling others about the results of research.

Research funded through this programme includes work on the causes, care and cure of Alzheimers.

Similarly Help the Aged funds and commissions research to provide answers to specific policy research questions in areas such as fuel poverty, crime, transport and health matters. It also provides funding in response mode for biomedical research.

Small organisations working at a local level rarely have enough money to commission research, but may be able to develop relationships with researchers to support small-scale projects without funding. For example, Marian Barnes became a co-opted member of the Birmingham Advisory Council of Older People (BACOP). BACOP was constituted as a representative group of older people to advise both the city council and local health agencies on issues affecting older people. The constitution included a place for an academic expert and Marian was recruited in this capacity. Marian was somewhat concerned that the group mainly operated in response mode – responding to issues on which statutory agencies wanted a view, rather than determining their own agenda to seek a response from service providers. She suggested research as a means of making the running on an issue identified as important by older people. As a result Marian worked with a small group of BACOP members to design and carry out a survey of older people's experiences of being in hospital, with particular reference to MRSA and other hospital acquired infections. The results of this were then used to challenge hospital managers to respond with proposals of how older people's experiences might be improved.

A rather different example of older people as commissioners of research comes from France where the University of the Third Age (UTA) has promoted research for and with older people (Viriot-Durandal, 2006). Such research has been carried out in a number of different fields associated with ageing:

- Studies of the social and biological aspects of ageing.
- Evaluations of the effectiveness of programmes designed to support positive ageing.
- Studies of older people as service providers.

- Research that focuses on the environmental and living conditions affecting experiences of ageing.
- Research that focuses on older people as citizens, beneficiaries of public services and as service users. (see French language references)

The UTA has also supported research in local history in which older people have been involved as interviewers.

RECOMMENDATIONS

- Consider different stages of the research process and identify the appropriate stage(s) to involve older people including:
 - prioritising research
 - commissioning research
 - identifying research topics
 - planning and designing research
 - undertaking research
 - disseminating research
 - evaluating research
 - using research in campaigning

SECTION 4

GOOD PRACTICE

4.1 Good practice issues

This review of the range of ways in which older people can be involved in research suggests that it is not possible to draw up a precise template that defines how older people should be involved in research in all contexts. In common with other aspects of research design and implementation, decisions about how older people might be involved need to be reached by reference to the nature and purpose of the project concerned – but beyond this they need to be reached in discussion with older people. Hanley et al (2004) suggest that at each stage of the research process people may be consulted, collaborate with researchers, or carry out research activities on their own. Decisions about which approach will be adopted have implications for the precise way forward.

There must be space and flexibility for creativity and opportunities to challenge the way in which research is prioritised, commissioned, designed, conducted and disseminated with older people. Underpinning the successful experiences of participatory research involving older people is the capacity to build effective relationships. Viriot-Durandal (2006) suggests that success stories result from ‘a conjunction of individual factors (senior citizens’ motivation), in a structural and cultural positive context (support of the university and local authorities)’. Simply following a checklist of do’s and don’ts will not guarantee success, but there are both principles and practical learning from the work that has been discussed here and other work on participatory and emancipatory research that is also useful for those wanting to increase opportunities for successful involvement of older people in research. Much of what follows assumes that older people are involved as active participants, advisors or commissioners rather than active subjects.

a. Who gets involved

Participants in a user involvement workshop organised by ERA-AGE suggested that older people who took part in decision making about research would need to be representatives of older people’s organisations, not individual experts. This reflects a commonly held concern about the ‘representativeness’ of users, citizens and community members who become involved in participation initiatives. But it is worth reflecting on both the necessity and implications of such a requirement. ‘Representing older people’ was not one of the purposes for involving older people in research considered above. If it were to be made a requirement it would mean that older people not already involved in groups or organisations would be excluded from involvement in research. This is likely to mean that those who are already marginalised: such as very frail older people, those whose first language is not the majority language and those who live in poverty are unable to take part. Acting as a representative requires a system for consulting with a constituency, feeding back to this constituency and being held to account for actions taken within the forum. This can not only place considerable burdens on older people, but can also constrain open deliberation and make it difficult for new ideas and perspectives to emerge from discussion.

It is very rare for researchers or policy makers who are invited to take part in, for example, discussions about research priorities, to be invited as representatives of a constituency. Rather they are invited because they have particular knowledge and/or experience that is considered likely to make a valuable contribution to discussions. In view of the purposes for older people's participation suggested in section 2, a similar rationale for selecting or inviting participation from older people also applies.

What is important is to ensure that the older people who do take part are those who have experience relevant to the research topic. For example, if the research focuses on hospital care, then older people with experience as patients should be involved, if it addresses the impact of migration on the experience of old age, then older people with experience of migration in early or later life are key participants. Both Cormie and Warren (2001) and Hanley et al (2004) emphasise the importance of being clear about what sort of people need to be involved by reference to the substance and aims of the project concerned. Hanley et al suggest it is worth drawing up a 'person specification' to assist this. Both also identify a number of ways of contacting or identifying potential participants such as:

- Via voluntary agencies, service user, self-help or community groups.
- Referrals from service providers.
- Adverts in public places such as libraries, social services offices, Citizens Advice Bureau offices, GP surgeries.
- Advertising through the local media.

Hanley et al (2004) also emphasise the importance of enabling people to say *how* they want to be involved and of thinking about what they want out of it. This will affect whether people get involved in the different ways identified above, but it also reminds us of the importance of ensuring that the experience of involvement is a positive one that meets the aspirations of participants. And as the OWLV study discussed above illustrates, this may change during the course of involvement - people may be hesitant at first and uncertain of what they can bring to research. But if the process is designed well and people develop skills, confidence and enthusiasm they may wish to extend the nature of their involvement and researchers need to be flexible enough to respond to this.

b. Practical considerations

Effective involvement requires face-to-face interaction and thus there are considerations about where and how such meetings take place that are basic to good practice. Experience suggests that good preparation prior to meeting can make a real difference. This can include ensuring that participants have easy to read information setting out what will be involved, but it is even better if researchers or others involved in the process visit older people in advance of starting work in order to talk through what is likely to be involved and to answer any questions older people may have about this. A preparedness to visit people on their own ground, to ask how people would prefer to be involved and answer queries is a good start to building up the trust that is necessary for effective collaboration.

Getting practical things right will also go a long way to underpin good relationships. Cormie and Warren (2001) provide advice that focuses specifically on involving older people who may be quite frail. They emphasise the need for:

- Venues that are accessible, comfortable, small enough for people to hear and see each other, but big enough so that there is space for wheelchairs and zimmer frames, warmth, and light enough for people whose sight may not be good.
- Transport to be arranged to enable people to get to meetings, with journey times that are not too long, agreed collection times that are confirmed as a reminder to participants.
- Reminder cards that are sent to all participants.
- The availability of refreshments.

Beyond these practical considerations both they and Hanley et al identify factors that affect the conduct of meetings:

- The need to agree ground rules.
- Effective facilitators and a separate note taker.
- Avoiding the use of jargon.
- Providing comfort breaks.
- Ensuring everyone can have their say – which may require the use of interpreters in some cases.
- Ensuring people receive feedback .

These practical requirements emphasise the need to ensure there is a sufficient budget to support people's involvement – to cover issues like transport costs, refreshments and the possibility that older people who are carers may have to purchase substitute care whilst they are away. Some older people are ambivalent about being paid to get involved although good practice requires that budgets should be constructed on the assumption that if older people are working alongside others who are being paid to do a job, they should be too.

c. Training

Training is essential to effective participation in research. Training in specific research skills needs also to recognise the knowledge and experience that older people can bring to the research process. Indeed, some older people will have been researchers when they were younger and may be able to *deliver* training as well as be recipients of it. Recognising existing expertise is important in its own right, but also because in some cases older people who have substantial experience may find it hard to be on the receiving end of training from a considerably younger researcher. Designing training programmes in a way that enables older people to demonstrate the skills they already have is important in ensuring that training is not experienced as patronising.

Most of the examples discussed above link training to specific projects. This has the advantage of ensuring that training is focused on the particular requirements of the project and will ensure that the skills and enthusiasm generated by the training programme can be realised through their practical application in work that has a clear end result. The following example indicates the frustrations that can arise in the absence of this.

Researchers at the University of Birmingham developed a collaborative bid for research funding with a local Agewell group. The research was to be an action research project to explore ways in which diverse groups of older people in the area might become more actively involved in influencing local policy and service delivery.

This was a topic that both researchers and Agewell members were committed to and the process of bid development took place over a series of meetings to ensure that all were signed up to it. The bid was not successful and there was considerable disappointment and frustration amongst both Agewell members and researchers as a result. There was a sense that a lot of time had been spent building understanding as well as on the practical task of preparing the bid and this was likely to be wasted. Older people who had become interested in research and had been looking forward to taking part in this were left without any opportunity to apply this interest. As a result it was decided to go ahead with a research training programme. This was seen as a way of developing the relationship and strengthening future funding applications because it would be possible to bid with a group of older people who had already undertaken research skills training. However, the training could not be focused on a specific project and there was no opportunity for the older people who took part to apply their skills after having developed them. The Agewell group subsequently approached the university researchers to work with them on bids for research projects that were outside their interests and remit, and none of these approaches could be followed up.

In contrast to this experience the work reported by Cook, Maltby and Warren, (2004) demonstrated the benefits to participants as well as to the project from the training older women went through in the context of the “Older Women’s Lives and Voices’ (OWLV) study. As well as the planned training workshops that took volunteers through both the practical and methodological aspects of research the researchers recognised and were able to respond to the desire of volunteers to be more fully involved in the project. This led to additional sessions on data analysis, preparation of data for presentation in a range of formats and contexts, and reflections on the experience and motivations of both researchers and older women in taking part in this project. The training approach adopted here, and that adopted to involve older people in evaluating the Fife User Panels project (Barnes, 1999) was of integrating training with participation in the process of developing research design. Thus, in the Fife study the training sessions were also designed to enable older people to contribute to the detailed design of interview schedules, and in the OWLV project the volunteers also took part in discussing and debating coding of interview transcripts. This approach is also valuable in avoiding the potential that older people will feel condescend to or lectured at because the process is explicitly one of working together in order to address research tasks, at the same time as enabling learning through this participative process.

The Fife example demonstrates that it is not necessary to be overly cautious in terms of the research methods to be adopted. In this instance Marian Barnes was influenced by the need to ensure consistency and comparability of data when interviews were being carried out by six different interviewers, none of whom had previous research experience. She was concerned that the results of the evaluation would be accepted as valid by policy makers and service deliverers who had been somewhat sceptical about the project and who ‘needed to be convinced’ if they were to take seriously the proposals and recommendations coming from Panel members. This led to the development of a more structured interview schedule than Marian would have used if I had been carrying out the interviews herself. But after carrying out the interviews the older people who did these commented that they thought they would have obtained more information and insights if they had not been so constrained by the particular questions predefined on the schedules. They noted that it was often after the formal interview ended that interviewees opened up and talked in some detail about their experiences. In contrast the older women who took part in the OWLV project were trained to conduct narrative interviews and generated rich data as a result.

The Royal Bank of Scotland initiative reported above (Dewar, 2005) has the benefit of being based in a Centre with an ongoing programme of work focused on issues to do with ageing and older people, rather than being linked to one specific project. Thus it has been possible to develop training courses which have enabled older people to develop generic research skills, and skills that have broader relevance such as building confidence, having a voice in formal arenas and getting hold of information, in the confidence that there will be a range of opportunities for older people to make use of these skills in ongoing work of the Centre. A variety of approaches have been used to improve the accessibility of the training process and reduce the power differential between researchers and older people – for example, creative techniques such as collage and interactive theatre. Researchers at the Centre are also exploring ways in which opportunities to take part in these programmes can be widened, for example, by delivering them in residential homes or by developing a buddying system whereby older people who have attended the course share their learning with those who are restricted in attending courses.

d. Research relationships

The importance of training for older people to enable them to develop research skills has been discussed. Researchers and other stakeholders also need training and awareness raising to understand the value of participative approaches to research and to develop appropriate skills to support this. One group that took part in the ERA-AGE workshop suggested that researchers could spend some time working in older people's NGOs to develop the organisation's capacity to carry out research. This model of putting researchers in older people's spaces rather than vice versa has the additional benefit of increasing researchers' understanding of older people's issues. Although researchers still need to contribute specific skills and expertise (for example, in the details of both qualitative and quantitative analysis), their approach to working with older people in research should be a facilitative rather than expert one, aiming to draw out different skills and knowledge and ensure that the experience of involvement is positive.

There are some very basic factors that affect the building of relationships of trust and reciprocity necessary to effective engagement. For example:

- It is important to use language that is accessible but not condescending.
- It is important to be reliable: for researchers to turn up when they are meant to and to deliver what they promise to.
- Meetings can usefully take place in places where older people usually meet as well as on territory familiar to researchers.
- Regular and effective communication will ensure all feel they know what is going on.

The issue of unequal power relationships is fundamental to much of the discussion about involving older people in research. Research can be influential in determining policies and practices that affect the lives of older people and the ageing experiences and if the research process is controlled entirely by researchers and research funders, then this can contribute to the powerlessness experienced by many older people.

The issue of unequal power relationships within research has been the focus of much feminist work on developing ways of researching with people rather than on them.

This is addressed by Leane and her colleagues (2002) and also by Pat Chambers in her study of older widows (Chambers, 2003). In this article she reflects on the research process from her own perspective and also reports on follow up interviews in which she explored how the older widows experienced being asked to talk about what becoming a widow in old age meant to them. This attentiveness not only to creating a context in which older people feel able to be active subjects in contributing their knowledge and understanding in generating research data, but also to enable reflection on the process from the perspective of participants, emphasises the nature of research as a relational activity. Insights from such studies can help researchers be more aware of the impact they have on those with whom they research and how often unacknowledged power relationships may affect responses.

In the context of research in which older people are active participants rather than or in addition to being active subjects, it is important to recognise that simply 'taking part' does not necessarily mean that power relationships are or can be equalised. Invitations to take part usually come from researchers to older people rather than vice versa and the terms of reference for involvement are often strongly influenced by the way in which researcher and/or research funders construct the value of this. This does not mean that the nature of involvement is entirely fixed from the start – as the OWLV project demonstrates. Researchers can affect the extent to which the experience of involvement is 'empowering' by paying attention to the practical and attitudinal issues outlined above. But they also need to be honest about the way in which the context in which the research is being conducted can place constraints on the extent and nature of influence that is possible. For example, much research on ageing is commissioned by government departments or by other bodies that define the research topic, sometimes the methods to be used, and the timetable within which the work has to be completed. Such bodies may encourage, or indeed require, user involvement in the research process, but this does not mean that older people can influence fundamental decisions about the way in which the subject matter is defined. This may have been influenced by older people at another level – if older people are involved in determining commissioning priorities. But what can be problematic is when central commissioning priorities are not consistent with the local priorities at the point at which older people are involved directly.

Good relationships take time to build. One implication of this is that effective involvement of older people in research is more likely to happen in the context of on-going and sustained relationships rather than on the basis of a one-off input. The structure of research funding does not always facilitate this, but relationships can be maintained in ways other than via continuing research activity. Links between older people and researchers based in universities can be maintained, for example, by involving older people in contributing to teaching and through researchers' membership of or contribution to local older people's groups and organisations.

e. Resources and systems

As the above point indicates, the context in which research is commissioned, funded and carried out can affect the extent to which it is possible to build collaborative research relationships and support older people's involvement in research. Existing resources and systems that can support this are identified here.

- Older people's participation in research is part of a broader commitment to older people's participation in policy making. In the UK the Better Government for Older People initiative, the implementation of the National Service Framework for Older People within the NHS, as well as the development of Senior Citizens' Forum, Older People's Advisory Groups and other local initiatives provide diverse opportunities for older people to have their say and create a context in which older people can develop skills and confidence that can also be applied to research involvement.
- Older people's NGOs and local groups led by older people can also provide an environment in which older people can gain access to research opportunities. NGOs often use research in their campaigns, they can influence what research is commissioned and can, through their own practices, model the value of older people's involvement.
- Research funders can make user involvement a condition of funding. In the UK the Department of Health and the Joseph Rowntree Foundation (a charitable trust that commissions research in the broad area of social welfare) require attention to be given to how users will be involved in the research process and this has prompted an expansion of participative approaches to research. INVOLVE, previously known as the 'Consumers in NHS Research Support Unit' - <http://www.invo.org.uk> - provides advice, support and information to researchers, service users and policy makers about participative research and hosts conferences, publishes reports and newsletters intended to promote good practice (e.g. Hanley et al, 2004). Also in the UK the Economic and Social Research Council (ESRC), the major research funder of social science research, encourages attention to relationships with research users, although does not make participation a condition of funding. The Growing Older programme funded by ESRC was regarded as an example of good practice in older people's involvement at both programme and project level. Commitment to participatory research at this level has a clear impact on the extent to which researchers need to consider how projects can be designed in inclusive ways.
- Small amounts of funding can enable innovative research to be developed that can build relationships, develop skills as well as generate useful findings. The Averil Osborn Fund was established by the British Society for Gerontology in 1994 for just such a purpose (Warren and Maltby, 2000). One of the advantages of small funding sources such as this is that they can support locally identified research priorities and the projects supported by this fund have typically been change oriented, focused on specific local issues and initiatives.
- In France the establishment of the University of the Third Age in 1973 and the massive development of older people's organisations created a situation in which research for and with older people was promoted and university researchers working across different fields were encouraged to develop collaborative approaches.
- The development of research institutes that adopt participative methods as core to their ways of working, such as the Athena Institute in the Netherlands and the Royal Bank of Scotland Centre for the Older People's Agenda in Edinburgh, can help to ensure that older people's participation in research is not restricted to 'one-off' projects.

- At the European level AGE – the European Older People’s Platform has requested active involvement of user representative organisations in EU research project proposals and was successful in ensuring user involvement will be more effectively promoted in the 7th Framework Research Programme.

RECOMMENDATIONS

- Ensure there is a sufficient budget to support older people’s involvement and consider the issue of payment for involvement
- Develop clear criteria for recruiting older people - include a person specification
- Utilise existing resources to contact older people including:
 - voluntary agencies, service user, self-help or community groups
 - referrals from service providers
 - libraries, social service offices, Citizens Advice Bureaus, GP surgeries
 - local media such as radio, free newspapers etc
- Identify and invite appropriate older people whose experiences are relevant to, and may enhance the development of, the research process in question
- Develop flexible and innovative approaches to establish and maintain regular effective communication and working relations with older people. When possible, commence this activity in advance of research processes. Avoid using jargon in verbal and written communication
- Consider practicalities when arranging meetings such as:
 - venues for meetings: are they accessible, comfortable, warm, light and small enough for people to hear and see each other? If relevant, do they accommodate wheel chairs, zimmer frames etc? Are they located in places familiar and/or acceptable to older people?
 - transport: does the chosen form of transport enable older people to get to meetings quickly and comfortably? Have collection and drop off times been agreed with older people?
 - communication: have user-friendly reminder cards / letters been sent to all participants?
 - refreshments: what refreshments should be made available during the meeting? Do any participants have special needs?
 - comfort breaks: are there adequate comfort / refreshment breaks incorporated into the meeting agenda?

(continued on next page)

RECOMMENDATIONS (continued)

- Agree ground rules / mutual expectations with participants at the meeting. Develop a culture of respect for mutual expertise
- Identify an effective / experienced facilitator(s), a separate note taker and, when appropriate, an interpreter(s) for meetings
- Ensure that all participants have the opportunity to have their say during meetings
- Identify, develop and implement appropriate training for participants. Consider:
 - older people's involvement in the development and delivery of training
 - how the content of research training supports and accommodates the research process in question
 - the appropriateness of timing for training sessions – are they conducive to older people's lifestyles
 - possible existing training for older people that may be accessed and utilised for the research process in question
- Ensure that stakeholders deliver what they promise
- Provide feedback to all participants after the research has ended and try to keep in touch
- Explore ways of developing on-going relationships between researchers and older people's organisations that provide a context in which older people as well as researchers can initiate ideas for research

CONCLUSION

5.1 Conclusion

The impetus for this guide came from work at a European level not only to encourage the development of ageing research but to do so in such a way that end-users and those affected by such research, in particular older people themselves, are engaged in this. ERA-AGE and FORUM reports encourage the development of collaborative networks of researchers across Europe in order to enable the generation of research methods and data sets that will enable comparative work to be undertaken. However, much of the innovative work in this area is being undertaken at a local level and often involves quite small-scale activity. Establishing on-going trusting relationships through which research collaborations can be built often involves developing links between university departments or research institutes and older people in the local area. But that does not mean that older people are interested only in research that will have a direct impact on their lives. Many explicitly acknowledge that the policy and service delivery benefits that may accrue from research will benefit subsequent generations rather than themselves, and women involved in the Leane et al and the Chambers projects saw value in making public aspects of ageing that may be poorly recognised or understood. Thus whilst research relationships might be best established at local level, this does not mean that the research in which older people can and want to get involved with is restricted to that which has immediate and solely local implications.

The challenge then is how to support positive collaborations at the local level, and create the networks between older people and researchers that will enable national and international comparative work to develop. Key to this will be funding that is not tied solely to specific research projects or programmes, but which includes resources to support networking activity. Such resources can be routed both through research institutes and academic departments, and older people's NGOs and campaigning organisations. Such networks could then provide a means to support the representation of older people at the European level.

Another challenge is how to ensure that older people's involvement is not restricted to research that has the label 'ageing' attached to it. Much policy research: for example in the areas of crime and community safety, transport, housing as well as health and welfare services, has significance for older people. Older people have interests and a part to play in civil society, politics and governance and hence could contribute to research in these areas. There are other areas in which participative research approaches are more developed than in ageing research, for example research involving disabled people, empowerment evaluation and community based action research. In building a discipline of 'ageing' (recommended by ERA-AGE and FORUM) the value of interdisciplinarity must also be asserted and supported and links made with those who might not regard themselves as researchers in ageing, but as having an interest in older people's participation across a spectrum of research areas.

But as this guide has demonstrated, there are examples of older people successfully playing a significant role in research in a variety of ways and contexts. Hopefully this guide will stimulate the sharing of such experiences more broadly.

SECTION 6

SUMMARY OF RECOMMENDATIONS

Below is a summary of recommendations for involving older people in research processes.

- From the outset, consider the focus of research studies and why it is, or it is not, important to involve older people
- Ensure there is a sufficient budget to support older people's involvement and consider the issue of payment for involvement
- Consider different stages of the research process and identify those which may involve older people including:
 - prioritising research
 - commissioning research
 - identifying research topics
 - planning and designing research
 - undertaking research
 - disseminating research
 - evaluating research
 - campaigners of research
- Consider how older people may be involved in research processes and identify appropriate approaches to enrich research development and the production of relevant outcomes for end users
- Develop clear criteria for recruiting older people - include a person specification
- Utilise existing resources to identify and make contact with older people including:
 - voluntary agencies, service user, self-help or community groups
 - referrals from service providers
 - libraries, social service offices, Citizens Advice Bureaus, GP surgeries
 - local media such as radio, free newspapers etc
- Identify and invite appropriate older people whose experiences are relevant to, and may enhance the development of, the research process in question
- Develop flexible and innovative approaches to establish and maintain regular effective communication and working relations with older people. When possible, commence this activity in advance of research processes. Avoid using jargon in verbal and written communication

- Consider practicalities when arranging meetings such as:
 - venues for meetings: are they accessible, comfortable, warm, light and small enough for older people to hear and see each other? If relevant, do they accommodate wheel chairs, zimmer frames etc? Are they located in places familiar and/or acceptable to older people?
 - transport: does the chosen form of transport enable older people to get to meetings quickly and comfortably? Have collection and drop off times been agreed with older people?
 - communication: have user-friendly reminder cards/letters been sent to all participants?
 - refreshments: what refreshments should be made available during the meeting? Do any participants have special needs?
 - Comfort breaks: are there adequate comfort / refreshment breaks incorporated into meeting agendas?
- Agree ground rules / mutual expectations with participants at the meeting. Develop a culture of respect for mutual expertise
- Identify effective / experienced facilitator(s), a separate note taker and, when appropriate, an interpreter(s) for meetings
- Ensure that all participants have the opportunity to have their say during meetings
- Identify, develop and implement appropriate training and mentorship for participants. Consider:
 - older people's involvement in the development and delivery of training
 - how the content of research training supports and accommodates the research process in question
 - the appropriateness of time schedules for training sessions – are they conducive to older people's lifestyles?
 - possible existing training for older people that may be accessed and utilised
- Ensure that stakeholders deliver what they promise
- Provide feedback to all participants after the research has ended and try to keep in touch
- Explore ways of developing on-going relationships between researchers and older people's organisations that provide a context in which older people as well as researchers can initiate ideas for research

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