A better future for ageing

Summary Guide of Good Practice for Involving Older People in Research
Welcome to the ERA-AGE summary Guide to Good Practice for Involving Older People in Research. This summary is shortened version of the recently published guide dated 13th August 2007. It is intended to identify the main principles of good practice but it does not discuss the main issues in detail. A fuller discussion will be found in the main guide which can be obtained via the ERA-AGE website www.shef.ac.uk/era-age

The main guide is intended primarily to encourage those engaged in various aspects of research to consider and endorse appropriate approaches to involving older people in research. It 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. 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. I would like to invite you to contribute new information to the data base and, especially, examples of good practice by contacting ERA-AGE using the following email address: r.n.saddler@sheffield.ac.uk

I would like to thank the authors of the summary and main guides, on behalf of the ERA-AGE partners, for their clear and succinct analysis and all those who have informed the development of the guide.

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Background

The European Area in Ageing Research (ERA-AGE) has further developed the recommendations of the European Forum on Population Ageing Research and subsequently endorsed 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.

The ERA-AGE summary 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 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.

This guide alludes to some examples of 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. A fuller discussion can be found in the main Good Practice Guide ‘Involving Older People in Research: examples, purposes and good practice’.
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. It can, for example:

- produce research that is considered relevant and important by older people.
- provide an understanding what ageing means to older people.
- ensure that research has a bigger impact.
- develop skills amongst older people.
- challenge ageist assumptions.
- generate data to be used as a campaigning resource by older people.

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.

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.
- 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.
- 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 practice

The examples discussed below will 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. Various other examples are provided in the main good practice guide. 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.

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.

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.

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).
As advisors

The aforementioned projects have involved older people who have undertaken 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.

The ‘older people as advisors’ model has been used in the context of a number of 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 focussed 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.

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 Alzheimer’s 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.

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 Alzheimer’s.

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.
Good practice

The full review of the range of ways in which older people can be involved in research in the main guide 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. 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.

Who gets involved

It has been suggested that older people who take part in decision making about research should be representatives of older people’s organisations, not individual experts. But it is worth reflecting on both the necessity and implications of such a requirement. 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. 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 place considerable burdens on older people, 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.

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.
Research relationships

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.

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.

Resources and systems

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. There are various resources and systems that can support this including:

- Older people’s Non Governmental Organisations (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’ - 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).
- 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.
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Conclusion

The impetus for the main 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 encourages 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, there are challenges including 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 and 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.

This summary guide provides some examples of older people successfully playing a significant role in research in different ways and contexts. A fuller discussion can be found in the main guide which can be accessed via the ERA-AGE website www.shef.ac.uk/era-age. Hopefully this guide will stimulate the sharing of such experiences more broadly.
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.
  – using research in campaigning.
• 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 ongoing 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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