A GUIDE TO USER INVOLVEMENT IN AGEING RESEARCH
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March 2014
INTRODUCTION

This guide aims to help researchers strengthen older people’s involvement in research projects. It was developed by Dr Brendan Murtagh, Queen’s University Belfast, on behalf of The Centre for Ageing Research and Development in Ireland (CARDI) and funded by the Office of the First Minister and Deputy First Minister (NI).

While anyone involved or interested in the research process can benefit from the guide it is primarily aimed at the research community involved in ageing in Ireland, North and South. There is extensive good practice guidance on user involvement in research and this guide does not our attempt to repeat or replace what already exists. Rather, it builds on and complements this work, specifically in age research.

It is important that the quality of research and the impact of the funding are maintained and enhanced. These can all be strengthened by the appropriate involvement of older people in the planning, implementing or disseminating the results of a range of projects.

Our approach in this guide is informed by the following objectives:

1. To strengthen the involvement of older people in age research;
2. To demonstrate the advantages of involvement for the quality and impact of age research;
3. To help researchers think through the involvement of older people in the design, implementation and dissemination of their projects;
4. To provide practical supports to researchers wishing to extend user involvement in their research project.
DIFFERENT NEEDS

Different people in the research process have different needs. Funders need to ensure that their programmes support and make provision for user involvement in specifications, timescales and resources. Two Can consultants have set out a useful framework for commissioners, researchers and participants to consider appropriate strategies and the tasks related to each. The diagram below shows three routes. The first highlights the needs of the user at each stage of the research process. The second emphasises the need to support user involvement by making sure that participants and researchers are supported and trained to deliver involvement effectively. Finally, the route map helps researchers think about the practicalities of involvement in specific projects. The route map can be accessed at: http://www.twocanassociates.co.uk/routemap/.

User involvement values

This approach is based on 5 core values:

- **Quality** Involvement of older people and representative organisations must add to the overall reliability and validity of the research process;

- **Accessibility** Ensuring that the involvement of older people permits them to play a serious role in the research process. Avoiding tokenism.

- **Application** Ensuring that the type of user involvement maximises the opportunities for policy impact and strengthening practice.

- **Commitment** Ensuring that time, resources and training are put in place to allow for effective involvement in the design, delivery and dissemination of the research.

- **Transparency** Setting out the relationship between the researcher and older participants at the outset and being clear that involvement does not mean that things will always change.
A number of terms describe the way in which researchers involve users in the design and implementation of their work and the table below clarifies some of the terminology used in this document. At the heart of this approach is the need to avoid tokenistic involvement and build effective strategies that bring forward relevant and timely research. The box below sets out the rationale for involvement, the various levels at which involvement takes place and what is meant by the terms used in the guidance. It also indicates the practical strategies possible at each level and how they improve the overall research project.

**THE SCOPE OF USER INVOLVEMENT**

A number of terms describe the way in which researchers involve users in the design and implementation of their work and the table below clarifies some of the terminology used in this document. At the heart of this approach is the need to avoid tokenistic involvement and build effective strategies that bring forward relevant and timely research. The box below sets out the rationale for involvement, the various levels at which involvement takes place and what is meant by the terms used in the guidance. It also indicates the practical strategies possible at each level and how they improve the overall research project.

<table>
<thead>
<tr>
<th>Involvement: where members of the public are actively involved in research projects and in research organisations</th>
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<tr>
<td>• as joint grant holders or co-applicants on a research project;</td>
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<td>• involvement in identifying research priorities;</td>
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<td>• as members of a project advisory or steering group;</td>
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<td>• commenting and developing patient information leaflets or other research materials;</td>
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<tr>
<td>• undertaking interviews with research participants;</td>
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<tr>
<td>• user and/or carer researchers carrying out the research.</td>
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<tr>
<th>Participation: where people take part in a research study</th>
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<tr>
<td>• people being recruited to a clinical trial or other research study to take part in the research;</td>
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<td>• completing a questionnaire or participating in a focus group as part of a research study.</td>
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<th>Engagement: where information and knowledge about research is provided and disseminated</th>
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<td>• science festivals open to the public with debates and discussions on research;</td>
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<tr>
<td>• open day at a research centre where members of the public are invited to find out about research;</td>
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<tr>
<td>• raising awareness of research through, for example, television programmes, newspapers and social media;</td>
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<tr>
<td>• dissemination to research participants, colleagues or members of the public on the findings of a study.</td>
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Source: INVOLVE, 2012, p. 7 Resource 1

For some the best approach is to co-produce knowledge between professional researchers and older people. This means that older people are involved in meaningful ways to affect what is researched, how it is undertaken, how data are collected and how information is analysed and used to improve their lives. Some methodologies, such as participatory action research in community development, place involvement at the very heart of the process. For others, participation might be at specific points in the research process and not all projects will lend themselves to user involvement. It is clear that there is no one standard model but a diversity of needs and approaches.
WHY INVOLVE OLDER PEOPLE IN RESEARCH?

The involvement of older people in research can help to strengthen the quality, relevance, usability and confidence in projects on ageing in Ireland today. INVOLVE (2012) describes a number of reasons why involvement is promoted in research:

- fundamentally, it strengthens the quality of the research by enabling a more rounded and informed interpretation of the data and produce findings that have greater credibility with funders and other key stakeholders;
- it places a focus on the outputs from the research by making it more likely that it will make a difference to older people’s lives;
- it enables the researcher to gain a greater knowledge and understanding of older people involved in the research;
- it will also enable researchers to reach a wider audience with reports and presentations, in particular reaching the people who are most likely to make use of the results;
- involving older people as beneficiaries also gives them the opportunity to learn new skills and build confidence;
- the involvement of older people shapes research according to the needs and views of beneficiaries;
- users can monitor progress of the research, address problems and provide useful feedback;
- it helps projects to get better insights into the experiences of older people and assists the project team to consider the potential impacts of approaches and techniques on beneficiaries.

WHAT ARE THE OBSTACLES TO STRONGER INVOLVEMENT?

There are barriers to user involvement. Some are practical but others relate to professional resistance and a concern that this will interfere in the integrity or the independence of the project. These barriers need to be better understood and worked on:

- The expectations of beneficiaries may be raised only to lead to disappointment if they feel that their views are not heard or acted on;
- Lack of time and resources for user involvement, particularly at the early design stages before funding has been obtained;
- Professional researchers might need to adopt a different role from their usual one because of the need to support users rather than just conduct the project;
- In some highly technical projects user involvement may be meaningless if the participants do not have the core knowledge required;
- Involvement might also raise unrealistic expectations about how much the research itself is likely to create change;
- The lack of knowledge among participants and researchers about how to manage and maximise the benefits of user involvement.
IDENTIFICATION OF OLDER PEOPLE FOR USERS’ ROLES

The success of user involvement will depend on clarity about whom to involve and the techniques for recruitment. It may be appropriate, for example, to use the assistance of advocacy or membership organisations or more focused sectors according to the research topic, e.g. housing or sporting organisations. Public advertisements may prove useful, as could access via the health sector (GPs, for example), although the latter will have time and confidentiality implications. NGOs receive a wide range of requests to assist with user involvement and it is important that they are not overburdened but see clear value from participation, especially for the older people they might recommend.

INVOLVING OLDER PEOPLE

The level at which older people are involved in research is critical. Barnes and Taylor (2007) describe four types of involvement: active subjects in the research; advisers to researchers; research practitioners working on their own or in collaboration; and direct commissioners of research for use in campaigning work. Similarly, Blackburn et al (2010, p. 37) state that the critical success factors in effective user involvement include:

- Building relationships – working in partnership with service users, demonstrating that their expertise is respected and valued;
- Going the extra mile – making an extra effort to ensure service users can be involved in a way that meets their needs;
- Honesty – being clear that research takes a long time and does not necessarily lead to change, as well as being open and transparent about the work;
- Being aware that some topics are going to be very sensitive and emotional;
- clarity about roles – taking time at the beginning of a project to explain what is needed from the people you involved and how they can help;
- Being mindful of the practical issues and minimising the costs for service users – the 'little things' really matter and may determine whether an individual can get involved; and
- Investing time – especially when planning the involvement of people and supporting them during the project.

METHODS AND PRACTICES

INVOLVE noted that people get involved in research for a variety of personal and social reasons. For some, these are linked to personal experiences of health or social care and a desire to bring about change in the quality of care or to improve treatment and services. For others, it is a way to have a voice and influence policy or processes or it might be to influence research by giving something back and helping others through their involvement. For a number of participants, the research is a way of strengthening their understanding and skills on a policy issue or area of concern. There are also a number of formal and informal methods of user involvement, which can be used independently or in combination depending on the topic, methodology and stage of the research design process. The box on the following page helps to define some of the approaches that might be considered. Not all may be suited to any particular project.
Steering and advisory groups that help to manage research projects provide an important opportunity to engage older people. To be able to engage effectively it is best to consider more than one participant and to ensure that they are properly briefed on the nature of the work.

Public meetings provide an opportunity to consult large numbers of older people. Meetings can be organised to allow for small group discussions with oral feedback. They offer opportunities for participants to set or influence the agenda and to ask questions about the research and its design. More general meetings are good for scoping the research design, surfacing issues from users and feeding back results to larger groups.

User forums are a regular meeting of older people and typically comprise members of civic, political, professional, economic or social groups with an interest in a specific age issue (rural isolation, dementia carers and so on). Forums can be a useful way of involving groups who are traditionally excluded from decision-making processes, such as older people. However, it is often the ‘usual suspects’ or those who are already involved in organisations who will participate.

Discussion groups enable formal and informal groups to listen to the views of older people. They often provide a way to avoid using older people purely as a resource and it might be possible to keep a standing group informed with newsletters, informal contacts and feedback sessions.

Relational research forms a close relationship between the researcher and older people, especially to develop more ethnographic understandings of their issues and needs at the start of the research process.

Direct participation involves directly recruiting older people and training them to undertake survey interviews, group discussions, in-depth interviews and where relevant literature and policy reviews. In this instance, older people bring their experiences to bear in the collection and analysis of various forms of data.

Web-based engagement may not always suit older people but their use of the internet and social media in particular is growing. There are a variety of web-based engagement processes to choose from, such as online discussion forums and blogs, Facebook, online surveys, social networking, ratings and voting and digital interactive TV. Web-based activities enable people to choose where, when and for how long they want to participate.

Citizens’ juries involve a group of older people who are representative of the wider group to consider a complex issue by gathering evidence, deliberating and then reaching a decision. Jurors can ‘cross-examine’ expert ‘witnesses’ (the researchers) who may offer differing perspectives on the issue or topic at hand before reaching agreement or producing a short report of recommended actions. Normally an advisory panel with expertise in the area considers the jury’s findings or report and determines what, if any, actions should be taken. A variation of the method is citizens’ panels, ongoing groups of some 1,000 to 2,000 people who are representative of the age community. Such panels are surveyed several times a year, by post, telephone or online.

Deliberative panels are useful for forming research ideas, especially where the subject is complex and uncertain. People are invited to join a panel related to a specific project to represent the views of everyday people. A panel should be made up of a broad range of people to better represent the older community and its views. A deliberative panel is educated by the researchers by being given information, receiving presentations and attending discussion groups. The panel members’ views are obtained on an ongoing and iterative basis.

Source: based on Hanley, 2005
STRATEGIES FOR INVOLVING OLDER PEOPLE

The diagram below shows that it is helpful for researchers to think about the involvement of older people at each stage of the research process. Five broad phases are described with a suggested set of activities to improve involvement, but clearly these need to be applied selectively to the individual projects and will not suit all circumstances, research designs or aims. They are designed to be helpful rather than prescriptive and to encourage researchers to think through the issues that might help strengthen their respective approaches.

<table>
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<tr>
<th>Phase</th>
<th>Activities</th>
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| 1. Engaging Older People | • Establishing governance structures  
• Ensuring older people have access  
• Engaging NGO’s within and outside the age sector |
| 2. Setting the priorities | • Reviewing the rationale for the research  
• Drawing out relevant research questions  
• Setting project aims and objectives |
| 3. Methods and implementation | • Involvement in the research design and selection of the research instruments  
• Involvement in field work and data collection  
• Participation in the interpretation and analysis |
| 4. Disseminating and advocacy | • Involvement in preparing and distributing briefing documents and papers  
• Involvement at conferences and seminars  
• Use of research in advocacy campaigns |
| 5. Evaluating performance | • User feedback on their experiences  
• What works and does not work  
• Disseminating the experiences of involvement and reflecting on practice |

It is important to recognise the potential power imbalance between researchers and researched. Involving older people is neither about ceding control of the research process nor compromising methodological standards. It is used where it makes sense, adds value and strengthens the relevance, use and ultimately the impact of the work. These guidelines aim to help researchers and users think through the rationale, tactics and limitations of involving older people in age research.
Stage 1 Involvement of older people

Some participants in research will have more expertise than others on, say, areas such as housing, dementia, caring and so on and this experience should be used appropriately. The number of people, when and how they will participate should be considered at this stage. For example, this might include steering or advisory groups, seminars and conferences, group discussion or more open public meetings. Older people's groups, NGOs and government agencies might help but there should be clear criteria to ensure an appropriate mix of participants in each project.

Older people, as with any group, have distinctive needs that must be considered when facilitating their involvement. If a meeting or event involving older people is planned, the practicalities must be considered:

- Researchers should aim to meet in places and times that suit participants and be mindful of accessibility by public transport as well as within buildings.
- Accessibility is especially important, as is easy parking, and for some participants the researcher will need to provide transport including accessible taxis.
- Practical aids such as microphones, hearing loops, and large-print media help to ensure that materials are accessible.
- Meetings should have a clear agenda and include regular breaks and opportunities for all members to participate – say, through break-out sessions or small group discussions.

The way in which users are involved must be considered. For example, the researcher’s language could unintentionally marginalise many people who are involved in the research process. The following recommendations should help:

- Use clear language and avoid jargon.
- Always ensure that the outcomes of meetings are reported back to participants and that they clearly understand any subsequent actions relevant to their ongoing role.
- Ensure that participants have an opportunity to feedback on the meeting and with any observations on how the work should progress.
- Some topics might be sensitive or raise emotional issues for older participants. Make sure ethics and risks have been considered and that older people properly understand the implications of involvement and can provide informed consent.
- Make contingencies by ensuring that, if required, participants affected by the research can be referred to the appropriate professional care and support.

Stage 2 Setting the priorities

Most research projects are designed within a framework such as the priorities or eligibility criteria set by funders. However, even within these constraints, users have an essential role in the formative stages of the research design. Involving older people in setting the priorities for research strengthens its relevance, usability and impact. Older people’s input could be used in a number of ways:

- The preparation of the proposal could usefully involve older people in setting or evaluating research questions, the assumptions underpinning the work or the rationale for the project.
- The co-production of clear research questions is itself an important discipline in the design of valid and reliable methodologies.
- Care should be taken to ensure that there is time to engage older people in group discussions or meetings, via online media or through formal surveys.
- Dedicated organisations that can help to make an informed contribution to the formation and the design of the research should be asked for advice.
Stage 3 Methodology and implementation
A key phase is the involvement of older people in the design and implementation of the research; group discussions, seminars and conferences can help scope and debate the methodological issues.

- It is important to make explicit the rationale for the research design as well as the detail of what is proposed.
- This includes sample sizes, and selection of respondents, the relationship between the various data-gathering instruments used and how the researchers propose to analyse the results.
- Older people can also assist in the interpretation of the data and provide a practical perspective that can strengthen the analysis with the research team.
- They can also check and validate data and highlight the significance of results that researchers may not fully appreciate.

It is also possible that older people can be involved in advising the research project – for example, in steering groups.

- This ensures that older people’s perspective is included throughout the process, in commissioning specific pieces of work and changing the design or direction of the planned approach.
- It also ensures that older people’s involvement is properly planned and resourced across the various stages of the research process.
- It can assist in practical ways to facilitate access to, and recruitment of, older people as the subjects of research and to maximise the reliability of research designs.
- Researchers also have access to ongoing advice as problems and issues emerge or when user knowledge is vital to the progress of the work.
- It is important to consider the role of older people in selection panels for research staff as well as in commissioning sub-contractors, especially where fieldwork involves direct contact with the older community.

Older people can become involved in more direct ways by identifying and collecting relevant documents that they value as important for the research. In this regard they can also offer testimonies and experiences that could identify the need for more detailed analysis. Their role could be extended to undertaking literature reviews or policy analysis from an age perspective, conducting interviews and holding or participating in group discussions. Additionally, older people could play a valuable role in peer-reviewing research reports and validating their content.

Stage 4 Disseminating and advocacy
One of the key advantages of user involvement is the ability to inform new practices, policy and legislation. Evidenced-based policy is becoming an increasingly important feature of decision-making, and information produced and used by older people is likely to make a stronger impact than standalone projects. Older people can also be involved directly in dissemination activities, including presenting results at conferences and seminars, attendance at policy-related meetings and preparing peer-reviewed papers.

- Older people can become involved in the preparation of briefing papers, staged reports or newsletters linked to the project.
- They can ensure that the results of the research are fed back to the older community, strengthening the legitimacy, trust and reputation of researchers.
- It is good to engage older people at the outset about dissemination tactics and outputs and especially on how they think the research should be used.
It is important that practical actions relating to dissemination and impact are thought through at the early stages of the project.

• It is vital that NGOs and relevant advocacy organisations are also involved at the start of the process and to explore what media might best support their efforts.
• Also important is the identification of programmes, policy or legislation that might be affected by the project, as well as organisations that could work alongside older people to make an impact.
• Research needs to be translated in a way that is usable by advocates.

Researchers should work with older people and NGOs to help interpret their data in order to ensure a stronger policy effect.

Stage 5 Evaluating performance

The final stage is evaluation, which might be handled in both formal and informal ways. Clearly, evaluation of a research project should cover more than older users where this is relevant. Consider asking older people to reflect on their experiences through formal debriefings, by keeping a diary or journal or by giving informal advice on how to improve practice. If a larger number of users is involved, group discussions, feedback questionnaires or online surveys can help.

• The first task is to identify what worked, what did not and why. How these practices might be built upon or changed in future research projects would be a key outcome of this phase.
• The critical issue is to identify whether and how involvement makes a difference to the participants, researchers, funders and the broader political, policy and practitioner community.
• It is also important to acknowledge and profile key successes and build an evidence base that supports user involvement in age research in Ireland.
• The experiences of user involvement might be disseminated through academic and professional research networks and among practitioner organisations.

CONCLUSION

The quality and impact of research can be strengthened by the appropriate involvement of older people in ageing research. User involvement can help make research more relevant to both older people and policy makers. However, user involvement can also pose challenges for researchers as they must consider whether it is appropriate for a particular research project and whether, if used, it allows older people to make a meaningful contribution that adds to the research. This guide provides an overview of the key factors to be considered when embarking on such research and is intended to build on and provide a reference point to other resources on the topic.

The full research report on which this guide is based is available at www.cardi.ie
ADDITIONAL RESOURCES

Resource 1: INVOLVE Briefing Notes
INVOLVE is the national advisory group that supports greater public involvement in NHS, public health and social care research. Part of the National Institute of Health Research (NIHR), it offers advice and guidance that is generic and can be applied to a range of research areas. It supports invoNET, a forum for people with an interest in researching and building an evidence base on active public involvement in the research process. INVOLVE provides detailed guidance, case studies and resources to strengthen participation in research.


Resource 2: JRF Researcher Users and Empowerment
The Joseph Rowntree Foundation also has extensive resources on user engagement in both service delivery and research. For a review of publications, and in particular its work on empowerment research, see: http://www.jrf.org.uk/publications/browse/category/u#user-involvement


Resource 3: ERA-AGE Good Practice for Older Engagement
The European Research Area in Ageing 2 (ERA-AGE 2) is a three-year project funded by the European Commission under the Seventh Framework Programme. It provides a range of resources to support user engagement, including a specific report on the involvement of older people:

http://era-age.group.shef.ac.uk/assets/files/05.01.2009kc%20%20User%20Involvement%20Good%20Practice%20Guide.pdf


Resource 4: UK Statistics Authority User Engagement
The UK Statistics Authority has attempted to strengthen user engagement in official statistics and their guide includes useful information on users’ attitudes to statistics: www.statisticsauthority.gov.uk/.../strengthening-user-engagement.pdf


Resource 5: Royal College of Nursing (RCN)
The RCN has produced guidance on user engagement in research specific to the nursing profession. The guidance sets out the rationale for engagement, how and when to participate and how to reach seldom-heard groups. The report is available from http://www.lnr-repp.org.uk/resources/cat_view/7-guides


Resource 6: Biomedical research guidance
This guidance is particularly useful in biomedical research. It sets out the role of user involvement in key stages of the process and especially the need to comply with ethics procedures and standards. The guidance is available from http://www.biomedicalresearchcentre.org/Resources/Professionals/Supportservices/brc-user-involvement-staff-on-intro-guide.pdf


REFERENCES


