Acknowledgements
This research forms part of a programme of independent research commissioned by Office of the First Minister and Deputy First Minister OFMDFM to inform the policy development process and consequently the views expressed and conclusions drawn are those of the author and not necessarily those of OFMDFM.

Dr Brendan Murtagh
Queen’s University Belfast

March 2014
# CONTENTS

Executive summary  

1. Introduction  
   Research objectives  
   Research methodology  
   Structure of the review  

2. User engagement definitions and concepts  
   What do we mean by users?  
   What value does user involvement add?  
   Achieving user involvement  
   Barriers to user involvement  
   Evaluating user involvement  
   Power and user involvement  
   Conclusions  

3. The practice of user engagement  
   Codes of user practice in the UK  
   Rational methods and the value chain  
   User engagement and older people  
   Controlled research  
   Conclusions  

4. Perspectives from practitioners  
   Attitudes to older people’s participation  
   Factor analysis of attitudes to user engagement  
   Conclusions  

5. Practices and experiences  
   Involvement structures in user involvement  
   Product-testing and the end user  
   Participatory age research  
   Supporting user involvement  
   Strategic barriers  
   Conclusions
6. Implications for practice and conclusion

Stakeholder perspectives
Key issues in involvement
Implications for the guidance
Conclusions
References
Appendix 1: a guide to user involvement in ageing research

Table of figures and tables

Figure 1: user involvement in research: a route map
Figure 2: respondents to the e-survey
Figure 3: typology of researchers and attitudes to users
Table 1: definitions of user and involvement
Table 2: terms and examples of their application in research practice
Table 3: power and emancipatory research
Table 4: levels of user engagement and age research
Table 5: a rational staged approach to user engagement
Table 6: user engagement methodologies
Table 7: impact of user engagement
Table 8: barriers to user engagement
Table 9: priorities for user engagement and age
Table 10: principal component analysis
Table 11: component structure
Table 12: outline needs of user groups
EXECUTIVE SUMMARY

Ageing research flourishes when the research community connects with the relevant players from government, voluntary and community sector, business and older people themselves. As a result many funders of research and researchers themselves are recognising the benefits of engaging with service users. However, we need to understand to a much greater degree how older people’s involvement in research can be appropriate, meaningful and beneficial.

This research reviews the nature of user involvement in research and how this can be strengthened to improve the quality of age research in Ireland, North and South.

The objectives for the study included:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To review the conceptual and practical basis of user involvement in research on issues and topics relevant to older people;</td>
</tr>
<tr>
<td>2</td>
<td>To identify the types, levels and impact of different methods of user involvement;</td>
</tr>
<tr>
<td>3</td>
<td>To evaluate the attitudes of researchers and practitioners to older people’s involvement in age research;</td>
</tr>
<tr>
<td>4</td>
<td>To create a guide on the involvement of older people in age research in Ireland, North and South.</td>
</tr>
</tbody>
</table>

The methodology for this research consisted of a review of the literature and practices on user involvement, an e-survey of practitioners in the age sector and a series of semi-structured interviews with age researchers and users.

KEY FINDINGS

There is a need to define and differentiate between involvement, participation and engagement.

The advantages of effective involvement include producing research that is considered relevant and important by older people; understanding what ageing means to older people; ensuring that research has a stronger impact; developing skills among older people; challenging ageist assumptions; and generating data to be used as a campaigning resource by older people.

Involvement must be appropriate to the needs of the research. It must add value and strengthens its reliability, validity and impact.

Older people get involved in research for a variety of reasons, including a desire to make a difference, to work on an issue or policy area that has affected them personally, to strengthen their skills and to socialise through an interesting participatory activity.
Practice suggests that some of the key elements of successful user involvement include building relationships and working in partnership with service users;

- making an extra effort to ensure service users can be involved in a way that meets their needs;
- making it clear that research takes a long time and does not necessarily lead to change;
- being aware that some topics may be very sensitive and participants might need support;
- clearly explaining roles and what is expected of participants;
- being mindful of the practical issues and minimising the costs for service users;
- and investing time, especially when planning involvement and supporting people during the project.

A number of reviewers highlight the power imbalance between the researchers and the researched and that effective involvement, which avoids tokenism, can help create more accountable, relevant and inclusive work.

A number of guides for funders, researchers and users advise on how to strengthen involvement; they emphasise the need for a clear rationale for participation, strategies that select the appropriate number and type of users and approaches that build them into key stages of the research process. One format clearly does not fit all projects but where possible the involvement of older people should include research design, data collection, interpretation and dissemination.

The survey data in this research, while limited in its scope, shows that there are positive attitudes to user involvement in age research although, as shown in other parts of the survey, this varied across the research community. Some of the barriers exist for valid reasons and relate to the integrity of the research design. They include a reluctance to forfeit valuable research time to prepare methodologies or change design to suit older people; concerns over making data available to others before it has been checked by the researchers; a potential lack of control over ownership and commercial rights. There are also concerns that data might be misused or misinterpreted, particularly by non-academic users; and that confidentiality and/or data protection could be breached if multiple users are involved.

The research also shows that a range of effective practices are available in user involvement, especially in the age sector. A number of structures have been established to involve older people in reviewing research priorities, directing specific projects and feeding back on fieldwork. Older people have been involved in data-gathering and disseminating work at conferences and public meetings. There is evidence of older people being actively involved in the application of findings in specific lobbying campaigns and in action research designs.

The research highlights the need to develop stronger practices to engage older people in the research process; strengthen their role in setting and shaping the priorities; help to include them in the design and implementation of data-gathering and analysis; work to apply research to make an effect on policy; and enable older participants to evaluate research and its impact on their lives.

Resources and tool kits are available to support user involvement across a range of disciplines. Research units should capitalise on these tools to strengthen practice and the skills of researchers and older people. This may help to build a stronger culture of user engagement in age research in Ireland, North and South.

**RECOMMENDATIONS**

There is a need to develop stronger practices in the area of user involvement in ageing research in Ireland, North and South.

Planning and constructing a clear rationale for user engagement is vital at the outset of a research project.

Researchers should avail of existing guidance from a variety of disciplines, including this paper when planning user involvement in any research project.
1. INTRODUCTION
This report sets out a review of user involvement in research, especially that related to age and ageing. It focuses on understanding user needs, the value of involvement and how practice might be strengthened within the age research community in Ireland, North and South.

The rationale for this approach is that user involvement adds value to the quality, relevance and impact of research. There are concerns that age research (and work with other vulnerable groups) has the potential to be exploitative, irresponsible and even wasteful (Kerr and Kerr, 2003; JRF, 2005a). Moreover, UK Statistics Authority (2005a) noted a loss of trust in official statistics, not least because their production is hidden from the public. Public disquiet about the recording of unemployment, crime and economic statistics underscore the need to make research more transparent and accessible to a wide set of users.

However, Hanley (2005) points out that there is comparatively little comprehensive evidence that user involvement produces better quality research and much of the evidence is anecdotal or confined to case studies of particular projects. Indeed, part of the problem is that a number of initiatives have been tokenistic or ineffectual, thus discrediting the purpose of user involvement in transformative applied research. CARDI aims, through this research, to review the scope of user involvement and help to promote effective, practicable and meaningful engagement strategies in age research.

**RESEARCH OBJECTIVES**

<table>
<thead>
<tr>
<th>The objectives of this research are:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 to review the conceptual and practical basis of user involvement in older people’s research;</td>
</tr>
<tr>
<td>2 to identify the types, levels and impact of different methods of user involvement;</td>
</tr>
<tr>
<td>3 to evaluate the attitudes of researchers and practitioners to older people’s involvement in age research; and</td>
</tr>
<tr>
<td>4 to inform guidance on the involvement of older people in age research in Ireland, North and South.</td>
</tr>
</tbody>
</table>
RESEARCH METHODOLOGY

The methodology is sub-divided into four interrelated phases:

1. **Phase 1** A review of the literature and best practice on user involvement.
   
   This focused on levels and qualities of engagement and the need to move up a ladder from tokenism to effective involvement in order to deliver effective participatory strategies (JRF, 2005b). However, we need to be clear about why and when older people are involved, their capacity and interest and how it will add value to the quality or impact of research produced.

2. **Phase 2** Examination of practices and methodologies in user involvement linked to age and allied research areas.
   
   User forums, expert panels and the involvement of older people in commissioning have been used, with mixed results and effects. While research procurement, implementation and application are complex processes it is important to identify the particular value added of user involvement.

   We also need to be clear about what or whom we mean by involvement, engagement and participation. There are multiple users including older people, NGOs, the academic community, policy-makers and the private sector. How these are all included in ways that do not disrupt the integrity of the research process is unclear.

   Users do not always want the same thing and their perspectives might well be oppositional. It is important to appreciate that the focus of this review is about the involvement of older people in the research process and how this might be strengthened.

3. **Phase 3** Validation of the research with research actors in government, academia, NGOs and applied research projects.
   
   This examines the extent of user engagement and how researchers have attempted to involve users and partners in procurement, delivery and evaluation of age related research. Linked to this is an analysis of an e-survey of 50 practitioners in age research in Ireland, North and South to assess their priorities for user engagement strategies and methodologies.

4. **Phase 4** The separate development of guidance in the involvement of older people in age research that aims to strengthen practice across disciplines, sectors and professions in Ireland, North and South.

STRUCTURE OF THE REVIEW

Section 2 describes the key messages from the literature and in particular draws out the importance of power and powerlessness in research, especially that involving vulnerable groups. Section 3 looks at practices and initiatives that have added value in research, especially research linked to older people and age-related issues. This sets the context for an analysis of practitioner perspectives in Section 4 and examples of practice, mainly by researchers, in Section 5. Section 6 briefly reviews the implications for user involvement as a basis for developing research guidance.
2.

USER ENGAGEMENT DEFINITIONS AND CONCEPTS
It is important to recognise that user involvement is itself a controversial subject. Critics point to a lack of compelling evidence that it adds value, while advocates are critical of the tokenistic nature of previous attempts to engage older people in research and advocacy.

This section briefly reviews some of the key principles and terms before considering the complexity of participatory levels and their implications for practice. User engagement and specifically the involvement of older people has emerged as a key issue across Europe, well expressed in the Futureage process (http://futurage.group.shef.ac.uk/). It also highlights the importance of the terms and concepts and how they apply to age research:

User involvement means to concretely engage users at all stages, to design with them their role throughout the process, to take into account their needs and concerns throughout the whole process, to carefully encourage, recruit, support and train them. This implies the need for sufficient resources, which are not only related to research funding, but also to human support. User involvement implies the sharing of research outcomes with the users who take part in the activities, as well as involving them in the evaluation and eventual follow-up (FUTUREAGE, 2011, pp. 85–6).

WHAT DO WE MEAN BY USERS?

A key theme running through the literature is that there is no single accepted definition of users, involvement, participation or engagement; rather, the overall approach needs to be seen as a continuum of practices, levels and methods, each one appropriate to the needs of the project under consideration (Kitson et al, 2008). More recently, the UK Statistics Authority (2012) specifically highlighted the need for government statisticians to better understand the needs of the community and voluntary sector in setting priorities and getting access to data sets. In her work on mental health research Staley (2012) offers a conceptual definition of service user and involvement as set out in the table below.

<table>
<thead>
<tr>
<th>Table 1: Definitions of user and involvement</th>
<th>Source: Staley, 2012, p. 8</th>
</tr>
</thead>
</table>

| The term **‘service user’** is used to refer to people with current or past experience of mental health problems and the use of mental health services. We recognise that this term is not universally supported. Other terms used include ‘mental health survivor’ or a ‘person who uses services’. |

| The term **‘involvement’** in research is the term used to describe the active engagement of service users and carers in the design, delivery and dissemination of research – where service users and carers are partners in the research process and can influence what research is done and how it is done. |

INVOLVE (2012) defines public involvement as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. It is one of the few government-funded programmes of its kind in the world. It includes, for example, working with research to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants. Their understanding of the key terms and how they are applied to practice is set out in the table on next page.
Table 2: Terms and examples of their application in research practice

<table>
<thead>
<tr>
<th>Involvement: where members of the public are actively involved in research projects and in research organisations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• As joint grant holders or co-applicants on a research project;</td>
</tr>
<tr>
<td>• involvement in identifying research priorities;</td>
</tr>
<tr>
<td>• as members of a project advisory or steering group;</td>
</tr>
<tr>
<td>• commenting and developing patient information leaflets or other research materials;</td>
</tr>
<tr>
<td>• undertaking interviews with research participants;</td>
</tr>
<tr>
<td>• user and/or carer researchers carrying out the research.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participation: where people take part in a research study</th>
</tr>
</thead>
<tbody>
<tr>
<td>• People being recruited to a clinical trial or other research study to take part in the research;</td>
</tr>
<tr>
<td>• completing a questionnaire or participating in a focus group as part of a research study.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Engagement: where information and knowledge about research is provided and disseminated</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Science festivals open to the public with debates and discussions on research;</td>
</tr>
<tr>
<td>• open day at a research centre where members of the public are invited to find out about research;</td>
</tr>
<tr>
<td>• raising awareness of research through, for example, television programmes, newspapers and social media;</td>
</tr>
<tr>
<td>• dissemination to research participants, colleagues or members of the public on the findings of a study.</td>
</tr>
</tbody>
</table>

The UK Statistics Authority (2010b, p. 12) also sets out a number of definitions useful for this review, especially the notion of a value chain, emphasising the role of user involvement at each stage in the production of official statistics:

- ‘engagement’ – activities which allow statistical producers to provide information and to seek views and feedback from the users of their statistics;
- ‘consultation’ – one form of engagement with users, generally relating to a formal process of gathering views;
- ‘statistical value chain’ – a conceptual model of the way in which statistical services are provided: identifying needs; collecting or compiling data; converting data into statistics; describing what the statistics show; publishing this commentary and the underlying statistics; and helping users understand, and make use of, the statistics and the messages they contain.

The UK Statistics Authority (2010a) surveyed 22 government statistics producers and showed that they use various methods to understand users including monitoring the press, blogs, analysis of web statistics and membership of lists of research organisations. They broadly define users as policy-makers, politicians, the media, the private, business sector, and third sector and activists. The key issue is the concept (noted above) of the statistical value chain:

The steps in the value chain start with planning what statistics will be beneficial in the future and do not stop until the statistics, or perhaps advice based on them, are used to some beneficial effect. The job of statisticians extends from the planning stage through to guiding the user. ... To increase the value of the planning process, producers should identify both the expected users of the statistics and the communities of users associated with each use. Involving those communities in an active dialogue at that stage will help ensure not just that the right statistical products are produced but that the ground is laid for effective user engagement later on (2010b, p. 12).
WHAT VALUE DOES USER INVOLVEMENT ADD?

The benefits of user engagement are not strongly evidenced but Blackman et al (2010, p. 37) defined some of the critical success factors that produce better-quality research:

- Stay focused on the useful outputs from your research, to make it more likely that your research will make a difference to people’s lives;
- Get the language and approach right, throughout your project – in your recruitment material, research tools and reports;
- Get better-quality data, and produce a more rounded and informed interpretation of the data and findings that will have greater credibility with your funders and other key stakeholders;
- Gain personally from new relationships and a greater knowledge and understanding of the people you work with;
- Reach a much wider audience with your reports and presentations – in particular, the people who are most likely to make use of your results.

Fundamentally, active engagement implies a move away from tokenism to a process whereby older people are involved in commissioning, trained as co-producers and help to evaluate projects (Walker, 2008). Walker argues that there are ethical and practical reasons for user involvement, especially as scientific knowledge often misses the fundamental experiences of older people in areas such as cancer. Brown et al (2006) showed that people affected by cancer have been involved in commissioning organisations, project-level advisory groups, reviewing research proposals and publications, data-gathering and reporting as co-researchers in the analysis of data.

ACHIEVING USER INVOLVEMENT

Barnes and Taylor (2009) point out that the value of user engagement is two-way, for the older people and the researcher. The levels at which older people are involved in research are critical. Barnes and Taylor (2009) described four types: active subjects in the research; advisers to researchers; research practitioners working on their own or in collaboration; and direct commissioners of research to use in campaigning work. They outlined six key reasons for the involvement of older people, including:

- the need to produce research that is considered relevant and important by older people;
- to enable understanding of what ageing means to older people;
- to ensure that research has a better impact;
- to develop skills among older people;
- challenge ageist assumptions;
- and to generate data for a campaigning resource for the age sector.

Similarly, Blackburn et al (2010, p. 37) state that the critical success factors in effective user engagement include:

- building relationships – working in partnership with service users, showing you respect and value their expertise;
- 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 how you are working;
- 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 you need from the people you involve and how they can help you;
• 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 a lot of time – especially when planning involvement and supporting people during the project.

INVOLVE (2012, p. 12) reviewed a number of user involvement approaches and showed that the public 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 services and a desire to bring about change in the quality of care or to improve treatments either for themselves or for others with a similar condition. 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.

BARRIERS TO USER INVOLVEMENT

Beresford and Andrews (2012) argue that government policy is contradictory regarding user involvement in health and social care; cuts in spending on mainstream programmes (and research) make it more difficult to pursue serious participatory strategies. Moreover, the timescales on programme delivery truncate any real attempt to manage engagement in inclusive ways.

Staley (2012) evaluated 45 mental health studies across England and identified a number of barriers to user involvement including:
• a lack of time and resources – particularly at the early design stages before funding has been obtained;
• a lack of know-how – particularly with involvement in steering groups;
• recruiting service users and maintaining involvement – finding service users with the right skills and experiences as well as managing periods of ill-health;
• managing the employment of service user researchers – particularly in ensuring sufficient flexibility at work to be responsive to service users’ needs and to support their career development after a project has ended; and
• the attitudes and awareness of academic colleagues – in particular, managing situations where colleagues are opposed to user involvement.

The study showed that researchers wanted help in finding service users to get involved, training in service user involvement and developing skills in inter-disciplinary work. However, they also wanted to be assured that there was genuine commitment behind user involvement:

Some researchers expressed a general concern about involvement becoming an essential requirement of funders ... when there is little reward for doing it well. They suggested that researchers would benefit from greater support at early stages to understand how and why involvement could bring added value to their research. Researchers also need better incentives for following good practice and avoiding approaches that are tokenistic (Staley, 2012, p. 6).

NORFACE (New Opportunities for Research Funding Agency Cooperation in Europe) (2007) also noted that it is important to acknowledge that user involvement takes time and money to implement effectively but that the orientation of the discipline also has an effect. Medical and scientific researchers are often less tolerant of participatory methods in general and user engagement specifically. Social scientists, especially sociologists, ideologically prefer co-production in order to counter the powerlessness of subjects in academic research.

For some researchers, the prospect of involving service users as partners in research is frightening, as it challenges traditional notions about who the expert is and who is the recipient of this expertise – and who has power and who has not (Hanley 2005, p. 16).
Hanley identifies the payment and the entitlements of older people in the research process as a critical area in its implementation. One argument is that these considerations corrupt the relationship and research subjects are further incentivised into the agendas of the researchers. Funding is important because it enables the payment for their time, the development of user-derived outcomes, training and mentoring, consultation of wider groups of service users, time to respond to changes to the study recommended by service users and the opportunity to share the research findings widely. However, there is also ‘a danger that, in their eagerness to involve service users, ... researchers may present their project as having more potential for change than in fact it has’ (Hanley, 2005, p. 20).

**EVALUATING USER INVOLVEMENT**

It was noted earlier that the evidence base for effective involvement is not strong and in their work on Knowledge Transfer and Utilisation, OPAN (http://www.opanwales.org.uk/documents.htm) established a dedicated unit that emphasises the importance of learning and evaluating practice. Understanding the impact of user involvement means:

- identifying what works (or not);
- identifying whether and how involvement makes a difference;
- generating evidence of the value of involvement to convince others – to ‘prove that it works’;
- celebrating success – recognising achievements;
- sharing learning;
- improving the planning of future projects;
- providing another mechanism for involving users.

One area to note in this respect is that the UK government’s assessment of university research performance, the Research Excellence Framework (REF), placed a stronger emphasis on impact on policy-making, practice and professional competence. User engagement and participatory methodologies underscore the importance of impact on the design and delivery of social science projects in particular. Whyte (2012) points out that there is an increasing priority placed on data curation and how high-cost data sources are used to their full effect. Evaluating the use and impact of existing stocks of data and user engagement is integral to its effective application in practice.

**POWER AND USER INVOLVEMENT**

Service delivery in the age sector has become more complex and integrated between the actors involved in designing, delivering and evaluating interventions.

As Bovaird (2007) noted, ‘services are no longer simply delivered by professional and managerial staff in public agencies but are co-produced by users and their communities’ (Bovaird, 2007, p. 846). The shift in emphasis to user engagement stimulated a debate about how effectively users are involved in co-producing policies as well as developing new methods for evaluating participatory processes (for a review of the toolkit methods see: http://www.serviceuser.org/agencydata/listtoolkits.php).

Power is at the centre of the debate about user engagement:

*Service user involvement in traditional or mainstream research is still not widespread. One of the fundamental barriers to the empowerment of service users in mainstream research remains the unequal relationship between the researcher and research participants (Hanley, 2005, p. viii).*
Wistow et al also make the point that:

‘a recurring theme in the literature is the powerlessness and a sense of tokenism, with service users complaining that they are not valued by the professionals and that they are patronised. Researchers have also commented on the tendency for there to be a small group of active individuals who become “insiders” in participation exercises’ (2011, p. 4).

For Wistow et al (2011) the key to success is the commitment of senior managers to developing a progressive culture of engagement, resources to enable it, joint commissioning structures and transparency in what is open to involvement and what is not. Fundamentally, Wistow et al draw a distinction between a citizen focus and a consumer focus in service delivery which is also applicable to research commissioning. In the former, processes are emancipatory, place older people at the heart of research planning, delivery and use, and put people, rather than research, first. In the latter, older people are restricted to service users, data-gathering is aimed at the needs of providers and older people are relegated in commission processes. Hanley (2005) specifies the characteristics of emancipatory research and the criterion that helps inform more inclusive strategies. The analysis also stresses that this tends to be more characteristic of qualitative methods and there is a need to challenge normative and highly controlled methodologies that tend to dominate gerontological research.

**Table 3: Power and emancipatory research**

<table>
<thead>
<tr>
<th>Who controls research?</th>
<th>Emancipatory research is controlled by service users from the beginning of the process. Researchers who are not service users may be involved in the process, but control must be retained by disabled people.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are some research methods more emancipatory than others?</td>
<td>To date, most emancipatory research has focused on qualitative methods. However, this type of research is not about methods, but about who has control. Therefore, any research methodology could potentially be adopted by user-led organisations and used for user-controlled or emancipatory research.</td>
</tr>
<tr>
<td>How can we focus more on people’s experience?</td>
<td>It is important that emancipatory research is driven by people’s experiences, priorities and concerns, and draws more general conclusions based on these experiences.</td>
</tr>
<tr>
<td>What happens to research after it is complete?</td>
<td>Emancipatory research must lead to changes, not act as an end in itself.</td>
</tr>
</tbody>
</table>

The table on page 17 develops these conceptual differences in a more graded approach that illustrates the range of tactics open to researchers and commissioners. Arnstein (1969) identified a conceptual ladder of participation that has been applied to a number of policy areas and programmes including health (Titter and McCallum, 2006). Level 1 is the best methodological approach, with more and more power given or shared between the user (older people) and the researcher. Level 8 is the weakest, with involvement corrupted by manipulating the user to achieve the outcome desired by those conducting the research. This may be intentional or unintentional but the ladder serves to show that there is not one type of user involvement but different intensities of practice and what might appear as engagement may not be in the interests of older people. In short, the further up the ladder, the better the quality of participatory practice.
### Table 4: Levels of user engagement and age research

<table>
<thead>
<tr>
<th>Type</th>
<th>User</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Citizen control</td>
<td>Researchers co-produce their work with older people in the design, delivery and evaluation of the project. Older people are integral to the formation, commissioning, implementation, preparation and use of the research and set the agenda as well as data-gathering techniques. Older people are trained and involved in the collection and interpretation of the results.</td>
</tr>
<tr>
<td>2. Delegated power</td>
<td>Organisations act as advocates on behalf of older people in the research process to undertake action research centred on older people’s exclusion or isolation. Methods such as deliberative juries can make participation more engaged and meaningful.</td>
</tr>
<tr>
<td>3. Partnership</td>
<td>Older people work in partnership with agencies to deliver research projects. This might involve advisory committees and links with NGOs representing older people in the research process. The research process is not wholly left in the hands of professionals but there is a degree of separation between the user and the researcher or research team.</td>
</tr>
<tr>
<td>4. Placation</td>
<td>Consultation primarily aims to satisfy older people rather than reforming their role in research processes. They have a measure of involvement but it is often reductionist, implying a tick-box approach to their inclusion.</td>
</tr>
<tr>
<td>5. Consultation</td>
<td>Formal methods of hearing but not listening to older people in research design. Here, older people are often subjects to be included in empirical work rather than as designers or co-producers in the process. These approaches include questionnaires, surveys, group discussions and public meetings. These are useful for scoping but treat older people passively and their application is best limited to understanding and framing issues.</td>
</tr>
<tr>
<td>6. Informing</td>
<td>A one-way communicative flow where people are simply given information about a research project or event through, for example, advertising, press releases and information leaflets. There is little implication that older people will be engaged in the research but are made aware of its conduct.</td>
</tr>
<tr>
<td>7. Therapy</td>
<td>User involvement is not transformative or even inclusive. It gives participants the impression of engagement but adds little to their control over research processes.</td>
</tr>
<tr>
<td>8. Manipulation</td>
<td>User involvement is corrupted in order to use older people as a means to researchers’ (self-promoting) ends. In this instance, research prefers a particular agenda, interest group or outcome. It can be highly politicised and sometimes effective, but older people and their interests might be marginalised to accommodate claims made in the research.</td>
</tr>
</tbody>
</table>
Ultimately, the objective is to aim for level 1 where practicable, as this is where empowering older people in the research process has most effect. Empowerment means challenging service users’ exclusion and disempowerment. Two aspects to empowerment are regularly identified: personal and political empowerment. Personal empowerment is concerned with strengthening the individual’s position, through capacity and confidence-building, skills and assertiveness training, to be able to gain more power. Political empowerment is concerned with seeking to make broader changes that will increase the objective power (political, cultural, social and economic) available to people. A particular appeal of the idea of empowerment is the way it can address and unite these two concerns: individual and social transformation in research designs (Hanley, 2005, p. 15).

CONCLUSIONS

The extent to which such transformation is achievable and the cultural change and practices to achieve it are considered in greater detail in section 4. The simple articulation of reformist strategies is insufficient as there are important reasons why researchers, especially in ageing, do not involve users in these ways. Clearly, the aim is to avoid tokenistic and ultimately meaningless approaches and the next section examines the methodologies that can push participative methods further up the involvement ladder.
User engagement in age research

3.

THE PRACTICE OF USER ENGAGEMENT
There are a number of frameworks and methods to guide the implementation of user involvement. The first part of the analysis examines government approaches before reviewing the different ways in which user needs are understood, mapped and managed. This section makes the point that the best models have user involvement at each stage of the research process, from planning through to commissioning, reporting and ultimately dissemination. The approach needs to be proportionate and to enable researchers and researched to gain value from the participatory processes.

**CODES OF USER PRACTICE IN THE UK**

Reviewing stakeholder views of official statistics in the UK, the United Kingdom Statistics Authority (UK Statistics Authority, 2010a) highlighted an important disconnection between the producers and consumers of research, the relevance of what is produced and the timeliness of the output. In addressing these problems the UK Statistics Authority produced a Code of Practice governing the production, quality control and dissemination of official statistics. As part of the process it also produced a strategy to strengthen user engagement, embedded within the code (UK Statistics Authority, 2010b). The UK Statistics Authority highlighted the links between the key elements of the Code of Practice and how this relates to user engagement. It states that ‘effective user engagement is fundamental both to trust in statistics and securing maximum public value’ and sets out the following actions to strengthen practice:

1. Identify users, document their statistical needs and their wishes in terms of engagement.
2. Make users aware of how they can find the information they need.
3. Take account of users’ views on the presentation of statistics and associated commentary, data sets and metadata.
4. Provide users with information about the quality of statistics, including any statistical biases.
5. Involve users in the evaluation of experimental statistics.
6. Seek feedback from users on their experiences of the statistical service they receive, data quality, and the format and timing of outputs. Review the feedback systematically.
7. Consult users before making changes that affect statistics (for example, to coverage, definitions or methods) or publications.

The Code of Practice concludes that while there is considerable evidence of effective engagement the following is needed:

- better understanding of the use currently made of official statistics and the value to society that flows from that use;
- better communication with a wider range of users; and
- better exploitation of the existing consultation structures and technologies to ensure that user engagement is effective.
RATIONAL METHODS AND THE VALUE CHAIN

Martinez-Uribe and Macdonald (2010) advocated a rational approach with user engagement a central task in each stage of the formation, implementation and evaluation of the research, as set out in the table below. This is similar to the value chain approach and those who see user engagement not as a one-off exercise but as an integral part of the research process.

Table 5: A rational staged approach to user engagement

| A. | Calls for proposals (i) should engage users in the definition of research programmes and projects to maximise the benefit of their expertise; (ii) should consider a two-stage process involving an initial expression of interest and a subsequent call for proposal defined either through (a) agency assessment of the expressions of interest; (b) a meeting of users and researchers identified through the expressions of interest; or (c) consultation with a funding partner. |
| B. | Adjudication should evaluate the quality of researcher-user partnerships based on their participation in project development, the application process and the governance model as well as their plans for operational management and knowledge mobilisation. |
| C. | Knowledge mobilisation (i) should go beyond dissemination through academic journals; (ii) should be supported by research agencies (including the costs of knowledge translation, mining literature and data on policy-relevant issues, and project-related expenses incurred by users); (iii) should be planned within a research project, from the outset, in collaboration with users; and (iv) should include designated places and times for researchers and users to meet. |
| D. | Evaluation (i) should allow time for long-term assessment of intended and unintended outcomes; (ii) should be based on a framework, including clear objectives, established at the outset by researchers, users and funders; (iii) should involve independent evaluators; and (iv) should engage users, researchers and funders. |

INVOLVE also developed a systematic approach to user engagement and research planning. It supports invoNET (http://www.invo.org.uk/invonet/), a forum for people with an interest in researching and building an evidence base on active public involvement in the research process. INVOLVE compiled Briefing Notes for Researchers as an online resource and develops training and support along with Two Can consultants.

This support involves interactive, web-based resources which aim to meet the needs of research commissioners, professionals undertaking empirical projects and people interested in becoming more involved in research that affects their lives. Figure 1 shows that there are three routes including support for researchers, commissioners and participants (http://www.twocanassociates.co.uk/routemap/).
Two Can suggests that the approach can improve research in a number of ways: relevance and usability; strengthening confidence in validity; increasing the likelihood that the research will be used by others; increasing the prospects for fundraising; and strengthening the advocacy potential. In planning user involvement, the following priorities are important:

- why you want to involve service users;
- whom to ask to get involved;
- where and when to involve them;
- how best to do it;
- what resources are needed in terms of staff and money;
- what you hope to achieve; and
- what you will need to do to get started.

When the Stroke Association recruited people to get involved in its research programme, the staff worked with the Stroke Research Network (SRN) on a joint recruitment process, in order to be more cost-effective. They put an advert in The Guardian which spelt out clearly what the Association and the SRN wanted and had a reasonably good response – about 30 applicants in total. They then went through a formal recruitment process to appoint people to the SRN, selecting two people for the Stroke Association’s Research Awards Committee.

Staff found it helpful to have worked on the recruitment together as they were able to ‘to sit down and thrash out what we were going to do and what we wanted. This helped in the development of the advert and the role descriptions, and in thinking about the whole process’.
One of the emerging patterns in user involvement is the creation of arms-length structures with varying degrees of formality to assist researchers to collaborate and communicate results. As the example from Canada illustrates, CARDI has many of the components necessary for effective user involvement in place.

The Centre on Ageing at the University of Victoria (Canada) established a Friends group who ‘assist in the communication of research results, collaborate with researchers in the dissemination of new knowledge about ageing, and assist with various events and awards of the Centre.’

The activities they participate in include providing research snapshots by summarising findings in short, easy-to-read articles that are available to a wide audience; facilitating communication and the dissemination of research and knowledge of ageing to the community; providing assistance with research projects to faculty and students; providing information on the research needs of seniors in the community through dialogue and feedback; and assist with Centre events by helping to organise activities and research gatherings, other meetings and discussion media such as the Community Forum.


The New Dynamics of Ageing Research Programme funded by five UK Research Councils (ESRC, EPSRC, BBSRC, MRC and AHRC) also placed the involvement of older people high on its agenda (http://www.newdynamics.group.shef.ac.uk/). This includes the creation of the first Older People’s Reference Group in a Research Council programme. The European Research Area in Ageing (ERA-AGE http://era-age.group.shef.ac.uk/) has also made this a priority and has produced a good practice guide including an international source book on participatory research with older people.

Hardill and Clark (2012) point out that there are a number of methods for developing what they term user-controlled partnership research, including advisory groups, deliberative panels, citizen juries, co-authorship and joint presentations at conferences. The ESRC Growing Older (GO) Programme, launched in 1999, set out to encourage participative approaches to ageing research. There were 24 separate research projects to investigate different aspects of quality of life in old age. The projects range from small to large scale and span most social sciences disciplines. Researchers used different approaches to involve older people, including those set out by Hanley below.

Table 6: User engagement methodologies

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion groups</td>
<td>A research project on social exclusion in deprived urban neighbourhoods used a range of different formal and informal groups to listen to the views of older people. The project was keen to avoid using older people purely as a resource and kept in contact with the groups via newsletters, informal contact and a final feedback session.</td>
</tr>
<tr>
<td>Relational research</td>
<td>A research project on the role of spiritual beliefs in adjustment to bereavement used longitudinal research that involved visiting a small sample of older spouses three times in the second year of their bereavement. The close relationship formed between the researcher and the older people became therapeutic. The participants felt that taking part in the research had been personally helpful.</td>
</tr>
<tr>
<td>Participation</td>
<td>The project Older Women’s Lives and Voices recruited ten older women and trained them to interview the individual members of the 11 discussion groups on which the research was based.</td>
</tr>
</tbody>
</table>
USER ENGAGEMENT AND OLDER PEOPLE

The Joseph Rowntree Foundation (JRF) research into the relationship between older people, information and advocacy found that the older community ‘suspected that too many information initiatives were designed to benefit services rather than older people’ (2005a, p. 1). JRF argued that an effective user-advocacy approach could be strengthened by involving older people in testing and peer-reviewing the research design, valuing older people’s organisations, especially those run by older people themselves and by preparing research materials and outputs in ways that older people will fully understand (JRF, 2005a, pp. 3-4).

JRF (2005b) also makes the point that involving older people in services is not about taking on a token representative; consultation after decisions have been made; one-off meetings; an agenda set by officers; set-piece committee meetings; older people being unsupported or unprepared; management-centred engagement; giving information out; or market research. It is about involving older people being from start to finish; having a say in setting the agenda; being represented in sufficient numbers; being resourced to take part; the potential for action as a result of involving older people; and involving older people in decisions about their own lives. In sum, JRF (2005b) suggests that users should ask of the service provider, research commissioners and even themselves the following questions:

- Why you are being involved in this process?
- How will it make a difference to older people’s lives?
- Is adequate funding available to enable older people to be involved in the project?
- Will older people influence what it does?
- Will older people have a say in the conclusions and delivery of the grant? (JRF, 2005b, p. 3).

CONTROLLED RESEARCH

European Foundation for Good Clinical Practice (EFGCP, 2012, p. 4) points out that ‘the absence of proper recruitment or not enough presence of the older patients in the clinical development plan of new medical products is a fact for products not specifically devoted to ageing populations’. They also point out that there has been a rapid increase in the use of medicine among older people yet their participation in research and clinical trials remains low compared with other groups. Here, the European Foundation for Good Clinical Practice (EFGCP) places a particular emphasis on risk minimisation and informed consent, especially among the most vulnerable older people.

Vale et al (2012) also aimed to establish levels of consumer involvement in 138 randomised controlled trials (RCTs), meta-analyses and other studies carried out by the Medical Research Council (MRC) Clinical Trials Unit across the range of research programmes, predominantly in cancer and HIV.

Researchers generally felt involvement was worthwhile and that consumer participation had improved the credibility of the work. Benefits in design and quality, trial recruitment, dissemination and decision-making were also perceived and researchers especially valued it as a learning experience.

CONCLUSIONS

The analysis suggests a need to develop and formalise older people’s engagement in the research process. A range of structures, advisory groups and panels have been used as well as guidance on how to plan and provide for more effective participation. The key message is that it needs to be comprehensive and address the different stages and roles that older people play in decision-making, but also to allow flexibility for researchers to design interventions best suited to their project’s needs.
PERSPECTIVES FROM PRACTITIONERS
This section sets out the views and experiences of researchers and practitioners in ageing about the value and impact of user engagement. The approach consisted of a short e-survey of 50 activists in ageing and a series of 18 interviews undertaken in 2012 with stakeholders across the public, private and NGO sectors as well as researchers in the UK and Ireland.

The table below sets out the profile of respondents; although dominated by academics, there is also significant representation from the voluntary and statutory sector. It will be shown later that these variations are important in determining attitudes to, and acceptability of, user involvement in age research. Clearly there are variations in responses and it is important to evaluate the results as a broad indication of some attitudes of some researchers rather than an authoritative set of views of all those involved in age research. It should be noted that according to CARDI’s database, most researchers involved in age-specific research are in the university sector.

Figure 2: Respondents to the e-survey

<table>
<thead>
<tr>
<th>Sector</th>
<th>Percentage</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Organisation</td>
<td>46</td>
<td>23</td>
</tr>
<tr>
<td>Statutory Sector</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Voluntary Sector</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td>Private Sector</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Personal Response</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>
ATTITUDES TO OLDER PEOPLE’S PARTICIPATION

The table below examines a range of areas where older people might play a role in the research process. It shows in broad terms that respondents had a generally positive attitude to most activities. Eighty per cent thought that it was very important to involve older people in setting research priorities and 82% that older people should deploy research as a basis for lobbying and advocacy. Fewer respondents stated that it was very important for older people to be involved in selection panels (35%), undertaking ethical reviews (39%) or being involved in data collection (38%).

Table 7: Impact of user engagement

<table>
<thead>
<tr>
<th>Variable</th>
<th>Very important</th>
<th>Quite important</th>
<th>Not important</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting priorities for age research</td>
<td>80% (40)</td>
<td>20% (10)</td>
<td>0% (0)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Sitting on selection panels to award specific contracts</td>
<td>35% (17)</td>
<td>51% (25)</td>
<td>10% (5)</td>
<td>4% (2)</td>
</tr>
<tr>
<td>Involvement in the design of methodology in particular projects</td>
<td>42% (21)</td>
<td>36% (18)</td>
<td>22% (11)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Undertaking ethical reviews</td>
<td>39% (19)</td>
<td>55% (27)</td>
<td>6% (3)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Being involved directly in data collection, say as interviewers</td>
<td>38% (19)</td>
<td>34% (17)</td>
<td>26% (13)</td>
<td>2% (1)</td>
</tr>
<tr>
<td>Peer-reviewing research output</td>
<td>38% (19)</td>
<td>40% (20)</td>
<td>18% (9)</td>
<td>4% (2)</td>
</tr>
<tr>
<td>Using research to lobby and campaign</td>
<td>82% (41)</td>
<td>14% (7)</td>
<td>4% (2)</td>
<td>0% (0)</td>
</tr>
</tbody>
</table>

Similarly, it was recognised that there is professional resistance to user engagement (44%), and concern about the practical obstacles to organising and delivering effective participatory strategies (52%). A total of 44% stated that they were quite concerned and 24% very concerned that it risks tokenism, while 47% and 27% respectively felt that older people lacked the necessary technical research skills. Moreover, some held the view that involvement might create unrealistic expectations about the impact of involvement on research output, with 48% stating that this was a quite significant obstacle and 23% that it was very significant. Similarly, 46% thought that there were quite significant and 18% very significant obstacles to recruiting older people and ensuring representation of the wider interests of the community.
Table 8: Barriers to user engagement

<table>
<thead>
<tr>
<th>Variable</th>
<th>Very significant</th>
<th>Quite significant</th>
<th>Not significant</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher’s professional willingness to engage users</td>
<td>44% (20)</td>
<td>42% (19)</td>
<td>9% (4)</td>
<td>4% (2)</td>
</tr>
<tr>
<td>It risks tokenism</td>
<td>24% (11)</td>
<td>44% (20)</td>
<td>25% (11)</td>
<td>7% (3)</td>
</tr>
<tr>
<td>It adds little value to the quality of the research</td>
<td>18% (8)</td>
<td>31% (14)</td>
<td>44% (20)</td>
<td>7% (3)</td>
</tr>
<tr>
<td>The time it takes to organise and deliver engagement properly</td>
<td>52% (23)</td>
<td>25% (11)</td>
<td>21% (9)</td>
<td>2% (1)</td>
</tr>
<tr>
<td>Lack of technical skills among older people</td>
<td>27% (12)</td>
<td>47% (21)</td>
<td>27% (12)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Fatigue of participants, especially in longer-term work</td>
<td>18% (8)</td>
<td>32% (14)</td>
<td>39% (17)</td>
<td>11% (5)</td>
</tr>
<tr>
<td>Ethical constraints involving vulnerable groups</td>
<td>23% (10)</td>
<td>39% (17)</td>
<td>34% (15)</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Individual older people may not be representative of wider interests</td>
<td>18% (8)</td>
<td>46% (20)</td>
<td>36% (16)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Users might have unrealistic expectations about what they are able to influence</td>
<td>23% (10)</td>
<td>48% (21)</td>
<td>25% (11)</td>
<td>5% (2)</td>
</tr>
<tr>
<td>The financial costs of proper engagement are too high</td>
<td>21% (9)</td>
<td>41% (18)</td>
<td>30% (13)</td>
<td>9% (4)</td>
</tr>
<tr>
<td>It is difficult to access older people for this type of work</td>
<td>11% (5)</td>
<td>46% (20)</td>
<td>41% (18)</td>
<td>2% (1)</td>
</tr>
</tbody>
</table>

The table on page 29 shows that respondents felt that a range of practices were important in developing user engagement. Seventy-three per cent thought it very important and 27% quite important that older people should be involved in setting research priorities. The figures for data collection were 30% and 41% respectively; and for evaluating research reports, 30% and 59% respectively. Less than half (46%) also felt that it was very important and 36% quite important that funders should stipulate engagement as a condition of funding. Respondents also felt, in general, that user engagement should concentrate on the application of information especially in translating research for advocacy (71% stating very important) or involving NGOs in research commissioning and use (68% stating very important).
Table 9: Priorities for user engagement and age

<table>
<thead>
<tr>
<th>Variable</th>
<th>Very important</th>
<th>Quite important</th>
<th>Not important</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The involvement of older people in setting research priorities</td>
<td>73% (32)</td>
<td>27% (12)</td>
<td>0% (0)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Training older people to participate in commissioning and evaluating research projects</td>
<td>50% (22)</td>
<td>41% (18)</td>
<td>9% (4)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Evaluating research reports and related outputs</td>
<td>30% (13)</td>
<td>59% (26)</td>
<td>7% (3)</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Developing older people’s panels or citizens’ juries</td>
<td>57% (25)</td>
<td>34% (15)</td>
<td>7% (3)</td>
<td>2% (1)</td>
</tr>
<tr>
<td>Pilot-testing research instruments such as questionnaires</td>
<td>59% (26)</td>
<td>41% (18)</td>
<td>0% (0)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Involving age-based NGOs in research commissioning and use</td>
<td>68% (30)</td>
<td>14% (6)</td>
<td>14% (6)</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Older people trained to collect data and analyse research findings</td>
<td>30% (13)</td>
<td>41% (18)</td>
<td>30% (13)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Translating findings for use in advocacy and political activity</td>
<td>71% (31)</td>
<td>27% (12)</td>
<td>2% (1)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Funders stipulating engagement as a condition of a grant awards</td>
<td>46% (20)</td>
<td>36% (16)</td>
<td>16% (7)</td>
<td>2% (1)</td>
</tr>
</tbody>
</table>

FACTOR ANALYSIS OF ATTITUDES TO USER ENGAGEMENT

Clearly, attitudes and perceptions vary and even the acceptability of user engagement is contested. A total of 18 indicators were selected from the survey for more detailed factor analysis, which attempts to reveal specific clusters or subsets of attitudes from the data. (The 18 indicators are set out in the table describing the component structure). The table below shows that four main factors emerge which bring together respondents who share a similar behavioural profile. The first cluster accounts for 21% of the variation in the data; factor 2, a total of 18%; factor 3, 12%; and factor 4, 9%; hence, in total these four factors account for 59% of the 18 variables. Factor analysis simply summarises relationships between more than one variable to produce subsets or clusters of respondents who share the same attitudes. The larger these groups, the larger the percentage weighted to each one and how they contribute to the explanation of variation on the data set.
<table>
<thead>
<tr>
<th>Component</th>
<th>Initial eigenvalues</th>
<th>Extraction sums of squared loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>% of Variance</td>
</tr>
<tr>
<td>2</td>
<td>3.159</td>
<td>17.551</td>
</tr>
<tr>
<td>3</td>
<td>2.142</td>
<td>11.898</td>
</tr>
<tr>
<td>4</td>
<td>1.651</td>
<td>9.173</td>
</tr>
<tr>
<td>5</td>
<td>1.404</td>
<td>7.799</td>
</tr>
<tr>
<td>6</td>
<td>1.060</td>
<td>5.887</td>
</tr>
<tr>
<td>7</td>
<td>.994</td>
<td>5.523</td>
</tr>
<tr>
<td>8</td>
<td>.804</td>
<td>4.467</td>
</tr>
<tr>
<td>9</td>
<td>.661</td>
<td>3.673</td>
</tr>
<tr>
<td>10</td>
<td>.653</td>
<td>3.628</td>
</tr>
<tr>
<td>11</td>
<td>.487</td>
<td>2.705</td>
</tr>
<tr>
<td>12</td>
<td>.346</td>
<td>1.923</td>
</tr>
<tr>
<td>13</td>
<td>.323</td>
<td>1.793</td>
</tr>
<tr>
<td>14</td>
<td>.195</td>
<td>1.085</td>
</tr>
<tr>
<td>15</td>
<td>.145</td>
<td>.806</td>
</tr>
<tr>
<td>16</td>
<td>.122</td>
<td>.680</td>
</tr>
<tr>
<td>17</td>
<td>.095</td>
<td>.528</td>
</tr>
<tr>
<td>18</td>
<td>.052</td>
<td>.286</td>
</tr>
</tbody>
</table>

Extraction method: principal component analysis.

The actual structure of the four factors is shown in the table below (and summarised in the diagram), which sets out the coefficients related to each variable so that a score nearer 1 strongly associates members with that opinion and –1.0 with a negative response to the variable. Figure 3 on page 31 summarises the four factors and their relation to each other.
a. **Factor 1** gives most weight to the variables that measure attitudes on the significance of the practical barriers to user involvement. They see some value in older people sitting on panels (0.330) and even a measure of peer review (0.263) but they are negative about their role in data collection (–0.032) or ethical reviews (–0.039). In this factor, there are comparatively high coefficients for a number of variables, including the professional unwillingness to engage (0.787), the time it takes to engage (0.775), cost (0.847) and the danger of raising unrealistic expectations (0.716). These attitudes tend to be more characteristic of academic or public sector researchers and the quotations drawn from the e-survey also reflect their attitudes and values.

“We just need to be careful that user engagement is proportionate and appropriate. It as your survey says ‘risks tokenism’ if it does not add value to the quality of research – we can’t just involve older people for the sake of it’.

‘Rather than automatically including users at all stages of the research process, it’s important for both parties that user involvement is carefully considered, so that service users are involved productively. I have been at meetings where, due to the technical or specialised nature of the discussions, user reps have been unable to contribute and have not been able to follow the discussion. This is pointless – it makes users feel out of their depth and it makes researchers feel that there is no point having them there’.

b. **Factor 2** gives most weight to those variables that relate to attitudes about the importance of involving older people in the research process. For example, attitudes emphasise the competence of older people sitting on selection panels (0.617), participating in research design (0.702) and conducting ethical reviews (0.575). Moreover, they reflect the view that older people should be involved in peer review (0.815) and do not feel that they lack the skills to do it (–0.423) or that their participation will raise unrealistic expectations (–0.337). This factor tends to reflect the attitudes of respondents from the NGO sector, who see the need to empower older people in defining research that matters to them and in applying more appropriate methods.

‘Older people are interested in the big questions of life and can find that research that is strongly focused on services, support and medical issues can become tedious over time.’

---

**Figure 3: Typology of researchers and attitudes to users**

<table>
<thead>
<tr>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>12%</td>
<td>22%</td>
<td>18%</td>
<td>9%</td>
</tr>
<tr>
<td>Value the scientific quality of the research process which user engagement does not (and cannot) add value to. See user engagement as tokenistic and even negative.</td>
<td>Accept that user engagement at a strategic level; setting priorities, dissemination and using results but not in the operational detail of the research process.</td>
<td>Believe that older people have the right to play a prominent role in the design, delivery and dissemination of the research. Their participation improves quality.</td>
<td>Emphasise the emancipatory dimension to research and its use as an instrument of political and policy advocacy. They have the skills to be effective in research.</td>
</tr>
<tr>
<td>Tend to be academics, especially in professions allied to medicine as well as the sciences</td>
<td>Mainly academics but also includes government statisticians and researchers</td>
<td>NGOs but also include private public and academic researchers especially in the social sciences</td>
<td>Mainly NGOs but some are academics committed to qualitative and ethnographic methods.</td>
</tr>
</tbody>
</table>

---

**USER ENGAGEMENT CONTINUUM**

<table>
<thead>
<tr>
<th>Weak</th>
<th></th>
<th></th>
<th></th>
<th>Strong</th>
</tr>
</thead>
</table>

% of respondents who describe their attitude to user engagement:

- Factor 1: 12%
- Factor 2: 22%
- Factor 3: 18%
- Factor 4: 9%
‘If older people are to have equal access to research funding as academics and professionals, there should not be a requirement for applications to be supported by universities. Sufficient funding needs to be available so to provide training and pay older people for their work. Older people need to set research agenda rather than academics, as they see the possibilities for improving the lives of older people in their communities, but it is difficult to get funding to pilot or implement these projects. Research funded often has little impact on lives of older people.’

‘I would like to point out the advantages of using an ethnographic approach in involving and training older adults in research at any level. Ethically and realistically research that involved the target group at all levels has more meaning, yet the barrier of ‘exhaustion’ in this group is quite high in general topics. But if we find the topics that really impact on their lives we would find a new energy… particularly if the research methodologies were ‘age-friendly’ such as using the creative arts.’

c. **Factor 3** gives most weight to variables relating to the usefulness of older people to the research process. They are not positive about older people setting research priorities (–.372), determining ethics (–.374) or being involved in the design of methodologies (–.088). Attitudes reflect a view that involvement will add little to the quality of the research (.715), that older people lack the basic skills to be involved (.504) as well as the ability to represent a wider constituency of interests (.629). The factor emphasises the importance of professional judgement, expertise and research quality as shown below.

‘Researchers need to be able to use their professional judgement otherwise we stop looking at quality – the research needs to be professionally done, not done to include older people – this is mixing up two quite different things. It is not to say they don’t have a role, only that research needs to be developed with reference to good research, not the amount to which different people feel they are involved. It is important that involvement is realistic and has a point to it otherwise it will frustrate older people and the researchers. There needs to be time and money given as part of the grant to do this properly and funders often accept responsibility for neither!’

d. **Factor 4** gives most weight to variables that stress the application and use of the research output, especially for lobbying and advocacy. For example, attitudes emphasise that older people can undertake ethical reviews (.552) and are most likely to encourage their participation in data collection (.30). Moreover, respondents scoring high on this factor are also the most likely to feel users should be involved in using research to lobby and campaign (.743).

‘Funding is required to ensure resources are put into older people’s involvement in research – to ensure it is of value and does not become tokenistic. It would also be useful to have access to training in how to engage older people in all stages of research – beyond carrying out research on them as respondents.’

‘Involving ‘users’ as participants in the entire research process is mutually beneficial. It benefits the research but it also benefits the participants, no matter what angle you are coming from. For example, a focus group will often provide a learning platform for participants to learn from each other, through the sharing of opinions leading to a sharing of the background knowledge. It can have similar effect to a peer support group. Engaging older people in the entire research process will also help ensure breadth and depth to the work’.
Table 11: Component structure

<table>
<thead>
<tr>
<th>No</th>
<th>Variance [%]</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Setting priorities for age research</td>
<td>.028</td>
<td>.521</td>
<td>-.372</td>
<td>-.238</td>
</tr>
<tr>
<td>2</td>
<td>Sitting on selection panels to award specific contracts</td>
<td>.330</td>
<td>.617</td>
<td>.361</td>
<td>-.182</td>
</tr>
<tr>
<td>3</td>
<td>Involvement in the design of methodology in particular projects</td>
<td>.096</td>
<td>.702</td>
<td>-.088</td>
<td>.093</td>
</tr>
<tr>
<td>4</td>
<td>Undertaking ethical reviews</td>
<td>-.039</td>
<td>.575</td>
<td>-.374</td>
<td>.552</td>
</tr>
<tr>
<td>5</td>
<td>Being involved directly in data collection, say as interviewers</td>
<td>-.032</td>
<td>.380</td>
<td>.265</td>
<td>.569</td>
</tr>
<tr>
<td>6</td>
<td>Peer reviewing research output</td>
<td>.263</td>
<td>.815</td>
<td>.078</td>
<td>-.207</td>
</tr>
<tr>
<td>7</td>
<td>Using research to lobby and campaign</td>
<td>-.100</td>
<td>.050</td>
<td>-.148</td>
<td>.743</td>
</tr>
<tr>
<td>8</td>
<td>Researchers professional willingness to engage users</td>
<td>.787</td>
<td>-.227</td>
<td>-.199</td>
<td>.132</td>
</tr>
<tr>
<td>9</td>
<td>It risks tokenism</td>
<td>-.044</td>
<td>-.133</td>
<td>-.228</td>
<td>.162</td>
</tr>
<tr>
<td>10</td>
<td>It adds little value to the quality of the research</td>
<td>.170</td>
<td>.494</td>
<td>.715</td>
<td>.178</td>
</tr>
<tr>
<td>11</td>
<td>The time it takes to organise and deliver engagement properly</td>
<td>.775</td>
<td>-.287</td>
<td>-.098</td>
<td>.317</td>
</tr>
<tr>
<td>12</td>
<td>Lack of technical skills among older people</td>
<td>-.362</td>
<td>-.423</td>
<td>.504</td>
<td>.130</td>
</tr>
<tr>
<td>13</td>
<td>Fatigue of participants, especially in longer term work</td>
<td>.555</td>
<td>-.016</td>
<td>.448</td>
<td>-.189</td>
</tr>
<tr>
<td>14</td>
<td>Ethical constraints involving vulnerable groups</td>
<td>.713</td>
<td>-.324</td>
<td>-.261</td>
<td>.135</td>
</tr>
<tr>
<td>15</td>
<td>Individual older people may not be representative of wider interests</td>
<td>-.204</td>
<td>-.217</td>
<td>.629</td>
<td>.275</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>---</td>
<td>----</td>
<td>----</td>
<td>----</td>
<td></td>
</tr>
<tr>
<td>Variance [%]</td>
<td>20.594%</td>
<td>17.551%</td>
<td>11.898%</td>
<td>9.173%</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>The financial costs of proper engagement are too high</td>
<td>.842</td>
<td>.131</td>
<td>.080</td>
<td>-.039</td>
</tr>
<tr>
<td>18</td>
<td>It is difficult to access older people for this type of work</td>
<td>-.213</td>
<td>-.121</td>
<td>.170</td>
<td>.078</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis.
a. 6 components extracted

**CONCLUSIONS**

It is clear that most researchers and practitioners support older people’s involvement in the research process. There are a range of practical reasons why users do not engage and it is clear that, for some projects, there are limitations on the level and type of involvement strategies that are feasible. In general, researchers responding to both the survey and qualitative interviews value older people’s involvement but wish to see flexible guidance rather than a rigid set of standards or codes.
PRACTICES AND EXPERIENCES
This section sets out the views and experiences of academics and practitioners, showing that there is a range of innovative practices in user involvement in age research. These include the establishment of structures to ensure that older people have influence over the design and implementation of projects as well as participatory methods, especially with regard to action research designs. Time, training and resources are critical to the success of more engaged models of user involvement.

INVolvEMENT STRUCTURES IN USER INVOLvEMENT

There are a number of models of user engagement within government research in Northern Ireland. NISRA has established the Statistics Advisory Committee (SAC) and discipline-specific user groups to ensure that a range of data consumers feed into data production and dissemination. The main concern here is data relevance, trust and impact, together with an emphasis on structures that facilitate an exchange between the producers and consumers of government research.

The Statistics Advisory Committee (SAC) is a statutory group to oversee the production, use and evaluation of data produced by Crown bodies. Recent legislation has extended the coverage of government statistics producers to include, for example, agencies such as the Housing Executive.

SAC has a particular focus on relevance of data to government and business users and the alignment of research with government priorities and PFG objectives. There are also dedicated user groups established for the Census of Population and the Northern Ireland Longitudinal Survey (NILS). The Census User Group places a particular emphasis on the format of outputs that key groups would find most practical from the 2011 analysis but there are also dedicated user groups for areas such as agricultural statistics and economic data. NINIS (neighbourhood statistics) has established an e-zine, interactive website and online updates as NINIS is populated with new spatial data sets.

Nationally, the UK Statistics User Forum was set up to make sure that the needs and views of the statistical user community are properly taken into account. The Forum comprises 38 member organisations and is recognised as representative of the diversity of the user community and as a source of informed opinion. It has provided responses to a number of consultations and parliamentary enquiries on the UK statistical system. SUF annual conferences attract a wide range of users and producers and have discussed issues such as regional statistics, statistics from administrative sources and transforming official statistics to match social change and future needs.

Similarly, the Housing Executive has established a number of structures to facilitate a range of users including tenants, partner agencies and government departments. The Supporting People initiative is an illustration of the governance mechanisms to ensure a wider consideration of research planning and application in the age sector. Age NI is also developing an initiative aimed at knowledge transfer in research and data produced about older people along with CARDI and other NGOs. Age NI noted that there was a vast quantity of research on older people in Northern Ireland but work is needed to ensure that best use is made of current knowledge. Its work is in the early stages but has identified rural development issues as a priority for the sector.
The **Housing Executive** uses its Housing Community Networks established at Northern Ireland Area and District level to recruit participants for group discussions, create awareness of new research and disseminate the results, especially of Estate Based Surveys. The Housing Executive has a dedicated research programme on **Supporting People** and its implications for older people in Northern Ireland.

The group is compromised of a cross-section of academics, NGOs, private sector and government representatives. A planned programme of research was commissioned via experts in specific areas and the initiative is overseen by a professor of housing at the University of Ulster. Research has been completed on areas such as demography and housing needs, equity release, assistive technologies, sheltered and supported housing and home improvement services. The projects sit within the context of the Supporting People policy but participants prioritise issues and methods, ensuring that the work has a high degree of policy relevance in a way similar to the Research User Forum in Britain.

The Patient Client Council in Northern Ireland has also developed a range of user engagement models as a way of evaluating services and setting policy priorities. It has also used people aged 16–21 to inform research into health and social care for young people and this provided important insights into the design and delivery of services. The Council points out that it is essential to recruit informed and literate participants, otherwise the approach risks tokenism and trivialising the role of the user. The Council briefs and trains participants on policy issues and has used community organisations to recruit participants. It is also considering a citizens’ jury to examine transport in the Southern Health and Social Care Trust area. A number of the larger NGOs also highlight the value of research as a basis for policy change and working with older people as advocates, with Age UK’s Knowledge Hub provision a good example of a strategic approach.

The **Age UK Knowledge Hub** provides information about policy and research and accessible statistics on older people in Northern Ireland, the UK and globally. Age UK also publishes evidence reviews: in-depth reports providing evidence to underpin decision-making, fundraising, influencing and service commissioning.

Age UK’s toolkit **Knowledge Translation on Ageing and Health: a framework for policy development 2012** was developed with the World Health Organization and aims to assist policy- and decision-makers in integrating evidence-based approaches to ageing in national health policy development processes, specific policies or programmes addressing older population needs and other health programmes such as chronic diseases.

There are also a number of resources, including **Involve, Engage, Empower**, which sets out guidance on user involvement in advocacy under the following headings: defining user and stakeholder involvement; reviewing current levels of involvement; developing a strategy for involvement; methods of involvement; policy and procedure examples; and skills and knowledge.

PRODUCT-TESTING AND THE END USER

Some of the most innovative practices in user involvement have come from the private sector and in particular in academic-industry partnerships. Intel points out that the concept of patient-centred care has a danger of being rhetorical, the power imbalance between the medical profession and the client being unchallenged; the relationship is one-way and not co-produced. However, Intel’s experience has shown that even in laboratory trials, neuroscientists became convinced of the value of end user engagement in planning and diagnosis because it strengthened a deeper understanding of results. In Intel, anthropologists are embedded in product development, design and concept-testing. This highlights the value placed on interpretative approaches to engineering and science. It also demonstrates the emphasis placed on inter-disciplinary methods in a commercial research context and the value that technologists place on ethnographic techniques.

The Building Bridges project is part of the TRIL project at Trinity College Dublin. It explored how communication technology can be developed to reduce risks of loneliness and social isolation among older adults.

A user-centred design approach was used to develop a device for the home that provides opportunities for peer-to-peer social interaction. The system consists of a touch-screen computer in a custom-made stand, a phone handset with functioning cradle, and speakers. Home visit interviews were conducted to understand problems in real-life contexts and the research helped generate ideas for potential interventions.

For example, the project explored how a technology could be developed to encourage peer-to-peer social engagement. Interviews and focus groups with potential users revealed the importance of providing social interaction and the need for ‘common ground’ among users. This led to the development of the Building Bridges device, which is a touch-screen telephone that allows users to listen to daily broadcasts such as news and documentaries and then have a group chat (http://trilcentre.org/tril-research/home-deployments/building-bridges.html).

The box below also shows an interest in developing resources from Living Lab approaches and how toolkit methodologies can assist in developing skills in research translation and user engagement. In particular, it explores strategies for involving people throughout the process, demonstrating how it adds value to researchers and researched at each stage.

TRAIL (Translating Research and Innovation Lab), based at the University of Ulster, supports research and innovation activities across business, information and communication technologies, occupational therapy, art, health care, media studies research, social care and clinical medicine. In particular, it helps to develop new technologies, research perspectives and integrated services to help translate research into policy, practice and enterprise outputs.

Better Together: the TRAIL User Participation Toolkit for Living Labs includes an analysis of user participation in living labs, as well as the steps necessary to be taken to engage with people before, during and after participation exercises. The toolkit also includes several relevant profiles and a full case study, as well as a separate chapter on governance and ethical issues in participation. It aims to empower other living labs and communities generally to develop their own evidence base to help in decision making and development of solutions to their local problems.

Linked to this type of approach is work on ambient living where older people are research subjects but benefit directly and in real time from the emerging results of a participative action approach. CASALA at Dundalk Institute of Technology aims to apply the learning from the Netwell Centre commercially as well as in policy terms. One specific initiative here has been to feed the learning into Louth Age-friendly County, one of the first 33 worldwide areas to adopt the programme. The approach, which has been adopted in other Irish counties, draws on research to develop more integrated policies on age inclusion and livability.
Ambient Assisted Living in Great Northern Haven (GNH) Dundalk

This research involved working with a number of older adults living at the Great Northern Haven demonstration housing project, consisting of 16 purpose-built homes, each equipped with a combination of sensor and interactive technology to support Ambient Assisted Living for older people.

The researchers collected data from embedded sensors and models are being built to detect patterns in activities of daily living and health. The research not only monitors older adults in their homes but supports interventions that will allow residents to play a greater role in actively managing their health and help change behaviours to improve their well-being. The outcome is to assist older people to live independently for as long as is practicable. Hence, researchers installed two interactive devices in each home to deliver feedback gathered from the sensors to residents and to redesign services and support activities, which include, for example, cognitive games, socialisation initiatives to reduce isolation and loneliness, and the provision of health-related information and education. The team continues to work with residents to determine behaviour change, user acceptability and health benefits from the technology.

PARTICIPATORY AGE RESEARCH

The National Development Team for Inclusion (NDTi) (http://www.ndti.org.uk/) approach below is an illustration of older people engaged in data collection and analysis and the value of their contribution to programme evaluation. It takes time, training and finance to implement although the case study shows the importance of this type of approach to data interpretation, validation and application.

The NDTi Evaluation of the Changing Ageing Partnership (CAP) was based on a Realist evaluation design, which seeks to surface underlying assumptions or ‘theories’ held by different stakeholders and to test and refine these as a basis for understanding wider programme effects. The evaluation placed considerable emphasis on engagement with end users and the involvement of older people as researchers.

The core of the empirical work involved interviews with 132 older people about their involvement and participation in active groups, networks and lobbying activities. These were gathered through a postcard survey, six focus groups and six in-depth interviews and were timed to link with Age Awareness Week. The evaluation team consisted of four people from NDTi and two older people from Northern Ireland who were recruited and trained as Local Evaluators.

The evaluators were able to identify a range of issues regarding older people’s involvement in research, including the need to address practical issues such as transport, the timing of meetings and access for disabled people; specific arrangements for older people with caring responsibilities; and the skills to be involved effectively in both data-gathering and how to use the research. The evaluators pointed out that a lack of knowledge about the substantive issue being considered was a barrier to participation and that investment in skilling the user in the research topic (e.g. rural transport) was integral to effective engagement. The use of Local Evaluators was important because it enabled a different form of validation and triangulation, especially in reading drafts of research documents and presenting results at conferences; it enabled the lived experiences of older people to be brought into interpretation; allowed for a regional context and hence for cultural nuances to be better understood; and a counter to the professionalisation and technical nature of data collection.
SPARC at Trinity College Dublin (TCD) has developed a number of projects based on participatory research and shows that this needs to be seen as a continuum from the involvement of older people as subjects to more engaged and democratic models. SPARC makes the key point that researchers should be explicit about the type of engagement they are using, what the strengths and limits are, and what older people can realistically expect from their participation. In addition, it is important to recognise that to undertake it effectively, researchers need stronger facilitation skills and to promote a deliberative style in which discussions between the researcher and the participant negotiate their various roles and expectations. This is at the centre of the power dynamic in research and helps provide practices that enable it to be addressed in specific projects. In one project, Doyle and Timonen (2010) used Community-Based Participatory Research (CBPR) to assist the design and administration of a questionnaire exploring older people’s use and perceptions of community services. The nine principles of CBPR, as advanced by Israel et al (1998, pp. 178–80), are to:

1. recognise a community as a shared unit;
2. build on strengths and resources within the community;
3. facilitate collaborative, equitable involvement in all phases of the research;
4. integrate knowledge and action for the mutual benefit of all partners;
5. promote a co-learning and empowering process that attends to social inequalities;
6. facilitate a cyclical and iterative process;
7. address health from both positive and ecological perspectives;
8. disseminate findings and knowledge gained to all partners; and
9. foster a long-term commitment by all partners.

The Doyle and Timonen work highlights some of the tensions in the implementation of user engagement research. They point out that researchers should not assume that older people wish to be involved and it is important not to force unnecessary or tokenistic practice. Unsupportive university cultures that prize peer-review output, time and money are some of the practical obstacles, but ultimately stronger skills are needed to act on the principles above and to pursue non-hierarchical practices.

**SUPPORTING USER INVOLVEMENT**

The Irish Centre for Social Gerontology (ICSG) at NUI Galway has developed an integrated approach to older involvement that includes new governance structures, participatory systems, working with enablers, and skills development.

- The Centre established a consultative committee comprised of older people whose role has evolved over time but who serve to advise researchers in more formal ways.
- Specific research projects involved the establishment of local parliaments that could call in experts, take advice on topics and make recommendations from the perspective of older people.
- The training involves a formal research methods course that places an emphasis on peer learning based on a research topic or project brought forward by older people rather than academics.
- The ICSG also uses project enablers, who assist specific projects with recruitment, consultation and implementation of fieldwork.

The Centre’s staff emphasise the dangers of tokenistic inclusion but make the critical point that projects with a strong participatory content change the nature of the research, especially toward politically oriented action designs. Researchers need to be explicit about the type of methods they use and the precise nature of the involvement linked to each type. Emancipatory designs are valuable when the research supports advocacy or campaigns on a particular issue but not all projects or epistemologies will require or suit this type of engagement. Again, clarity about the design and opportunities for participation are critical to effective strategies for older people's involvement in the research process.
A good example of this approach was developed by Age Action Ireland, which placed a considerable emphasis on training and ongoing support at each stage of the research. It emphasises the need for different types of skills and knowledge to match different stages in the research process, including analysis and dissemination activities.

Age Action Ireland conducted research into older abuse in Northern Ireland and the Republic of Ireland and central to their research design was the recruitment of four older people to participate in the design and implementation of a series of eight focus groups (see Begley, 2011). The participants underwent formal training in stages. The first phase of one-day training concentrated mainly on research approaches and scope was built in for peer learning, questioning and agreement on the priorities. The group discussions involved the older people as co-facilitator with the university researchers but the older people wrote up the analysis as a record of the session. They then undertook a second training session based on analysis and interpretation to enable them to assist in the preparation of the research reports.

Participants were not paid and did not seek remuneration, although the researchers feel that this is an issue that needs to be more closely considered. Participants were valuable in challenging the use of language in research, providing a more nuanced understanding of the issues and adding a realistic dimension to the analysis and in drawing out conclusions and policy implications. The older people were involved in dissemination, including presentations, policy meetings, preparing training videos and drafting press releases.

Age Action point out that this type of participation does not suit all types of research and that researchers need to be clear about what the roles and relationships in the process are in each case. Older people, as with any user group, also bring perspectives and experiences that can influence the objectivity of research.

The Intellectual Disability Supplement (IDS) to TILDA demonstrated an especially innovative approach to involving people with a cognitive impairment in the design of the modules, checking materials and preparing multi-media dissemination. The Scientific Advisory Committee includes a range of users including older people’s representatives who help to validate the approach. The specific IDS module was designed via a consultative workshop with people with disabilities to review the survey material. This highlighted gaps such as loneliness and social isolation that were then addressed in the question coverage.

There was also a call to people with an intellectual disability to help design the logo for the survey. This generated a strong response, the final version being selected from the competition. A series of workshops also helped check the materials: this raised problems with literacy and the need for easy-to-read formats when surveying. The researchers received a grant to support innovation in research dissemination: users wanted to see the findings reported back to the disabled community, easy-to-read reports and a DVD version of the findings. This included an app link to the DVD, which involved people with an intellectual disability acting out six of the chapters in a way that was appreciated by the wider community.

The researchers point out that a values framework is essential to enable academics from across disciplines to agree what is important in the conduct and application of the research. The commitment to effective engagement, translation and responsibility to the users are at the heart of this and show that high-impact involvement is possible in areas such as cognitive impairment where the barriers appear formidable. The text box on page 42 demonstrates one example of involving dementia patients in an evaluation of an advocacy programme and again underscores the possibilities of deep engagement in age-based research projects.
As part of the evaluation of this project Praxis Care and ICR interviewed two clients who used the patient advocate (one male and one female). Before each interview, the appropriate advocate gave a brief description to the researcher of the case together with the nature of their involvement.

Each interview was conducted informally with the researcher asking the clients a number of questions from a pre-prepared topic guide. The questions were adapted for each client in order to take account of the background information supplied by the advocate. Both interviews were conducted in the advocate’s presence as the client had not met the researcher before and the researcher wanted to use the advocate’s presence as a visual cue to encourage the client to give pertinent answers. Verbal consent was obtained by the appropriate advocate before the interview and the researcher asked for verbal consent again before beginning the interview. One interviewee gave verbal consent for the session to be digitally recorded. Written consent forms were not used because consent with this client group is an ongoing rather than a one-off phenomenon. The researchers quote Cambridge and Forester-Jones (2003), who caution against the use of formalised consent processes where a person’s ability to comprehend may fluctuate on a daily basis.

STRATEGIC BARRIERS

The case for user involvement is not always clear to researchers and guidance needs to be realistic about its impact on professionals who see it as an imposition, not an aid. The interviews highlighted a number of barriers to participation, including the practical difficulties or limitations to user involvement in certain areas:

- a reluctance to forfeit valuable research time to prepare methodologies or change design to suit particular groups;
- concerns over making data available to others before it has been fully validated, checked and exploited by the researchers;
- lack of control over ownership and intellectual property and commercial rights if these are loosely defined with regard to the interests of multiple user groups;
- concerns that data might be misused or misinterpreted, particularly by non-academic users such as journalists; and
- the possibility, suggested by a number of researchers, that user engagement could be ethically counterproductive owing to the risk of confidentiality and data protection being breached if multiple users are involved, especially in data-gathering or the analysis of non-anonymised data.

It was also pointed out that users may also need support users, especially if the research reveals emotional or painful issues. Some researchers feel ill-equipped to deal with these circumstances and their impact on both subjects and participants.

CONCLUSIONS

This analysis reveals the complexity of user engagement from a researcher perspective. There are progressive strategies, structures and skills in age research that involve a wide range of users in forming projects, undertaking fieldwork and validating reports. It is important to recognise that user guidance is not starting from a blank sheet but should be based on effective if uncoordinated practices across the island of Ireland, sectors and disciplines.
IMPLICATIONS FOR PRACTICE AND CONCLUSION
The primary output from this work is a separate statement on user involvement in age research but this section sets out the implications of the review for the development of stronger practice. It summarises the perspectives of different users in the research process and what they would seek from a more active approach.

**STAKEHOLDER PERSPECTIVES**

The table below sets out the perspectives of different users and shows how they require very diverse benefits from applied research. These are, of course, highly generalised and do not capture all the needs and perspectives of each set of interests, which are also not as self-contained as the table suggests. However, it emphasises the positive and practical rationale for user engagement (albeit at different levels of intensity) across sectors.

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>User involvement and stakeholder interests</th>
<th>User perspectives</th>
</tr>
</thead>
</table>
| Statutory agencies | • A strong evidence base to justify policy, programme and legislative decisions.  
                            • Evaluative research that enables strategic decisions to be reviewed, evaluated or changed.  
                            • Quality in the form of reliable and valid data takes precedence over user involvement.  
                            • Research that is complementary to government priorities and agendas. | Developing trust and relevance in official data and research.  
                                                                                            Strengthen application by developing users for market research and intelligence about what is needed. |
| Academics          | • Research that is usable in scholarly outputs, especially peer-reviewed media.  
                            • Ethical compliance and risk management.  
                            • International and interdisciplinary focus. | Ethical compliance and recruitment of users as research participants.             |
| Media              | • Immediately consumable research.  
                            • Short and free of technical language and concepts.  
                            • A strapline or highlight on which a public interest narrative can be constructed. | Useful, especially if life histories or human interest stories can be prioritised. |
| Politicians        | • Research that backs a claim, which may be partial or which takes sides.  
                            • Work that helps challenge official views or allows new political agenda to form.  
                            • Research validated by the inclusion of people impacted by a policy or programme. | Research that validates constituent (as users) experiences will be more prized. |
| NGOs               | • Translated research that acknowledges complexity but needs more synthetic reports.  
                            • Research that is aligned to the campaigns priorities of the sector.  
                            • A role in deciding priorities and oversight of projects. | Users mobilised as advocates for change.                                          |
Stakeholders | User involvement and stakeholder interests | User perspectives
--- | --- | ---
Older people | • Research that relates to their daily life experiences.  
• Knowledge that enables new resources to be attracted or interests to be protected, although these are clearly complex and even contradictory.  
• Inclusive research that develops their skills base and where applied outputs can be determined. | Older people most concerned about their interests being protected and enhanced.

**KEY ISSUES IN INVOLVEMENT**

The core of the approach is the development of guidance to strengthen awareness, practice and access to support for the involvement of older people. However, this guidance needs to be supported by a range of actions:

- **Recruitment systems** In order to develop a more efficient approach, age sector organisations need to participate in recruitment, skills support and referrals to ensure that there are older people who are literate in research and can become involved in research.

- **Better skills** Participants and researchers need stronger skills and knowledge about the practice and benefits of user involvement. This would look at the rationale for user involvement, the limitations and impact of users, basic research skills, dissemination and application of effective practice, payment and ethics.

- **Resources** Research grants and commissioning organisations should be encouraged to support user involvement financially and researchers should be permitted to estimate and adjust timescales as a result of effective involvement strategies. This could, where appropriate, also include a provision to pay participants in the older involvement programme.

- **User resources** To further develop user guidance, website(s) could be created that contain bespoke resources, links to organisations such as Age NI, Age Action and the Age Sector Platform, advice, and research on user engagement with the aim of supporting (ongoing) practice within the age sector.

- **User forum** In order to develop a more corporate approach to involvement in age research, CARDI could host an annual forum representing a range of stakeholder interests across the public, voluntary, private and academic sector to review progress, evaluate dissemination and suggest priorities for the forthcoming year.
IMPLICATIONS FOR THE GUIDANCE

The guidance will consist of the following elements:

- The rationale, aims, structure and use and application of the guide. This section will also set out principles including, for example, the need to treat involvement in authentic ways; a commitment to quality, valid and reliable research; and relevance, by ensuring that research meets the priorities and expectations of users.

- The rationale for user involvement, setting out an analysis of the reasons why older people’s involvement is important and what the evidence tells us about its effects. Different levels of involvement; dangers of tokenism and the need for appropriate and practicable approaches.

- An examination of the obstacles to involvement, misperceptions about engagement and the need to manage expectations in the research process.

- A description of the fundamental stages in the involvement process and summary of the different methods of engagement and the options open to research users, such as reference groups, NGO involvement and use of older people as researchers; it would concentrate on the value chain that provides the basis for the proposed approach.

- The practice of involving older people at each stage of the research process and guidance on the following issues:

  - **Understanding older people’s needs** The first stage might be to better map the implications of the research for older people, map their interests and those of related stakeholders. In a sense the first stage is to understand the rationale for older inclusion in the specific research and acts as a basis for the development of practice. This would also include an assessment of timescales, resources, training and responsibilities for taking engagement through the project.

  - **Setting the priorities** This could set out advice on grant applications and research planning and how older people’s involvement will add value to the research project and its use. Applications need to specify how involvement will affect the objectives for the research, the overall plan and its use and appliance, especially with regard to dissemination.

  - **Methodology and implementation** Involving older people in the research process itself will depend on the project but researchers are asked to think about how to involve older people in the research design, balance between quantitative and qualitative methods and the instruments used. It could be emphasised that methods must be appropriate to the research design, in which scientific judgements are paramount.

  - **Analysis and evaluation** Older people could be involved in the analysis and interpretation of the results where this is practicable and might also act as peer reviewers or check reports and drafts before final publication.

  - **Dissemination and advocacy** How to involve older people in the use and application of research, which also involves thinking through strategic links with NGOs and the age sector specifically. The CARDI Briefing series is a good example of translational research that takes account of the data needs of different user groups.

  - **Evaluating impact** Older people could be encouraged to participate in evaluating research, especially for its impact and capacity to democratise their inclusion in research based advocacy.

  - **Resources** A series of resources for researchers and older people could be suggested to strengthen practice and would include guidance, case studies and web links.

This list of issues is indicative and needs to be re-presented in an accessible and usable format for older people, relevant NGOs, researchers and commissioning organisations.
CONCLUSIONS

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.

The guide that arises from this research 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.

RECOMMENDATIONS

There is a need to develop stronger practices in the area of user involvement in ageing research in Ireland, North and South.

Planning and constructing a clear rationale for user engagement is vital at the outset of a research project.

Researchers should avail of existing guidance from a variety of disciplines, including this paper when planning user involvement in any research project.


INTERVIEW RESPONDENTS

1. Eileen Beamish, Social Research Centre, TRAIL User Participation Toolkit.
2. Dr Emer Begley, Age Action Ireland, Dublin.
5. Dr Avail Craig, Patient Client Council in Northern Ireland.
7. Dr Julie Doyle, CASALA, Dundalk Institute of Technology.
8. Dr Martha Doyle, Research Fellow, Social Policy and Ageing Research Centre, Trinity College Dublin.
9. Joe Frey, Northern Ireland Housing Executive (NIHE).
10. Professor Mary McCarron, School of Nursing and Midwifery, Trinity College Dublin.
11. Dr Matthew North, Head of Social Research, Age UK, London.
12. Professor Chris Paris, University of Ulster, Older People’s Research Programme, Supporting People, NIHE.
13. Dr David Prendergast, European Social Science and Design Lead, Intel, Ireland and Visiting Fellow, Trinity College Dublin.
14. Heather Porter, Research Unit, NIHE.
15. Louise Richardson, Vice-President of AGE Platform Europe.
16. Dr Kieran Walsh, Irish Centre for Social Gerontology, NUI Galway.
17. Marie Webb, Corporate Services, Northern Ireland Statistics and Research Agency (NISRA).
APPENDIX 1
A GUIDE TO USER INVOLVEMENT IN AGEING RESEARCH

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 on page 52 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.

Source: http://www.twocanassociates.co.uk/routemap/
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>
</tr>
</thead>
<tbody>
<tr>
<td>• as joint grant holders or co-applicants on a research project;</td>
</tr>
<tr>
<td>• involvement in identifying research priorities;</td>
</tr>
<tr>
<td>• as members of a project advisory or steering group;</td>
</tr>
<tr>
<td>• commenting and developing patient information leaflets or other research materials;</td>
</tr>
<tr>
<td>• undertaking interviews with research participants;</td>
</tr>
<tr>
<td>• user and/or carer researchers carrying out the research.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participation: where people take part in a research study</th>
</tr>
</thead>
<tbody>
<tr>
<td>• people being recruited to a clinical trial or other research study to take part in the research;</td>
</tr>
<tr>
<td>• completing a questionnaire or participating in a focus group as part of a research study.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Engagement: where information and knowledge about research is provided and disseminated</th>
</tr>
</thead>
<tbody>
<tr>
<td>• science festivals open to the public with debates and discussions on research;</td>
</tr>
<tr>
<td>• open day at a research centre where members of the public are invited to find out about research;</td>
</tr>
<tr>
<td>• raising awareness of research through, for example, television programmes, newspapers and social media;</td>
</tr>
<tr>
<td>• dissemination to research participants, colleagues or members of the public on the findings of a study.</td>
</tr>
</tbody>
</table>

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;
- 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.

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 feed back 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.
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 INVOLVE, 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-an-intro-guide.pdf

REFERENCES


User engagement in age research