



**INVOLVING OLDER PEOPLE IN RESEARCH:
A GUIDE FOR RESEARCHERS AND COMMUNITY GROUPS**
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This document is intended as a guide to assist researchers, older people, community and peak organisations to work together to achieve positive outcomes from research on ageing. It provides some practical tips on how working together can help make a difference to the lives of older people.

This guide is a product of an ongoing program of work within the ARC/NHMRC Research Network in Ageing Well and builds on the following three workshops:

- **Consumer-led Research** – convened by the Ageing Well Network and National Seniors Australia at the Building Ageing Research Capacity (BARC) Policy and Practice Colloquium on Ageing in Canberra in July 2006
- **Research Relationship with Older People: Promoting Good Practice** – convened by the Australasian Centre on Ageing at the University of Queensland in Brisbane in December 2006
- **Research Collaborations with Consumers: Participatory approaches to working with older people** – Convened jointly by the Ageing Well Network and National Seniors Australia in Melbourne in May 2007.

Population ageing is leading to increased demand for research that can be used to inform ageing policy and practice. No more is ageing solely about frailty, poor health and aged care. Ageing policies and practices now cover issues as diverse as economic development, health promotion, recreation and leisure, the environment, tourism, and planning and development. The result is a growing demand for good, multidisciplinary research into ageing issues.

At the same time, there is recognition that community members can, and some would argue should, make an active contribution to this body of research. Many individuals and groups want to have a say in the research that affects them. Researchers too recognise that developing partnerships with community members not only leads to more useful and valid research findings, but is increasingly a requirement for research funding.

The shift towards involving community members in research can be seen with the National Health and Medical Research Council (NHMRC) which is moving to align research funding with community needs and national health priority areas and released the “Statement on Consumer and Community Participation in Health and Medical Research” in 2002 (in collaboration with the Consumers’ Health Forum of Australia) followed by the release of “A Model Framework for Consumer and Community Participation in Research” in 2005 which extends the earlier document (see Attachment 1 for more information on the NHMRC/CHF approach to involving consumers and the community in research).

It seems that everyone is after good research with useable outcomes. However, how this is achieved is much less simple. There are clearly a range of different perspectives, needs, and approaches, as these questions suggest:

- What do community groups expect from researchers?
- What is research, and what isn't it?
- What is reasonable for researchers to expect from older people?
- How can community groups get the research projects that they need?

In this short guide, we consider these issues from all perspectives. As with any partnership, there are a number of viewpoints, and a need to understand the perspectives and priorities of others. We will discuss these issues under a number of key headings, presenting issues that have been debated in two key forums through the ARC/NHMRC Research Network in Ageing Well. We intend this guide as a starting point to suggest how researchers, individuals, community groups, peak organisations and policymakers can improve the ways that they currently work together. To assist in understanding the ways in which older people can be involved in research, we have provided a number of examples in the boxed sections below outlining the ways in which some of the organisations involved in the development of this guideline are promoting the involvement of older people in research.

Is research on ageing different from other forms of research?

Perhaps the first issue to consider is whether ageing research is any different from any other research involving people. In some ways, research into ageing issues is the same, and there are a number of useful and relevant guides that provide important information relating to ways that researchers and community members work together (see appendix). Furthermore, all research conducted in Universities and research institutions has to be conducted ethically, thus providing some minimum standards.

However, it can be argued that research into ageing is different from other research areas for the following reasons:

- Ageing is a priority area for governments, particularly in the changing demographic context. This is evidenced by the recent “Ageing Well, Ageing Productively” initiative established jointly by the NHMRC and Australian Research Council (ARC) and the Australian Government’s “Dementia – a National Health Priority” initiative. The interest in demographic ageing was also highlighted in the two Intergenerational Reports released by the Federal Treasury.
- There is an urgent need to fill some of the gaps in our knowledge of ageing. Ageing has been a neglected area in Australian research, and yet change is rapid. For example, baby boomers are now in their 50s and 60s, and are said to have quite different needs and expectations from the previous generation. More research is needed into what they are seeking in life, and their social, economic and health needs.
- Not all older people are vulnerable. However, it is important to recognise the potential for vulnerability, and researchers need to consider issues such as safety and frailty when researching with older people. There may also be differences in the ways that researchers see the world from the way that older people view it.

National Seniors Productive Ageing Centre:

The philosophy of the National Seniors Productive Ageing Centre (NSPAC) is to actively involve its consumer base in the design and conduct of research projects to further our understanding of issues around productive ageing. To achieve this, NSPAC maintains a Research Register. This is a database of National Seniors' members who have indicated that they are prepared to contribute to the research process.

The types of research that members can expect to be involved in are surveys, focus (or discussion) groups and interviews. Participation is purely voluntary and members may choose not to complete a survey or participate in a particular research project.

For example, research register participants provided anecdotal accounts of their positive and negative experiences with Queensland's road transport infrastructure and were involved in analyzing and making sense of the meaning/context of this information. Also, researchers have worked directly with register participants to better understand their attitudes towards and willingness to use assistive health technologies to manage their health and independence.

Considerations in working together

What is good research?

Whilst there is debate and different viewpoints over the *process* of working together, there is perhaps more common agreement on the *outcomes* of good research. These include:

- *Genuine and useful outcomes.* There is some research that is purely theoretical, however, most researchers are not looking for their research to end up on a dusty shelf. The vast majority want to undertake research that is relevant to people's lives and for their research findings to be used in practice.
- *Mutual gain.* There are advantages to researchers and community members in working together. Research benefits from the practical input of people who are living the phenomena under study. Similarly, groups or service providers may know the answers but systematic investigation is needed as confirmation.
- *Relevant and truthful.* Both researchers and community members are seeking truthfulness in research. Researchers expect older people to tell them the truth as they see it, and older people expect researchers to convey their true perspective in their research.
- *Reciprocal benefits.* Research should provide reciprocal benefits. Older people give their time to researchers in the expectation that there will be benefits, if not for themselves, certainly for other older people in the future. Researchers have an obligation to respond.

What is ethical research?

All research should be conducted using ethical principles as follows:

- The key principles of ethical research are the *requirement to do good*, and the *duty to avoid causing harm*. This protects individuals asked to take part in experiments.
- Research should be based on *respect for the person*. This includes ensuring that research is *confidential*, and that individual's *privacy* is respected. This includes being sure to gain *informed consent* from anyone participating in the research.
- *Certain social groups have been identified as vulnerable* and researchers are expected to take special care in protecting their interests.
- The *level of risk* associated with a project needs to be identified (e.g. high risk might be research with frail older people in a hospital setting).

What are the key considerations in working together?

There are a number of issues to be considered if the process of working together is to be effective. These include the following, which are discussed in more detail below:

- Speaking the same language
- The research process
- Clarifying roles
- Communicating with each other

The Benevolent Society:

The Benevolent Society (TBS) places a large emphasis on research and evaluation in order to ensure the effective delivery of our services and to contribute to the national and international evidence base. Our research agenda includes organisation-wide evaluation of services, examining the impact of TBS programs in clients' lives, conducting literature reviews, disseminating research findings broadly, and conducting research on innovative programs aimed at addressing social disadvantage. TBS collaborates with a range of other service providers, consumers, and universities in order to strengthen our evidence base around effective service delivery and to share important learnings.

Currently, TBS is embarking on a large-scale evaluation of our community-care services and will examine: i) the effectiveness of the processes involved with service delivery (e.g., staff, reliability, affordability); and ii) the impact services have in our clients' lives (e.g., quality of life, health, happiness, community connectedness). We are currently in the process of developing a research and evaluation framework to be used across all TBS community care services in order to assess process and impact outcomes for our 2,000 community care clients.

In addition, TBS employs innovative strategies for engaging older people in research and evaluation. Our Social Policy and Research team are currently working on a collaborative project with the Social Policy Research Centre (UNSW) on translating research findings into practice briefings for practitioners working in community care. Current Research to Practice briefings for community care include 'The World of Care Workers' and 'Community Connectedness for Older People'.

- Different expectations
- Who represents older people?
- The importance of mutual respect
- Disseminating findings

1. Speaking the same language

It is important when researching in partnership with older people or community groups that the language is simple enough for all to understand. In particular, jargon needs to be avoided. This includes specialist research terms, such as the methodology or theoretical interpretations, which may present barriers to broader community involvement

Terminology is important. Even words such as *consumers*, used by the NHMRC and in the workshops preceding this guide, can seem unclear – consumers of what? Furthermore, this term implies that all older people “consume” services, which places them in a particular relationship. *Older people* is the generally agreed term in Australia, and should be used by researchers rather than terms such as the elderly or old people. Researchers should particularly avoid terms with negative connotations and be sure to be *age sensitive*. By this, we mean that they should avoid any assumptions that older people are necessarily frail, unintelligent, have disabilities, and so on. There is a wide range of capacities within any age range, and such assumptions are ageist.

Remember too that community groups or peak organisations should avoid jargon and not refer to particular local knowledge of which researchers may be unaware. Community members should also remember that young researchers have to learn, so try and be tolerant. Sweeping comments about young people can offend young researchers and are just as ageist as comments about older people.

Overall, keep language clear and straightforward to avoid excluding any individuals or groups. In particular, being clear about what is required can help overcome some of the fear that may be a barrier to involvement in research.

2. The research process

Research is a *process* involving a set of stages. Older people can participate in research projects throughout the process (participatory research) or they can provide expert advice throughout the process. It should be noted that including a few older people just for the sake of it is tokenistic and should be avoided. Community involvement can occur at any of the research stages, and, particularly during the following stages:

- decisions about research priorities
- developing research questions
- discussions about the research process
- interpreting the findings
- promotion of research outcomes

It needs to be recognised that members of communities are far more than passive subjects for university researchers, and working together can make research more relevant, more meaningful and more useful. However, it is important that *the level of involvement is agreed and clearly understood from the beginning*. Further, roles need to be clarified and agreed.

Alzheimer’s Australia:

Alzheimer’s Australia (AA) is pursuing a number of strategies to engage older people in dementia research.

Firstly, AA funded a study tour by Dr Colleen Doyle, who has subsequently prepared a report on Australian and overseas experiences of consumer involvement in dementia care research and evaluation.

Secondly, AA publishes a weekly newsletter, Dementia News, which provides information on the latest developments in dementia research and treatment. Also, the Alzheimer’s Australia website includes information on current research projects and clinical trials as well as links to external websites that have useful information about dementia research.

Thirdly, the National Consumer Committee, which includes people with dementia as well as family carers from every State and Territory, is developing its role in setting research and policy priorities and is involved in work on the costs of dementia, respite care, and consumer-directed care.

Finally, AA facilitates research involving older people and dementia by funding a number of research grants and scholarships through its research arm, Alzheimer’s Australia Research. A key priority is to fund emerging Australian researchers to become involved in dementia research and to fund particularly under-resourced research areas, such as dementia care and prevention.

3. Clarifying roles

The term 'research' covers a broad diversity of possible approaches, which may involve a survey of thousands of people or an in-depth discussion with a few older people about their experiences. Deciding which approach to take is a professional decision, and *researchers are the experts in research design*. Research is a complex process, and whilst older people or a group can advise on developing the question, it is the role of the researcher to implement the research process. Community members can participate in research as co-researchers, and the experience can be empowering, however, adequate research training is essential.

This is not to say that the best research is done alone. Researchers may be experts in the research process, but older people are experts in terms of their lifetime experience, and service providers are experts in providing services. The best research draws on a *range of different perspectives*.

While the role of researchers is to provide the best possible research evidence for the issue under study, it is not their role to advocate for older people's issues. Their role is to provide good quality data that can then be used by advocates, like community and peak organisations.

4. Communicating with each other

Clear communication between researchers and older people or community groups is essential if research outcomes are to be achieved. Even complex research processes can, and should, be interpreted so that the large majority can understand them. Whilst researchers are the experts in research design, even the very best design is of little value if it is too complex. Similarly, findings written up so that only a select few can access or understand them are of little value if they are joint ventures aimed at improving policy or practice.

There are some strategies to improve communication between researchers and the community. Beginning with a clear commitment to understanding each other is a good start. In working together to achieve the best outcomes from a research project, one of the first considerations should be, how do we ensure that we have a good communication process? Methods for increasing participation and ensuring mutual understanding include:

- Advisory committees
- Working groups
- Formal and informal consultations with key stakeholders and individuals

Researchers also need to consider appropriate modes of communication, particularly in relation to technology. Many older people may use the internet and be comfortable with email, but researchers need to consider whether this is the best way to communicate. What about a study of rural ageing where access to the Internet is expensive? Or amongst those from different cultural backgrounds, where language ability may be an issue?

5. Different expectations

For researchers and community groups to work together requires mutual understanding. They may have different objectives, which need to be acknowledged when working together. For example:

Council on the Ageing:

Older people across Australia are active in research in the ageing sector through the various Council on the Ageing (COTA) organisations. COTA supports consumer representatives in steering group roles for research projects and is active in health consumer and aged care alliances.

COTA Seniors Voice uses its myCOTA magazine to seek the views of older people on research, undertakes regular surveys of members experiences of service provision, partners with tertiary and industry researchers and contributes to a number of university roundtables and research forums.

Recent research efforts include a South Australia wide series of consultations with people who receive care services in their homes, and a survey of older people's experiences of the health system, for which 2500 responses were received. This research directly informs government policies and programs such as the HACC triennial plan and restructuring the health system to meet the needs of older people. It is also used to assist industry partners in service design and delivery.

In 2007 COTA Seniors Voice and its members assisted 15 university based research initiatives including ARC grant projects and numerous government and non-government research efforts reflecting the research involvement of COTAs across Australia.

- *Priorities.* As noted earlier, researchers are not necessarily advocates and they may have different priorities from the community when they undertake a research project.
- *Time frames.* Research is time consuming, and good research will often take several years. This can be a source of frustration if community members are seeking research findings quickly.
- *Costs.* Most academic research in ageing is not well funded. Nevertheless, it is an obligation of researchers to ensure that if expecting research participants to give up their time and to contribute to research, then any expenses they incur should be repaid. Budgets should be designed to include costs such as travel costs and hospitality.

6. Who represents older people?

Ask yourself the question, is there just one individual who is typical of all older people? Then you realise that the question is clearly ridiculous. Older people are very different from each other, just like the rest of us are. They should not be stereotyped. Important areas of diversity include health, attitudes, capacity, socioeconomic status, cultural background, and so on. It is not uncommon to hear people say “baby boomers are more selfish than the older generation” or “older people are more conservative than the young”. These are sweeping generalisations and should be avoided. Researchers need to *avoid stereotypical approaches to ageing* and ensure that their research *recognises the diversity* of the older population.

Similarly, older people need to recognise that, whilst they have personal experience of ageing, they do not represent all older people. The experiences of one individual, or even a group or organisation, may not be common to everyone. In order to understand ageing in Australia, it is essential that researchers consider *many different viewpoints*. No one view is “right” on its own.

7. The importance of mutual respect

Good communication strategies, as well as good research processes, are dependent on mutual respect. Research conducted respectfully should therefore be ethical, representative and valid. Making expectations and roles clear at the beginning of a project can help avoid problems.

8. Dissemination of findings

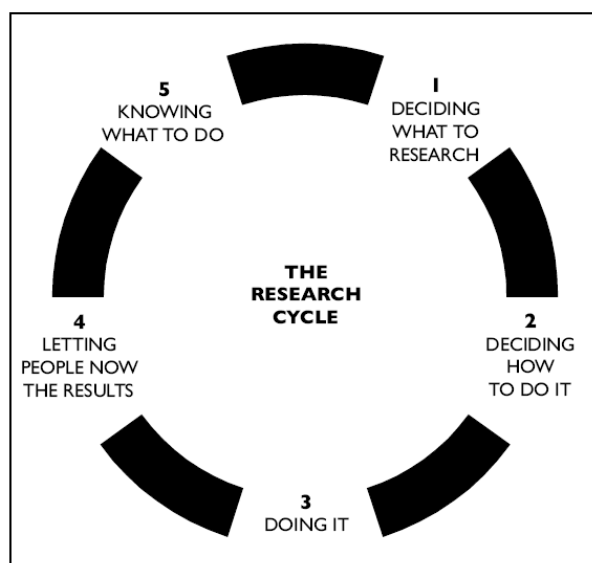
Researchers may not be advocates but they have an ethical responsibility to disseminate findings from their research to those who took part. However, researchers are very busy and may not have the time to “translate” their research findings and distribute them more broadly. Yet dissemination is critical if research is to have an impact. For those working in partnership with groups or organisations, broader dissemination can be effectively achieved if undertaken jointly. Research partners, such as government departments or community organisations, can help disseminate the findings of research to the community through their websites and publications. Some of the larger organisations can also provide expert presentation and marketing skills to promote the findings from research.

Conclusions

Indisputably there is a real need for more research evidence into ageing issues. The most useful research is that which is undertaken in partnership and which draws on the best of all worlds. To avoid some of the pitfalls associated with working with others, this guide suggests that both researchers and community groups need to consider a range of factors. Goodwill and mutual respect should drive the process, but clarifying roles and expectations, as well as developing a clear communication plan is also essential. Managed effectively, research partnerships can produce research that is relevant and truthful, with reciprocal benefits, and which has genuine and useful outcomes. This should be the aim of all those using this guide.

Attachment 1 – NHMRC/CHF Model Framework for Community Participation in Health and Medical Research

The *Model Framework for Consumer and Community Participation in Research* released by the NHMRC and the Consumers' Health Forum in 2005 identifies the stages in which input from consumers and the broader community can inform the research cycle. The cycle is depicted below:



The *Model Framework* extends the *Summary Statement on Consumer and Community Participation in Health and Medical Research* which was released in 2002. At each stage in the process above, the Summary Statement provided a number of considerations relating to consumer and community participation research. The dot points below are taken from the *Summary Statement* along with additional suggestions from the *Model Framework* on how consumer involvement can add value:

Deciding what to research

- Have consumers been involved in identifying their issues and concerns?
- Do consumers see how they will benefit from the research?
- Have the people who will be most affected by the research been consulted?
- Who else should be consulted?
- Have consumers been involved in deciding how to consult?
- How have consumers been involved (e.g. representation on steering group, focus groups etc)?
- Have formalised links been set up between consumer groups and academics?
- Has a flexible collaboration process been established between consumers and researchers?

In addition to the above considerations, the *Model Framework* suggest that consumer groups may identify research needs through consumer priority setting workshops and by asking consumer groups to consult with their members on research priorities.

Deciding how to do it

- Has the research project involved consumers in its design? How? Who?
- Does the research proposal have outcomes that will benefit consumers?
- Have consumers been involved in deciding on the research methods?
- Have research methods valued by consumers been included (e.g. qualitative methodologies)?
- Has a holistic, multidisciplinary approach been taken?
- Have consumers' rights been defined and addressed in the research proposal?
- Are opportunities for consumer involvement incorporated in the implementation plan?
- Has funding to ensure ongoing consumer involvement been sought (including innovative sources)?
- Have consumers' needs for skills development been planned for to ensure effective participation?
- Have strategies to disseminate results to consumers been planned?
- Has an action plan for the research outcomes been incorporated in the design?

The *Model Framework* suggests that consumers can add value to the research process by ensuring that the research methods are user friendly, helping to write information sheets, suggesting ways to maximise consumer participation, ensuring the research questions are relevant to consumers.

Doing it

- Have the consumers involved in or affected by the research been informed of the timelines, boundaries, security and confidentiality, and likely uses of the information obtained?
- Are consumers informed of the research as it unfolds including progress according to schedule, problems and delays?
- Are peer researchers being used wherever possible?
- Are participants in the research project (e.g. steering committee members) receiving sitting fees for their time?
- Is an action plan for the research outcomes being incorporated into the process?

The *Model Framework* suggests that consumer perspectives can add value by informing the conduct of research through their inclusion in steering committees or reference groups.

Letting people know the results

- Are the results available in a timely manner? Have participating consumers been informed about delays?
- Are the results available in layperson and relevant community languages?
- Have the participants and their health care providers, such as general practitioners and pharmacists, been informed about the results?
- Are the results accessible to consumers through a variety of media, not just professional journals?
- Are the results of community interest? Have a range of ways of providing the results been considered (e.g. newspaper, radio talk-back programs that allow a two-way discussion, programs that allow a regular update, news items on television, newsletters, consumer and community organisations)?
- Has care been taken to ensure that preliminary results are not provided in a way that is misleading for consumers?
- Have consumers been involved in reality testing of the researchers' interpretations and in discussion and evaluation of the results?
- Do consumers and participants have some control over the dissemination of the results?

The *Model Framework* identifies three potential groups of consumers to consider when disseminating research: 1) those who participated in the research; 2) other people in the same situation; and, 3) the wider community. Dissemination could be in the form of regular newsletters, consumer journals, local community seminars and national magazines read by the general community.

Knowing what to do

- Does the feedback loop include implementing the research findings and assessing the outcomes of the implementation?
- Do consumers have questions which the research does not answer?
- Do the target group feedback on the research?
- Have consumers been involved in identifying and considering the limitations of the current research to guide subsequent research?
- Are consumers being supported to take the next step with their own research or implementation plans?
- Go back to the beginning for a continuous cycle of quality improvement in research.

The *Model Framework* suggests that research participants can add value by feeding back their experiences from the research process which could inform future research activities and that consumer and community advisory committees may provide valuable insights into future research directions.

(taken from National Health and Medical Research Council and Consumers' Health Forum *Model Framework for Consumer and Community Participation in Research* (2005) and the *Summary Statement on Consumer and Community Participation in Health and Medical Research* (2002).

The *Model Framework* and *Summary Statement* are available on the NHMRC website at <http://www.nhmrc.gov.au/publications/synopses/r22syn.htm> (last accessed 26 May 2008).