

Building Ageing Research Capacity Colloquium

Research Development and Communication Processes Workshops

Morning Workshop 1–Consumer-led research

Day 2–5 July
10:35–11:55 AM

Presented by:



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Disclaimer:

This is a background document that has been produced by the ARC/NHMRC Research Network in Ageing Well and is only to be used for the purpose of informing discussion at the workshop on 5 July 2006. The materials contained herein are not available for the purposes of quotation until the workshop discussion has been incorporated. An updated version will be sent to all workshop participants and will be made available on the Network website (www.ageingwell.edu.au).

Any statements about proposed Network actions or directions are statements of possibility only. Directions will be determined at a later date after taking into consideration the discussion at the workshop.

Research Network
Convened at



Major Partners



Consumer-led research

Background and Overview

Increasingly the potential for consumers to make an active contribution to the research process is not only being recognised, but is becoming a requirement for research funding. For example, the Consumers Health Forum of Australia Inc (CHF) and the National Health and Medical Research Council have worked in partnership with consumers and researchers to develop the *Statement on Consumer and Community Participation in Health and Medical Research* (2002). ARC Linkages grants are particularly appropriate to support partnerships between consumer bodies and researchers to address questions of priority to consumers.

Consumer advocacy organisations in Australia - such as National Seniors, Council on the Ageing (Australia), Carers Association, and Alzheimer's Australia – have had an increasing interest in developing research agendas and funding research projects (see activities to date below). The National Seniors Productive Ageing Centre undertakes research and related activities into the needs of seniors in retirement, focusing on ageing and the productivity of seniors in the community. These developments reflect the value of applied research influencing the priorities of governments and, more widely, the views of the broader community.

In the United States, the major consumer organisation for older people, AARP, conducts research that informs the public and policy development as well as identifies marketing opportunities for providing services. In the UK, the Centre for Policy on Ageing (CPA) is an independent centre of research and reference to inform policy development, public debate, and public awareness of issues important for older people. The Nuffield Foundation, which funds the CPA, conducted a recent review of University Research Ethics committees. The review considered of ethics and morality, research governance and practice, older people as research advisors, service users' 'voice' in their future, and 'how it feels to be on the other side of the fence' (Tinker and Coomber, 2004).

In Australia there is a small and largely dated literature on the relationships between applied research and constituencies of older people. Researchers have responsibilities for the ways in which they collaborate with community groups in setting research agendas, conducting research, and representations of them in reporting the findings (Kendig, 1996). Case studies of Australian research illustrate how older people are stakeholders in policy research and the need to recognise the different views and power imbalances among older 'subjects', researchers, and funding bodies (Quine and Kendig, 1999). While consumer led research does not differ in its method from traditional methods, it is important that researchers are attentive to the methodological and ethical issues that can arise in conducting research with older people, particularly those who are frail or otherwise vulnerable (Quine and Browning, 2006).

The main body of this paper considers the process of conducting research. Participants at this colloquium are invited to reflect on the issues raised and how they relate to their own experience and concerns. For consumer led research to meet the goals both of the research community and the community being researched, a clear understanding of the contribution and limits of consumers in the research process is needed. The level of participation that is required, or even is appropriate, varies considerably from one research project to another even within the same disciplinary area. Consequently there are no hard and fast rules as to how to do consumer led research, rather there are a series of guidelines to help facilitate the process.

This paper concludes by presenting options for future directions including possible collaborative action by the Research Network and Consumer Organisations. The attachment summarises some current activities in consumer research with older people.

Consumer-led Research Processes

For researchers to demonstrate a genuine commitment to consumer led research processes need to be put in place at all stages to allow for appropriate consumer input. It is important to remember that consumer led research is an iterative and learning process. Each stage informs the next. Ideally effective high quality dissemination of research outcomes will inform topic selection for future research projects creating an ongoing feedback loop.

Topic Selection

Fundamental to ensuring the relevance of research projects is the need to be flexible and inclusive in the initial selection of research topics. The training received by researchers is rarely consumer focussed. Rather the process of getting a research higher degree and PhD usually starts from the point of reviewing existing studies to identify a gap in knowledge that can be at least partially filled by the research project.

Consequently, research which is of value and interest to the research community is often seen as irrelevant or trivial on the part of the public. Conversely issues of importance to consumers are often seen as repetitive and over done by researchers and simply going over old ground.

Methods of increasing consumer participation in the selection and development of topics for research include:

- Advisory committees;
- Formal and informal consultation with key stakeholders;
- Opt in processes such as research registers; and
- Feedback / survey input resulting from prior research and dissemination.

Research Design and Implementation

Whilst researchers are the experts in research design, the best research design from a technical perspective is of little value if it is too rigorous and complex to attract participants. The ongoing participation of consumers is critical for experimental and longitudinal studies however without appropriate incentives ongoing intrusion will not be tolerated.

At times it becomes necessary to compromise the ideal research design for a negotiated design which will deliver adequate results.

Consumer involvement at this stage of the process concentrates predominantly on communication. If participants are aware of the logic behind using different processes as well as the consequences for the overall project of dropping out then ongoing co-operation is more likely.

The types of issues which need to be considered in consumer led research at the stage of design and implementation:

- Compensation – will participants be paid for their time?
- Are the research methods used understood and valued by the consumers?
- Do participants need training to ensure their optimal input? i.e. do they have the basic skills required to carry out the tasks required of the research – if not what processes are in place to ensure that they develop these skills;
- Have participants been informed of confidentiality and privacy requirements; and
- Have consumers' rights been defined and disseminated?

Dissemination of Results

From a consumer perspective, one of the most common complaints is that without adequate follow up and dissemination of results people feel 'used'. Perceptions of appropriate time intervals tend to differ between researchers, who want to wait until the full process of analysis and review has been completed, and participants who are interested in the results immediately.

At times early release of results can lead to adverse research outcomes however to satisfy the need for information on the part of participants some close to immediate feedback mechanism for elements of the research need to be incorporated into the design.

In complex areas of research, particularly those involving health issues, legal issues or economic analyses multiple publications are needed to address the information needs of different targets. Further multiple methods of dissemination (hard copy, web site etc) are needed to reach all appropriate markets. To ensure that this actually occurs dissemination to consumers and participants needs to be costed into the overall budget of the research project.

Points to consider

- At what stage is the emphasis on consumer involvement greatest?
- What issues / problems have arisen during each of these stages?
- How have these, or could these, be overcome?

Co-production

Consumer led research takes participant involvement to a new level. No longer are consumers considered as subjects to be studied but rather they are actively involved throughout the process. As a result of the input of the consumer, research designs may be altered or new topics for study generated. In effect consumers become co-producers of the research process and therefore influence the research outcomes.

Whilst the concept of consumer as co-producer is relatively new to many researchers particularly those fields of research which are very technically complex and therefore traditionally expert driven, it is a notion that is well documented in the services marketing and management literature.

The notion of customers as co-producers of services is based on two premises. First is the idea that the creation of a service [research] cannot be separated from the influence of the consumers' behaviour or the producers [researchers] actions. Second co-production promotes the notion that the interaction between the parties has the potential to generate greater benefits together than either party could generate individually. The more closely and consistently the parties work together, the more positive the outcomes.

The inseparability factor means that the quality of the research outcomes is strongly influenced by the quality both of the actions of the researcher (eg accuracy in recording or consistency in questioning during focus groups) and the quality of the performance of the participant (e.g. keeping to pre-experimental instructions or willingness to divulge information).

The more that consumers are actively involved in the process of research and consulted at each stage of the process, the stronger their influence as a co-producer is. Maximising the quality of the research outcomes, therefore, is in part dependent on the management of the participant as a co-producer.

By re-conceptualising the participant as a co-producer of knowledge, rather than a subject to be studied, the nature of the relationship between researchers and consumers fundamentally changes. With this change comes the need for a shift in the way in which consumer – researcher interactions are managed.

Points to consider

- How relevant is the notion of participant as co-producer to different styles of research and different research topics?
- What issues / problems are likely to arise if such a conceptual shift is implemented?
- What are the potential benefits?

Issues

There are many issues to consider before embarking on consumer led research projects. The following are raised as points of discussion and are not exhaustive.

Appropriate Use

One saying in business that has long been discredited is that the customer is always right. In reality the customer is not always right – they are frequently wrong and the same is true for consumers involved in research. They may be ill informed, biased or simply confused about the issues and processes involved.

Consumer input is invaluable in research that impacts on the day to day lives of people to give a well rounded perspective. However when it comes to pure research or research projects that focus on a very detailed, complex and specific issue, arguably the role of the well meaning amateur in the form of the consumer is of limited value.

Before committing to the consumer led approach evaluate how consumer involvement is likely to add value and, just as importantly, to what extent could it have the opposite effect and actually be detrimental to the research process.

Who is the consumer?

Another core issue to consider when developing consumer led research is ‘who is the consumer that is doing the leading?’ Undertaking a full stakeholder analysis usually results in a long list of people and organisations who will be potentially impacted either by the process or outcomes of the research. The first major decisions to be made are who are the priority stakeholders? Which of these can be considered ‘consumers’ and therefore should be involved in the process?

Consumer orientation v consumer domination

Consumer led research should add value and relevance to the development of knowledge. While the notion of inclusive research is intuitively appealing, it can only be effective if the balance between expert knowledge and consumer desire is maintained. Enthusiastic adoption of a consumer perspective without due care to ensure that this balance is maintained can, and sometimes does, result in sub optimal outcomes as the process becomes consumer dominated rather than consumer oriented.

Timelines and Budgets

Involving consumers in the research process is both time consuming and expensive. If it is to be done right these time and monetary costs need to be explicitly included in any research application. Without proper resources, the notion of consumer involvement is reduced to ad hoc input and creates a perception of tokenism.

Language

Language is important not only in communicating concepts but in expressing attitudes (both explicit and implicit). Whilst it may seem trivial, shifting language away from labels such as ‘subject’ to ‘participant’ makes a significant differences in the way that those consumers involved in research believe they are perceived. In some quarters there is currently a push to move further away from what are considered euphemisms and instead of subject, participant, consumer or client, to simply refer to people involved in research as being ‘people’.

Future Directions

Consumer focussed research is an important trend however it is a mistake to believe that all research can and should be consumer oriented. Pure research that is conducted largely in isolation is still needed however for applied research with specific policy implications, involvement of the people who will ultimately bear the consequences is essential. Involvement of consumers should be a part of any project where people are the subjects, where the outcomes will influence lifestyle or policy or where there is a demonstrable need for the public to be kept informed to ensure that the research project and process conforms to community standards.

Possible Collaborative Actions by the Research Network and Consumer Organisations:

- Do we need a paper raising issues and promulgating best practice in consumer-led research?
- Should we advocate for more funding to support consumer-led research?
- Would there be value in collaborative workshops bringing together older consumers, researchers, and funders to consider better ways ahead for collaborative research?

References

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Current activities in consumer research

National Seniors Productive Ageing Centre (NSPAC) conducts research which focuses on the needs of seniors in retirement with an emphasis on ageing and the productivity of seniors. The Centre has just completed a major national project funded by the Commonwealth Government and National Seniors entitled “Mature Age Employment: From Redundancy to Reconstruction”.

The Centre also undertakes consultancies and tenders with all levels of government and the private sector. The centre is also developing short courses and conferences and contributes to policy debate in wide range of areas such as: mature age employment and unemployment; productive ageing (in relation to work, education, recreation, community service and personal quests); indicators of successful and unsuccessful ageing; retirement; seniors and road accidents; ageing activities (in relation to sheds, shops, radio, pets and pokies); and social losses among seniors (see <http://www.usc.edu.au/research/centres/nspac>).

The Council On The Ageing (COTA) aims to protect and promote the well-being of all seniors. COTA supports research and policy dissemination through the Australasian Journal of Ageing as well as through the Strategic Ageing series of occasional papers on major ageing policy issues and ReportAge, COTA’s bimonthly policy and parliamentary bulletin. (see <http://www.cota.org.au>)

Alzheimer’s Australia is involved in setting dementia research priorities in terms of: cause; diagnosis; prevention; treatment and cure; and types of dementia. In addition, Alzheimer’s Australia promotes the importance of dementia research by funding fellowships and grants available to Australian researchers. (see <http://www.alzheimers.org.au>).

Carers Australia works to identify key research areas relating to carer’s needs and to gather the data to support their arguments to policy makers. The primary issues for carers are: Financial security and income support; Workforce participation and flexibility; and Carer support services. (see <http://www.carersaustralia.com.au>).

AARP in the US has a Policy and Research initiatives including the following programs:

- Global Ageing Program - works with governmental and non-governmental organizations to exchange ideas and establish “best practices” in addressing aging concerns worldwide.
- Knowledge Management – conducts national and state-based research on the needs, concerns and interests of AARP members and the 50+ population.
- Office of Academic Affairs - establishes partnerships with higher education institutions and organizations, provides resources to the academic community, and manages AARP’s paid internship program for students in gerontology.
- Research Databases – provides extensive bibliographic databases on US and international research and policy relevant materials.
(see <http://www.aarp.org/research/about.html>)

The Centre for Policy on Ageing (CPA) in the UK initiates its own research programme seeking funds from outside sources; it takes on research work directly commissioned and funded by other bodies, including independent sector organisations; it acts as a consultancy undertaking reviews for health trusts and local authorities, analysing services for older people and making recommendations for future development; the Centre also works in partnership with other research/academic institutions seeking specialised input on older age issues. In addition to actively being involved in research, the CPA hosts the National Database on Ageing Research which aims to be a comprehensive listing of all non-medical research on ageing in the UK. (see http://www.cpa.org.uk/policy/policy_research.html)