


# BARC Policy and Practice on Ageing Colloquium, Canberra, 4-5 July 2006

## ARC/NHMRC Research Network in Ageing Well Research Development & Communication Processes

### Workshop 1 - Consumer-led Research Workshop

#### Presentation Slides:



**ARC/NHMRC Research Network  
in Ageing Well**

**Consumer-led research**

[www.ageingwell.edu.au](http://www.ageingwell.edu.au)

**BARC Colloquium  
5 July 2006**




### 1a. Key Issues: Process

- Topic selection
- Research design
- Research implementation
- Dissemination of results

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Convened at: The University of Sydney

Major Partners: ANU, Curtin, Monash, UNSW




### 1b. Key Issues: Co-production

- Consumer as co-producer
- Based on two premises
  - Inseparability of production and consumption of intangible products (services / research)
  - Quality of output is a function of the consistency and closeness of consumer involvement with service provider / researcher
- Management of consumer and co-producer of knowledge

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### 1c. Key Issues: Other

- Appropriate use of consumer focussed research
- Who is the consumer (consumer v stakeholder)?
- Consumer orientation v consumer domination
- Time lines and budgets
- Language

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## 2. Network Directions

- 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?

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## Workshop Summary

### **Workshop Chairs:**

Dr Susan Dann (Chair)

Head of Research, National Seniors Centre for Productive Ageing

Professor Hal Kendig (Co-chair)

National Convenor, ARC/NHMRC Research Network in Ageing Well

Research Professor of Ageing & Health, Faculty of Health Sciences, University of Sydney

### **Workshop Discussants:**

Dr Harry (Rick) Moody (International Discussant)

Director of Academic Affairs, AARP

Senior Associate, International Longevity Center - USA

Ian Yates (Local Discussant)

Council of the Ageing (COTA) South Australia.

### **Rapporteur:**

Christine Millward, Sociology Dept, La Trobe University

### **Introduction by Susan Dann**

This workshop was about the importance of including community input and guidance in conceptualising, planning, implementing, disseminating and acting upon research around ageing.

### **Definitions of concepts**

There were several definitional issues around the notion of 'consumer-led research'. Participants queried "consumers of what?" and suggested that we are talking about involving the social sub-groups for whom the research is relevant or at whom it is targeted. Other terms suggested were therefore 'participants', 'citizens', 'stakeholders', 'partners' or 'advisors'. Research was also seen as a 'service' to the public, so in that sense citizens are consumers of research as well as of private, community and government services.

### **Collaborative research model**

The process for consumer-informed research was outlined as being just as rigorous as academic research but that the design may need modification. Rather than just filling in the gaps in the academic literature the idea is to go out and consult a broad range of stakeholders to see what issues are relevant or pressing, then ask "Who will be affected by this study?". Suggested ways to engage and involve consumers/ citizens/ community were via: advisory committees which represented all sectors of society; formal and informal consultation with stakeholders before and during the process; an opt-in process such as a research register so that interested people can take part and in turn build up a knowledge of methodologies and issues; and iterative feedback to the participants about directions and findings. The emphasis was therefore upon 'co-producing' research by going beyond participation to priority-setting and 'co-production of knowledge' about a certain issue or social group.

### **Special considerations with older participants**

As well as having input into research directions, it was also noted that older participants have additional needs in the research process. This entails an ethical approach of respect and confidentiality, perhaps extra training and explanations and perhaps a reward or incentive. Also, older participants should not be overloaded and the research should be meaningful for them.

### **Problems with the 'co-production' approach**

However, the co-production of research involves people with a vested interest in the topic so can suffer from their lack of knowledge, bias of self-selection and domination by single issue lobby groups. It also requires expanded timelines and budget for consultation and feedback.

## EXPERIENCE AND FEEDBACK ON THIS APPROACH

### *International Discussant - Rick Moody*

Some examples were given of AARP consumer-led research initiatives including 'Elder Hostel' which was a scheme enabling college education for people after retirement and which was successful but had never been formally evaluated. The ethics around Alzheimer's research has also been investigated, with the inability of obtaining informed consent from sufferers resulting in care-givers being defined as consumers and the study focusing on the concerns and motivations of care-givers. The take-up and efficacy of 'Quiet Care' home monitoring devices was studied, which involved getting the confidence of families and users due to privacy concerns. Finally, AARP had conducted polling among seniors about support for the government paying for prescription drugs.

Main conclusions: that the interaction between government and research in Australia was very beneficial and is lacking in the USA; that a long-term perspective is needed for research, policy and service delivery; and that the real-life experience of people should be tapped because every little bit of knowledge helps draw a picture of the diversity of needs among older citizens.

### *Local Discussant Ian Yates*

A different perspective on consumer-led research could be one where consumers and advocacy groups were the leaders of research – so that service providers and policy makers are the subjects of the research. However, we can also ask 'why is research not consumer-led?' and this could be due to several factors: different perspectives on issues; well-meaning 'amateur' researchers were not researchers at all and not skilled in this area; and consumers would always be 'unequal partners'. So segmentation within spheres of knowledge and interest was inevitable as 'consumers' interact with lobbyist organisations or service providers, not policy makers or researchers. However, collaboration is still possible via a two-way partnering process, where specialist organisations represent groups of consumers and engage on the same level with researchers (and policy makers?) around conceptualising and implementing research.

### *From the floor*

Several workshop participants were from peak bodies or advocacy groups. Involvement was discussed at two levels. First was research driven by consumer organisations or with them as partners or 'players'? Schemes of consumer-directed care were funded in the UK, where there is a 'self-managed care' movement supported by great investment in new monitoring technology - but not in Australia as yet. The NSW government was noted as having extensive ongoing consultations with seniors for topics needing research. It was suggested that the 45 and Up study in NSW should ask "What is the most important issue for health in NSW?" to get more community input.

Second was engaging with individual senior citizens (or consumers) to gain their co-operation in the actual process. Older people were seen as experts on specific areas of life experience but that personal experience was socially and culturally situated and so lacked breadth of experience. On the other hand, a representative of the Association of Independent Retirees noted that cooperation with older respondents was marred by survey questions being wrongly worded, repetitive, inappropriate, misleading or patronising. More political advocacy was also needed to enable seniors to put forward important issues and to criticise current policies.

In general, workshop participants were more accepting of consumer-involved rather than consumer-led research. There appears to still be an expert bias in that whilst participants in the workshop were happy to have consumers involved at various stages during the research process, the idea of the consumers having a stronger role in defining research topics and leading the way in which research is conducted was not as well accepted.

## **POSSIBLE NETWORK ACTIONS**

- 1. Issues and Practice paper - Yes, a paper on best practice for consumer-led research would be helpful.**

In the general feedback session it was pointed out that NH&MRC has developed extensive guidelines already in their *Statement on Consumer and Community Participation in Health and Medical Research (2002)*. However, the workshop noted that broader community and policy research might benefit from a 'best practice' paper to map and scope topics and methodologies. This may pertain to research outside strict health and medical research paradigms, and could include input from all the national research centres on ageing.

- 2. Advocacy for more funding for consumer-led research – this possibility was not discussed.**

- 3. Collaborative consumer-researcher workshops - Yes, the group endorsed this possibility.**

It was noted by Peter Brady from 'National Seniors' that the protocols for engaging community and representing senior citizens had been work-shopped in NSW and similar workshops could be held, but they need to be state based. Also, from a policy perspective the peak bodies were not community-wide so represented their own membership, not all sectors of society, so the invited participant groups would need to be very wide-ranging.