

# CONSUMER PARTICIPATION RESOURCE FOR RESEARCHERS

## Involving consumers in your RESEARCH

### Consumer participation in research can:

- ensure that issues which are important to consumers are identified and prioritised.
- help to ensure that money and resources are not wasted on research that has little or no relevance for consumers.
- ensure that research does not just measure outcomes that are identified and considered important for professionals.
- enhance the recruitment of participants.
- support the dissemination of research results.
- ensure that changes are implemented.

[Adapted from Consumers in NHS Research Support Unit. 2005. Involving consumers in research and development in the NHS: Briefing notes for researchers. pp. 5 – 6 and Macaulay A, Commanda LA, Freeman WL, Gibson N, McCabe ML, Robbins CM and Twohig PL. 1999. Participatory research maximises community and lay involvement. *BMJ* 1999, Vol. 319:774-778]

## Frequently asked questions

### What is consumer participation in research?

Consumer participation is understood as the process of involving health consumers not only as 'subjects' of research but in setting the research agenda, designing data collection tools, undertaking data collection, analysing and interpreting research findings, disseminating the results of research and evaluating research.

Consumer participation in research is the *involvement of interested, non-professional individuals or organisations in the planning, assessment of proposals for execution, interpretation, and implementation of research.*  
(Cancer researcher)

### Who are consumers?

Consumers are people who are current or future users of health services. The term consumer also refers to patients or clients, family members, people who care for others and community members.

### Why do I have to involve consumers?

*Absolutely vital to hear their voices.*  
(Cancer researcher)

*They are the ultimate end users of our research and therefore it is beneficial to all to have consumers involved in research.*  
(Cancer researcher)

In 2002 the National Health and Medical Research Council in collaboration with the Consumers Health Forum of Australia published a *Statement on consumer and community participation in health and medical research* and in 2004 two resources for researchers and consumers to implement the Statement. The Statement and resources show that there is considerable evidence that involving consumers improves the quality of research.

### The NHMRC/CHF Statement on consumer and community participation in health and medical research:

Consumers and researchers working in partnership based on understanding, respect and shared commitment to research that will improve the health of humankind.

[National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2002. *Statement on consumer and community participation in health and medical research*. Canberra. p.iv]

## Evidence for consumer participation in research and how consumers have been involved.

*Consumer have had an impact on:*

- ▶ the research agenda by identifying topics of research, shaping the research agenda, initiating research projects, and influencing funding decisions
- ▶ research design and delivery by reshaping and clarifying research questions, improving the design of research tools and field testing them; ensuring that research methods are easy for people to participate; increasing recruitment and participation rates; increasing sense of ownership of the research project resulting in enhanced data collection and its relevance and reliability; enhancing analysis of data, writing up and dissemination of the findings
- ▶ research ethics by improving the consent process; and improving the ethical acceptability of research
- ▶ gaining new knowledge and skills, peer support and friendship

[Staley K.2009. Exploring impact: Public involvement in NHS, public health and social care research. INVOLVE. Eastleigh. United Kingdom.]

Consumer participation in my research:

*Helped with focus and perceived impact*  
(Cancer researcher)

*Improved awareness on both sides of key issues*  
(Cancer researcher)

*Identified areas of consumer research interest and highlighted areas deficient in supportive care*  
(Cancer researcher)

### **Do consumers want to participate?**

Many consumers who use health services want to have a say about the health and medical research undertaken in Australia in relation to cancer.

### **How do I find consumers to participate?**

Consider consumers and carers who attend health services or are involved as volunteers; also consumers who are involved in support or advocacy groups.

### **The consumers who use health services are unwell. How can they be involved?**

Always give consumers the option of participating and ask them how they would like to contribute their perspective. In all cases, consumers should be given the opportunity to participate actively in research and be involved in setting up research agendas. Alternatively consider including family members and carers as these people have valuable perspectives to offer.

### **What are the first steps I need to take to involve consumers?**

First, ask yourself, *why do I want to involve consumers in my research project?* Second, identify the types of consumers, carers or community members who will have this information. Then consider appropriate strategies for involving them.

More information on how to involve consumers in research and tools for consumers can be found in:

Consumers Health Forum of Australia. 2001. A guide for consumers doing health research. Canberra  
<http://www.chf.org.au/pdfs/rep/rep-269-research-guide.pdf>

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. A model framework for consumer and community participation in health and medical research. Canberra.  
[http://www.nhmrc.gov.au/publications/synopses/\\_files/r33.pdf](http://www.nhmrc.gov.au/publications/synopses/_files/r33.pdf)

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. Resource Pack for Consumer and Community Participation in Health and Medical Research. Canberra  
[http://www.nhmrc.gov.au/\\_files\\_nhmrc/file/publications/synopses/r34.pdf](http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/r34.pdf)

Consumers in NHS Research Support Unit. 2005. Involving consumers in research and development in the NHS: Briefing notes for researchers. pp. 5 – 6 <http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>

### How do I involve consumers?

There are a number of strategies for involving consumers. The strategies you choose depend on the stage of the research you want to involve consumers. Strategies commonly used are outlined in Table 1.

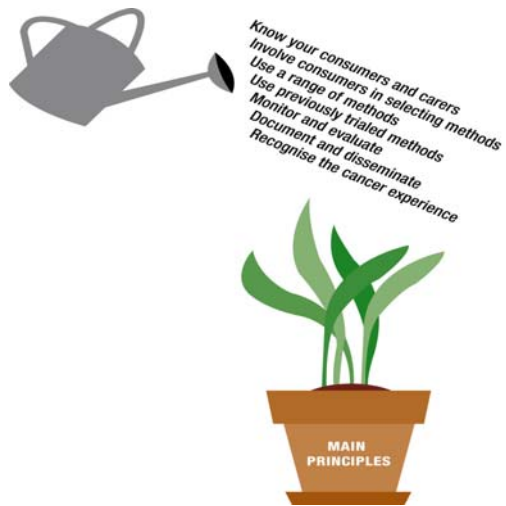
**Table 1: Strategies for involving consumers**

Types of participation	Objectives	Commonly used strategies
<b>Partnership</b>	<b>Involving consumers in setting up research agendas and conducting research</b>	<ul style="list-style-type: none"> <li>• Consumers in research teams</li> <li>• Consumer advisory or reference group</li> <li>• Working with support and advocacy groups</li> </ul>
<b>Consultation</b>	<b>Obtaining feedback from consumers</b>	<ul style="list-style-type: none"> <li>• Surveys</li> <li>• Focus groups</li> <li>• Patient forums</li> <li>• In-depth interviews</li> <li>• Working with support and advocacy groups</li> </ul>
<b>Information</b>	<b>Engaging the broader community</b>	<ul style="list-style-type: none"> <li>• Websites</li> <li>• Brochures</li> <li>• Public meetings</li> <li>• Seminars</li> <li>• Working with support and advocacy groups</li> </ul>
Useful information about these methods is available at <a href="http://www.healthissuescentre.org.au">www.healthissuescentre.org.au</a>		

**For a working model for consumer participation in research see the following pages.**

[This working model was adapted from Southern Melbourne Integrated Cancer Services and Health Issues Centre. 2007. *Optimising Consumer Participation in Cancer Services. Model for Consumer Participation in Quality Improvement*. Used with permission. Available at [http://www.smics.org.au/files/file/Publications\\_and\\_Resources/SMICS\\_ConsParticV1\\_0200710-FINAL.pdf](http://www.smics.org.au/files/file/Publications_and_Resources/SMICS_ConsParticV1_0200710-FINAL.pdf)]

## Principles



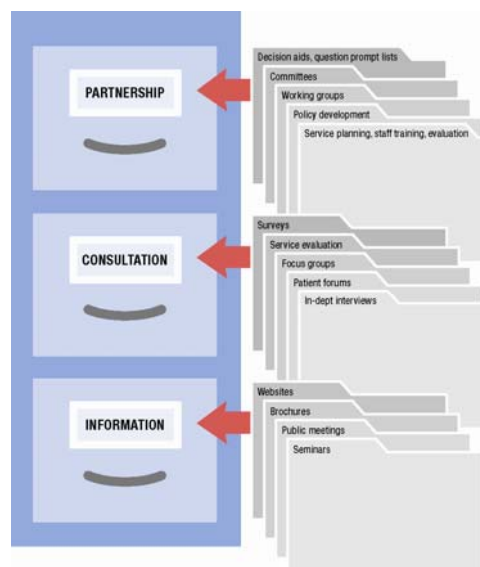
The selection of strategies for consumer participation will be informed by a set of main principles:

- Know your consumers, carers and community
- Involve consumers in selecting strategies of participation
- Use a range of strategies
- Use previously trialed strategies
- Monitor and evaluate
- Document and disseminate
- Use engagement strategies appropriate to cancer experience.

## Strategies

In the diagram below, each drawer represents a different type of participation—partnership, consultation and information—and each drawer includes a series of folders which are strategies for responding to the type of participation required.

- Websites
- Brochures
- Public meetings
- Seminars
- Surveys
- Working with support and advocacy groups
- Focus groups
- Patient forums
- In-depth interviews
- Consumers in research teams
- Consumer advisory or reference group



## Monitoring and evaluation

Consumer participation in research should be continuously monitored and evaluated to ensure that it is effective and meaningful. An evaluation cycle (as shown in the following diagram) includes the development and planning of a project, the implementing of the project, evaluating and monitoring the project, documenting and disseminating the results of the project, learning from evidence, and modifying the initial planning which in turns allows for the formulation of a new project. This cycle could also lead to continuing the original project having made modifications in response to the learning.

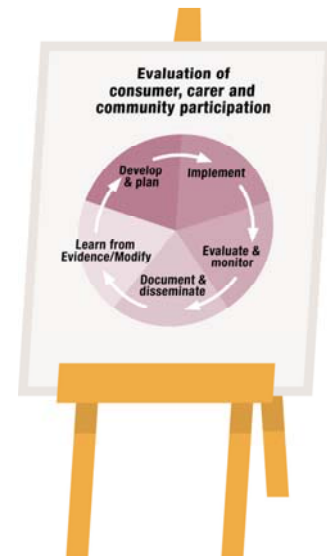


Diagram adapted from Victorian Department of Health, 2005. *Doing it with us and not for us. Participation in your health service system 2006-09: Victorian consumers, carers, and the community working together with their health service and the Department of Human Services.* Melbourne

## Check list for implementing consumer participation in research

### Purpose and context

- Identify the purpose for involving consumers
- Identify at what stage you want to involve consumers (i.e. defining research questions, designing data collection tools, collecting data, interpreting findings, disseminating results)
- Identify the characteristics of consumers to be involved
- Identify issues to seek input from consumers

### Prepare for involving consumers

- Determine how consumers will be recruited and engaged
- Identify strategies for involving consumers (i.e. member of research team, in advisory group)
- Identify suitable support to assist consumers to effectively participate (i.e. administrative support, transport, parking, contact person)
- Determine the types of information and orientation to be provided to consumers
- Determine strategies for clarifying and communicating consumers' roles
- Identify staff requirements
- Identify costs associated with involving consumers

### Monitor and evaluate process of involvement

- Identify monitoring and evaluation processes

### Further information and resources

Health Issues Centre [www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)  
Victorian Cancer Agency [www.victoriancanceragency.org.au](http://www.victoriancanceragency.org.au)