

Tips for involving consumers in research

WHY INVOLVE CONSUMERS IN RESEARCH?

Barwon Health strongly encourages consumer involvement in research to ensure the research we conduct is responsive to the dynamic healthcare needs of our regional community, and is directly translated into improved outcomes for the community.

The NHRMC Statement on Consumer and Community Involvement in Health and Medical Research (2016) summarises the significant benefits that arise from meaningful consumer involvement in research:

Benefits to the public include:

- Research being conducted that is relevant to community needs
- public awareness of, and support for, science and research
- more effective translation of research to deliver improved health outcomes.

Benefits to researchers and research institutions include:

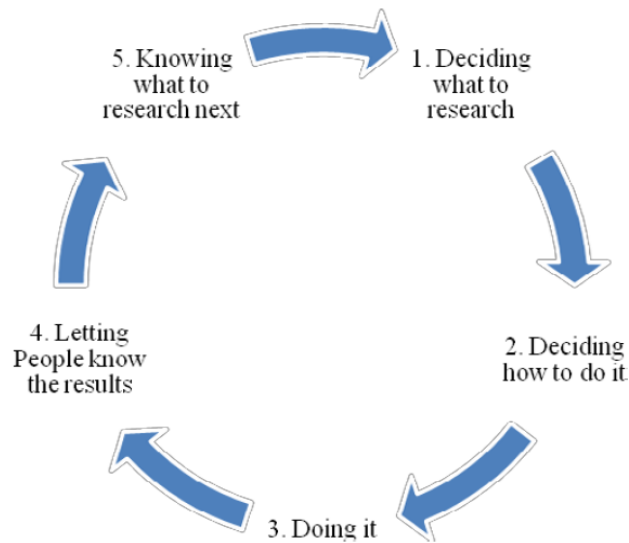
- increased community relevance, through improved research priorities and projects informed by consumer and community perspectives and lived experiences
- public confidence in research through improved openness and transparency in the conduct of research
- public confidence in research through improved accountability and openness over the use of public money
- communities being better informed and having a greater understanding of research
- increased opportunities to continuously improve the quality of research.

WHEN AND HOW SHOULD I INVOLVE CONSUMERS IN MY RESEARCH?

While the importance of involving consumers in research is clear, it can be a difficult task for researchers to put into practice.

The NHRMC provides the following guidance for researchers to consider how they will involve consumers and community members in the development, conduct and communication of their research:

- Research usually follows a cycle as illustrated below¹⁴:



Following are points for researchers to consider under each of the stages when the consumer and community involvement is being planned.

1. Deciding what to research:

- At the beginning of a project, consider where consumer and community involvement will be focused
- Have discussions with consumers, community members and organisations associated with the research topic about the potential research questions and the anticipated benefit of the research.
- If the research questions have already been decided, be upfront about the opportunities for input from consumers and community members
- Seek nominations of consumer representatives from recognised health consumer organisations to contribute the broad consumer perspective to the project
- Prepare a draft plain language summary of the research. Consumers and community members can help to finalise this
- Seek input regarding other people or organisations to consult
- Outline ideas for involvement activities. This might include the anticipated parameters of the involvement, support and training that will be offered, remuneration and roles and expectations of all members of the collaboration
- Discuss the evaluation of the involvement roles with the consumers and community members.

2. Deciding how to do it:

- Encourage consumers and community members to contribute to the development of the methodology for a research project by providing comment and advice on all documentation. This could include grant and ethics applications, consent forms and information sheets
- Include consumer and community members in discussions about recruitment as they can provide valuable insight into appropriate ways to reach vulnerable and/or minority groups
- Identify and discuss plans to disseminate research findings and results with consumers and community members. They will often have ideas and access to community groups who have an interest in the research as well as the wider community
- Consider inviting consumers, consumer organisations and community members to be investigators or co-authors if appropriate.

3. Doing it:

- Discuss any training requirements for consumers and community representatives
- Ensure that timelines, boundaries and confidentiality requirements are known by consumers and community members.
- Invite consumers and community members to be involved in discussions about research findings. They may be able to provide an understanding of unexplained or unusual findings due to their knowledge and lived experience
- Seek consumer and community input into report writing, the development of policy recommendations and/or translation plans, and
- Consider and consult with consumers and community members about the planned dissemination strategy and opportunities for translating results and findings into policy and practice.

4. Letting people know the results:

- Work with consumers and community members to develop plain language summaries of research results and findings. This can be especially helpful if the research results are unexpected or have the potential to be controversial
- Enlist consumers and community members to broaden ways to disseminate results and findings. These could include presentations at consumer and community events, writing for consumer and community publications and newsletters, and
- Invite consumers and community members to co-present at academic conferences, presentations and media briefings.

5. Knowing what to research next:

- Involve consumers and community members and their associated organisations in assessing and implementing the research findings and evaluating any outcomes from the implementation
- Seek consumer and community members' input in identifying questions which the research does not answer and may guide future research
- Approach recognised consumer organisations for their members' research priorities.

WHERE CAN I FIND CONSUMERS TO INVOLVE IN MY RESEARCH?

Health Advocacy Organisations

The health condition or issue you are researching may be represented by an advocacy, support or fundraising group or organisation. These groups may be able to advise you about consumers who could become involved in your research.

Consumer Groups

[Barwon Health Consumer Advisors](#)

Barwon Health supports people's right to participate individually and collectively in the planning and implementation of their health care. Barwon Health does this by partnering with Consumer Advisors.

[The Community and Research Network \(CARN\)](#)

Supporting health and health research in Geelong. The Community and Research Network (CARN) is a network of health professionals, health consumers and researchers, seeking to share their expertise and experience to promote good health and wellbeing for the community of Geelong.

[White Coats Foundation](#)

White Coats is a Not for Profit Australian based company with a global focus. The Foundation was established in recognition of the need to raise awareness about the role of clinical trials in advancing medical science and healthcare.

International Association for Public Participation (IAP2)

IAP2 promotes the values and leading practices associated with involving the public in decisions that impact their lives. IAP2 Australasia is a not for profit association advancing the practice of community engagement and delivering member support: www.iap2.org.au

Health Issues Centre

Health Issues Centre is Victoria's peak health consumer organisation. We listen to everyday people and champion improvements to our healthcare system. We use the principles of human-centred design to make sure that health solutions address consumer needs and reflect consumer priorities: www.healthissuescentre.org.au

Consumers Health Forum of Australia

CHF is the peak organisation providing leadership in representing the interests of Australian health care consumers. It works to achieve safe, good quality, timely health care for all Australians, supported by the best health information and systems the country can afford: www.chf.org.au