



Australian Government
National Health and Medical Research Council



Revised Statement on Consumer and Community Involvement in Health and Medical Research

Consultation version - August 2014

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STATEMENT OVERVIEW

Active involvement of consumers and community members in health and medical research benefits the quality and direction of research. The vision for the Statement is:

Consumers, community members and researchers will work in partnerships based on understanding, respect and shared commitment to research that will improve the health of all Australians.

Consumer and community involvement is about research being carried out *with* or *by* consumers and community members rather than *to*, *about* or *for* them. It includes consumers and community members working with research funders to prioritise research, being involved in grant funding processes and providing advice as members of project steering groups. This is distinct from people who are the participants in research projects

The current draft Statement and its predecessor were developed by NHMRC and CHF because many consumers, community members and researchers recognise that they can add value to health and medical research and that they have a right and responsibility to do so.

The initial 2002 *Statement on Consumer and Community Participation in Health and Medical Research* (the Statement) and companion *Summary Statement* were developed jointly by the NHMRC and the Consumers Health Forum of Australia (CHF) following the *Health and Medical Research Strategic Review* (the Wills Review) which was carried out in 1999. A *Model Framework* and companion *Resource Pack* were published in 2004.

The CHF believes the Statement provides the key to developing stronger partnerships between consumers, community members and researchers at all levels of health and medical research in Australia and calls for NHMRC to continue supporting this evolving process.

This updated draft of the Statement has been developed based on feedback provided to NHMRC from:

- surveys conducted with research institutions, researchers, consumers and community members which sought comment on the impact and value of the Statement
- consumer and community workshops
- consultations with health consumer and research organisations

The Statement provides key elements for research institutions, researchers, consumers and community members to work in active partnership to enhance involvement in health and medical research. This is supported by the values of NHMRC as outlined in its Strategic Plan.

DEFINITIONS

Community — a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Within this definition, it is important to recognise that different types of communities are likely to have different approaches to involvement in research.

Consumer — patients and potential patients, research participants, carers, consumer organisations and members of the public

Consumer representative — a member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision-making process. They may be nominated by a consumer or community organisation and be accountable to them.

Involvement – consumers, consumer organisations, community members, researchers and research institutions working in active partnerships to shape decisions about research priorities, policies and practices.

Stakeholders - An individual or group from within or outside research organisations with a key interest in research. This might include members of professional bodies, government agencies or funding bodies as well as consumers and community members. Stakeholders can provide support or expertise and may influence decisions about the research and its findings.

WHY IS CONSUMER AND COMMUNITY INVOLVEMENT IMPORTANT?

The World Health Organisation's Declaration of Alma-Ata states:

*The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.*¹

It is therefore important for research institutions, researchers, consumers and community members to work collaboratively to support, facilitate and value the contribution consumers and community members make to research.

The health consumer movement in Australia has seen steady growth over the past 25 years. It is now widely accepted across public and private health sectors that consumers and community members add intrinsic value to the decision making processes surrounding planning, policy development and service delivery. Shared decision making is recognised as being important to quality healthcare, integrating a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions¹.

As beneficiaries of advances in healthcare, consumers have an interest in promoting the translation of research into improved policy and practice. It naturally follows that health and medical research should develop processes and systems to incorporate and support sustainable consumer and community involvement.

Benefits of effective consumer and community involvement include:

- research being conducted that is relevant to community needs
- more effective translation of research to deliver improved health outcomes
- effective communication strategies between consumers, community members and researchers
- improved openness and ethical transparency in the conduct of research
- improved accountability and openness over the use of public money
- increased opportunities to continuously improve the quality of research

¹ refer <http://www.safetyandquality.gov.au/our-work/shared-decision-making/>, accessed 20 March 2014

- communities being better informed and having a greater understanding of research
- consumer and community perspectives and 'lived' experiences are valued and incorporated into the development of research priorities and projects
- consumer participation can be an important and an effective driver for change, especially through support for translation of research findings into improvements to policy and practice.

ELEMENTS FOR CONSUMER AND COMMUNITY INVOLVEMENT

The following key elements underpin effective involvement:

- Active involvement is integral to all stages of the development of research programs, policies, guidelines and strategies.
- Consumers and community members will be included on all decision-making committees.

The NHMRC's framework for Indigenous health research is a highly developed example of effective community involvement designed to ensure the community 'voice' is an integral part of all research conducted with Aboriginal and Torres Strait Islander people.

The NHMRC *Roadmap II: Strategic Framework for improving the health of Aboriginal and Torres Strait Islander People through Research* guides research that is conducted with Aboriginal and Torres Strait Islander People. Its underlying principles for community involvement are:

- Aboriginal and Torres Strait Islander community involvement in the development, conduct and communication of the research
- communication of research plans, progress and results to support effective capacity exchange
- ethical research aiming to be of practical value to Aboriginal and Torres Strait Islander People and their service providers.
- This framework is considered equally appropriate and applicable to all health research affecting Australians.

LEVELS OF INVOLVEMENT

A number of different models have been developed by various consumer and community organisations and researchers to describe levels of involvement. These range from providing consumers and community members with information about the research through to consumers and community members designing and leading research projects.

The level of involvement selected for any research activity will depend on the purpose of the involvement, the resources available and the type and subject of the research.

To ensure the integrity of health and medical research and accountability to the community, a researcher or research organisation intending to proceed *without* involving consumers and community members must be able to fully justify that intention.

Appendix 2 contains a range of models that illustrate different levels of involvement.

PUTTING THE STATEMENT INTO PRACTICE

This section includes information about what the Statement means for research institutions, researchers, and consumer and community members.

The following points are a guide to facilitating and supporting consumer and community involvement at all levels across all types of health and medical research:

- start planning and implementing involvement as early as possible

- consumer and community involvement must add value to the research
- reach out to an appropriately diverse range of consumers and community members to ensure the most effective involvement strategies are developed and implemented
- be inclusive – the more inclusive the processes are the more consumers and community members will be able to participate
- treat everyone – consumers, community members, researchers and other stakeholders with courtesy, respect and integrity
- work in partnership to develop the appropriate involvement activities
- keep everyone informed and involved by sharing information willingly and in language that everyone understands.

Appendix 4 provides examples of organisations that have worked to implement the Statement and what can be achieved.

The Statement and research institutions

In order to receive NHMRC funding research institutions are required to have written policies for accreditation purposes to ensure adherence to the *Statement on Consumer and Community Involvement in Health and Medical Research* and the *Australian Code for the Responsible Conduct of Research*. It is therefore important that research institutions not only recognise and understand the value of consumer and community involvement in health and medical research, but also support their research staff to actively involve consumers and community members. This might involve, but is not limited to:

- developing strategies to implement their policies on consumer and community involvement, in partnership with consumers, consumer organisations and community members
- building the capacity of researchers to involve consumers and community members as part of their research teams by providing training, access to resources and recognising good practice involvement initiatives
- building the capacity of consumers and community members to become actively involved in research and work in partnership with consumer/community organisations for training, support and guidance
- providing accessible and easy to understand information about the institution's research activities
- understanding processes for consumer and community involvement by including planned budgeted strategies in research projects.

The Statement and researchers

As each research project is unique, the development of plans for consumer and community involvement will be required for each research project. Effective planning for consumer and community involvement is best started by collaborating with all stakeholders who will make up the research team. This will include consumers and/or community members.

Tools such as the NHMRC Research Cycle and the INVOLVE Continuum (see Appendix 3) are helpful in guiding planning discussions and decisions. These tools guide opportunities for consumer and community involvement at various stages such as:

1. identifying and prioritising research
2. deciding how to do it
3. applying for funding and ethical approval
4. conducting the research
5. letting people know the results
6. translating results and evaluating the impact
7. knowing what to research next.

While Consumer and community involvement can be incorporated at any stage of the research cycle, ideally this involvement will inform the developmental stages of a project. Researchers, consumers and community members can work in partnership to decide which stages of the project will have consumer and community involvement.

The Statement and consumer and community members

This Statement acknowledges the unique contribution consumers and community members can make to research. It encourages the active involvement of consumer and community members working in collaboration with the research community to make decisions about:

- setting research priorities
- allocating funds at an institutional level
- setting research policies and strategies at an institutional level
- shaping individual research projects.

Increased consumer and community involvement brings benefits and shared responsibilities to all parties, such as ensuring the ethics and values of the research are maintained and being open and transparent about any conflicts of interest. For consumers and community members these include:

- adhering to confidentiality requirements
- respecting the expertise of all stakeholders
- working within the principles of consumer and community involvement
- supporting the agreed parameters of the research project
- seeking appropriate input from other consumers, community members and relevant organisations as required
- understanding research processes and policies

Ensuring consumers and community members' time and expertise is valued and appropriately remunerated or otherwise acknowledged, will assist in developing strong partnerships and guard against tokenistic involvement activities.

Consumer and community organisations should factor the Statement into their programs of support, training, mentoring and nomination in relation to consumer and community involvement in research.

RESOURCES FOR CONSUMER AND COMMUNITY INVOLVEMENT

Research institutions should allocate funds to support consumer and community involvement. This includes budgeting for items such as:

- training opportunities and support for all partners in the collaboration
- honoraria and payments for consumer and community members
- additional time for researchers to plan and support involvement activities
- administration support
- consultations and events associated with the involvement activities
- evaluation and reporting about the involvement activities to funders and the community.

Research institutions and researchers should have planned budgeted strategies to support, implement and acknowledge appropriate consumer and community involvement in:

- setting research priorities (where appropriate)

- conducting research projects
- disseminating findings and results of research
- translation of research results into policy and practice

This will ensure that Australian communities continue to support the highest quality national health and medical research strategies.

Researchers and Research institutions may consider the relative cost-benefit of these activities in order to achieve the highest level of consumer and community involvement with available resources.

Appendix 1: Overview of revision of the Statement

NHMRC and the Consumers Health Forum of Australia (CHF) have jointly developed this draft revised Statement with the aim of supporting consumer and community involvement across all types and levels of health and medical research.

The draft Statement is an update of the joint NHMRC/CHF *Statement on Consumer and Community Participation in Health and Medical Research* (the Statement) and companion *Summary Statement*. As these were published in 2002 (available at: www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34) it is now considered timely that they be updated.

NHMRC conducted a survey and other activities, including a national workshop in 2011, to inform the revision of the Statement. It was considered that the broad content of the Statement is still relevant and appropriate and the focus of the revision should be on improved language and accessibility. A Working Committee consisting of the following members was established in January 2012 to consider revisions to the Statement:

Mr Mitch Messer (Chair)	Mr Messer was the consumer representative on the NHMRC Research Committee for the 2009-2012 triennium. Mr Messer has been a health consumer advocate for more than 30 years, and is a former Chair of the Consumers Health Forum of Australia Ltd (CHF) and is a Trustee of the Australian Cystic Fibrosis Research Trust.
Professor Jon Currie	Professor Currie was a member of the NHMRC Research Committee for the 2009-2012 triennium and is a neurologist and addiction medicine specialist. Prof Currie has had a longstanding interest in the neurobiology of addiction and the acute and chronic effects of alcohol and other drugs on brain function and was a former Chair of the Victorian Drug and Alcohol Prevention Council.
Ms Sally Crossing AM	Ms Crossing is a nominee of CHF. Ms Crossing is an experienced and respected consumer advocate with long-standing interest and involvement in research. She has lead Cancer Voices NSW's Consumer Involvement in Research Program since 2005 and has a strong interest in processes and practice to enable consumers to contribute to research projects, grant review and the research agenda.
Ms Bec Hanley	Ms Hanley has around 20 years relevant experience working to promote the involvement of people who use services in health care and health research. During this time she has worked in partnership with people who use services and professionals to develop policy and practice on involvement in research.
Ms Anne McKenzie	Ms McKenzie leads and manages a Consumer and Community Participation Program at The University of Western Australia's School of Population Health and the Telethon Kids Institute. Her key role is to support and increase consumer and community involvement at the two organisations. She is also an experienced and respected consumer advocate serving on key health committees.
Mrs Mary Potter	Mrs Potter is a nominee of CHF and an experienced and respected consumer representative with a strong interest in ethics and medical research. Mrs Potter has a strong understanding of the consumer issues relevant to this work and strong links with community networks.

This draft revised Statement is based on the advice provided by the Working Committee and NHMRC Principal Committees, including the NHMRC Research Committee. The CHF Board and NHMRC Council recommended the release of this document for public consultation on 16 May 2014 and 20 June 2014 respectively.

NHMRC and CHF will take account of all feedback received from the public consultation stage in revising the Statement before seeking approval of the CHF Board and the NHMRC Council to recommend that the NHMRC CEO approve the revised Statement.

Appendix 2: Levels of Involvement

Following are models that illustrate different levels of involvement.

- International Association Public Participation's spectrum of public participation
www.iap2.org/associations/4748/files/IAP2%20Spectrum_vertical.pdf
- National Framework for Consumer Involvement in Cancer Control, Cancer Australia 2011:
www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf
- The ladder of participation adapted by the University of Western Australia and the Telethon Kids Institute:
www.involvingpeopleinresearch.org.au/images/pdf/fact_sheet_t03_ladder_of_participation.pdf

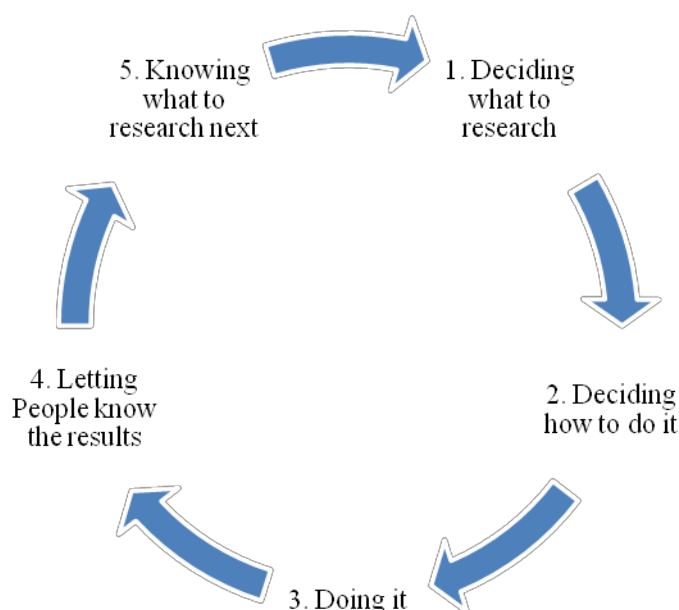
The rights, responsibilities and expectations of Aboriginal and Torres Strait Islander peoples participating in or conducting human research are highlighted in the following publications:

- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* which contains guidelines for ethical health research on Aboriginal and Torres Strait Islander peoples, and in accordance with guidance from Aboriginal people is written around a framework of Aboriginal and Torres Strait Islander values and principles. www.nhmrc.gov.au/files_nhmrc/publications/attachments/e52.pdf
- *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander Peoples about health research ethics* which was developed in partnership with Aboriginal and Torres Strait Islander communities, to help them make informed decisions about participating and becoming more involved in the health research journey www.nhmrc.gov.au/files_nhmrc/publications/attachments/e65.pdf

Appendix 3: Research Cycles

3.1 The NHMRC Research Cycle²

Research usually follows a cycle as illustrated below:



Following are points to be considered 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 informed 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 consumer and community members

² Resource Pack for Consumer and Community Participation in Health and Medical Research (2004), NHMRC. p.13.

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 consumer, consumer organisations and community members to be investigators or co-authors if appropriate

3. Doing it

- Discuss any training requirements for consumer and community representatives
- Ensure that time-lines, boundaries and confidentiality requirements are known by consumer and community members.
- Invite consumer 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
- Consider and consult with consumer 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

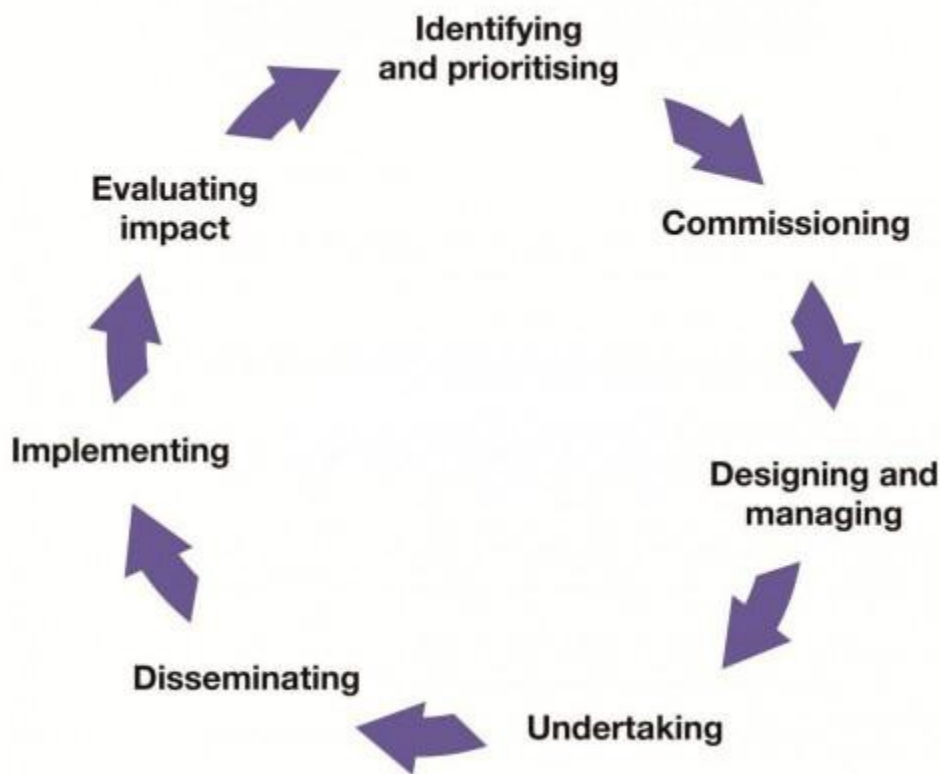
- Work with consumer and community members to develop plain language summaries of research results and findings. This can be especially helpful if the research results are unexpected or have the potential to be controversial
- Enlist consumer and community members to broaden ways to disseminate results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

5. Knowing what to research next

- Involve consumer 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.

3.2 The INVOLVE Research Continuum³

Another example of a research continuum is the UK INVOLVE Research Continuum.



This research cycle shows how members of the public are getting involved in a whole range of research activities, which include:

- helping to develop the research question
- applying for funding and ethical approval
- sitting on advisory groups
- carrying out the research, and
- disseminating the research findings.

The seven key points are:

1. Identifying and prioritising
2. Commissioning
3. Designing and managing
4. Undertaking
5. Disseminating
6. Implementing
7. Evaluating Impact

³ Refer www.invo.org.uk/posttypresource/where-and-how-to-involve-in-the-research-cycle/

Appendix 4: Useful Resources

4.1 NHMRC Publications

2002. Statement on Consumer and Community Participation in Health and Medical Research:

www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34

2003. *NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health Through Research*: www.nhmrc.gov.au/guidelines/publications/r27-r28

2003. *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* www.nhmrc.gov.au/guidelines/publications/e52

2004. A Model Framework for Consumer and Community Participation in Health and Medical Research: www.nhmrc.gov.au/files_nhmrc/publications/attachments/r33.pdf

2004. Resource Pack for Consumer and Community Participation in Health and Medical Research: www.nhmrc.gov.au/files_nhmrc/publications/attachments/r34.pdf

2005. Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics: www.nhmrc.gov.au/guidelines/publications/e65

2006. Cultural Competency in health: A guide for policy, partnerships and participation: www.nhmrc.gov.au/guidelines/publications/hp19-hp26

2007. *Australian Code for the Responsible Conduct of Research*: www.nhmrc.gov.au/guidelines/publications/r39

2007 –updated 2009. *National Statement on Ethical Conduct in Human Research*: www.nhmrc.gov.au/guidelines/publications/e72

2010. *NHMRC Road Map II: A Strategic framework for improving the health of Aboriginal and Torres Strait Islander People through research*

www.nhmrc.gov.au/files_nhmrc/publications/attachments/r47.pdf

4.2 Consumer and community organisations involved in research

Australian Organisations

International Association for Public Participation

www.iap2.org.au/

IAP2 Australasia 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

Involving People in Research

www.involvingpeopleinresearch.org.au

The Consumer and Community Participation Program at The University of Western Australia's School of

Population Health and the Telethon Kids Institute was established to support consumers, community members and researchers working together to increase and enhance participation in research. The Program's website includes a range of resources and information for researchers, consumers and community members.

The Lowitja Institute

www.lowitja.org.au/

The Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research, is an innovative research body that brings together Aboriginal organisations, academic institutions and government agencies to facilitate collaborative, evidence-based research into Aboriginal and Torres Strait Islander health.

Cancer Voices

www.cancervoices.org.au and www.cancervoicesaustralia.org

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, and nationally through Cancer Voices Australia. CVN's Consumer Involvement in Research Program has been operating since 2005. Its elements include research training for interested consumers, operation of a database of "graduates" who may be matched with researchers and research funders' electronic requests for the informed consumer perspective, and a process to gather consumers' research priorities.

Electronic requests may be made via the above websites

Four peer reviewed papers describe this successful Program, including how it implements the Statement.

International and Overseas Organisations

CES4Health

CES4Health.info

CES4Health.info is a free online mechanism for peer-reviewing, publishing and disseminating products of health-related community-engaged scholarship that are in forms other than journal articles. For example, videos, manuals, curricula and products developed through service-learning, community-based participatory research and other community-engaged work.

Cochrane Consumer Network

<http://consumers.cochrane.org/>

The Cochrane Collaboration invites consumers to work collaboratively with healthcare providers and researchers in over 50 areas of disease-based health care to ensure that evidence on the effects of healthcare interventions is accessible to the public. Its core function is to provide consumer input into developing and utilising the best evidence in health care. The Cochrane Consumer Network exists to support health care users, their parents and carers learn about evidence-based healthcare. It encourages consumers throughout the world to give their perspectives and help set priorities for health care.

Community Campus Partnerships for Health

www.ccph.info/

Community-Campus Partnerships for Health (CCPH) is a non-profit organisation that promotes health equity and social justice through partnerships between communities and academic institutions.

INVOLVE

www.invo.org.uk

INVOLVE is a national advisory group in England that supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by and part of the National Institute of Health Research (NIHR). It shares knowledge and learning on public involvement in research. The website contains a range of resources and publications for researchers and consumers.

TwoCan Associates and Association of Medical Research Charities route map for involvement in research

www.twocanassociates.co.uk/routemap/

This route map is for organisations that commission or fund research that wish to involve consumers and community members in their work. It provides advice on where to start as well as lessons from organisations that have already involved consumers and community members.

4.3 Australian Consumer Organisations

There are many consumer and community organisations in Australia. Following are the peak bodies at national and state levels. They can provide information about other consumer and community organisations which support specific interest groups.

a) National

Consumers Health Forum of Australia

www.chf.org.au

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

b) Australian States and Territories

Health Consumers NSW: www.hcnsw.org.au/

Health Consumers Queensland: www.health.qld.gov.au/hcq/default.asp

The Health Consumers' Council of WA: www.hconc.org.au

Health Issues Centre, Victoria: www.healthissuescentre.org.au

Health Consumers Alliance Inc of South Australia: www.hcasa.asn.au/

Health Care Consumers' Association of the ACT: www.hcca.org.au/

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WHO. <http://whqlibdoc.who.int/publications/9241800011.pdf>

Wills P. 1998. Health and Medical Research Strategic Review, the Virtuous Cycle- Working together for health and medical research. www.health.gov.au/internet/main/publishing.nsf/Content/hmrsr.htm

NHMRC 2003. *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, available at www.nhmrc.gov.au/guidelines/publications/e52

NHMRC 2004. Resource Pack for Consumer and Community Participation in Health and Medical Research.

www.nhmrc.gov.au/files_nhmrc/publications/attachments/r34.pdf

NHMRC 2005. *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*: www.nhmrc.gov.au/guidelines/publications/e65

INVOLVE 2013. *Ways that people can be involved in the research cycle*.

www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/