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National Health and Medical Research Council

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# STATEMENT ON CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH AND MEDICAL RESEARCH

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September 2016

| WORKING TO BUILD A HEALTHY AUSTRALIA |

**CHF** Consumers Health  
Forum OF Australia

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## Foreword

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The National Health and Medical Research Council and the Consumer Health Forum of Australia are pleased to release the *Statement on Consumer and Community Involvement in Health and Medical Research*.

In the time since our organisations' initial joint Statement in 2002, the importance of consumer and community involvement in research has become widely recognised. It is very pleasing that many charitable, research and government organisations have drawn from the Statement when developing their own policies and practices.

NHMRC also embraced the Statement. For example, applicants to NHMRC's Centres of Research Excellence scheme are required to demonstrate extensive involvement by research end-users and the community, and the Partnerships for Better Health initiative has provided an unprecedented opportunity for research end-users, including patient-focussed charitable organisations, to partner with researchers in the co-design of a research proposal and then seek a funding contribution from NHMRC.

CHF is committed to building research literacy and the capacity of the consumer sector to engage in research design, conduct and translation through a range of practical measures such as education and training. CHF also plans to pursue collaborations with established research networks and communities of interests to promote the value and uptake of consumer involvement.

The reasons for involving members of the public in research are numerous. Consumers and the community offer unique and valuable insights as research is framed, conducted and translated, helping to ensure research quality and relevance.

There is considerable value still to be gained through researchers and research institutions involving the community to a greater degree. 'Health and medical research' encompasses diverse activities ranging from investigation of the fundamental processes that underpin life, to discovering new ways to treat disease, characterising and preventing illness, learning how to develop and innovate health care services and determining how to close the gap in health and life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians. The Statement recognises that the form and degree of community involvement must be appropriate to the research activity and requires consumers and community members with differing backgrounds, interests and perspectives.

Our organisations are committed to the vision expressed in the Statement and will work together to promote its implementation across the sector. We are committed to regularly reviewing the Statement to ensure it remains contemporary and in line with emerging practice.



Professor Anne Kelso AO  
Chief Executive Officer  
NHMRC



Ms Leanne Wells  
Chief Executive Officer  
CHF

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# The Statement

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## **Vision:**

*Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.*

## **Our values:**

*Shared understanding, respect and commitment*

## **Purpose:**

*To guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research.*

NHMRC recognises that involving consumers and community members can add value to health and medical research and they have a right and responsibility to do so. The Australian Code for the Responsible Conduct of Research (2007),<sup>1</sup> the primary guidance for institutions and researchers in responsible research practices, states:

*Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.*

In addition, NHMRC encourages researchers to consider the benefits of actively involving consumers in their proposed research, when they apply to NHMRC for research funding.<sup>2</sup>

Research informs health care decisions and research institutions, researchers, consumers and community members should work collaboratively to support, facilitate and value the contribution that consumers and community members make to research, and its development, conduct and communication.

As beneficiaries of advances in health care, consumers and community members 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.

Effective consumer and community involvement benefits many stakeholders including the public and researchers.

The active involvement of consumers and community members in health and medical research benefits the quality and direction of research. Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them.

This Statement has been developed with the aim of supporting consumer and community involvement across all types and levels of health and medical research.

1 Refer: [www.nhmrc.gov.au/guidelines-publications/r39](http://www.nhmrc.gov.au/guidelines-publications/r39)

2 Refer: [www.nhmrc.gov.au/book/nhmrc-funding-rules-2016](http://www.nhmrc.gov.au/book/nhmrc-funding-rules-2016)

The Statement provides the key to developing stronger partnerships between researchers, consumers and community members at all levels of health and medical research in Australia, and calls for NHMRC to foster these partnerships.

This Statement replaces the Statement on Consumer and Community Participation in Health and Medical Research, first published in 2002 (referred to within as the 2002 Statement). The development of this revised Statement is outlined in Appendix 1.

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## Benefits of consumer and community involvement

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Benefits to the public include:

- research being conducted that is relevant to community needs
- public awareness of, and support for, science and research, and
- 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, and
- increased opportunities to continuously improve the quality of research.

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## Elements for consumer and community involvement

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Health and medical research encompasses different types of research, and opportunities to engage consumers and community members will depend on the type of research being undertaken. The following key elements underpin effective involvement:

- Consumers and community members can be, and are, involved at various levels of research activity and the institutions in which research is conducted. ‘Levels of research activity’ include planning, seeking funding, conducting the research, and communicating the outcomes. Consumers and community members should advise research institutions and researchers on their consumer and community perspectives and lived experiences.
- Consumers and community members may need skills, information and support in order to add value to the development, conduct and communication of research.
- Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability.
- Research institutions should commit to the involvement of consumers and community members in various levels of research activity.
- Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research.

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## Definitions

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The distinction between terms is more about difference in perspective. The people who are defined by 'community', 'community member', 'consumer', 'stakeholder' are as diverse as the Australian population in terms of gender, sexual orientation, age, socio economic status, physical abilities and religious beliefs. These definitions guide the reader as to the individuals and groups that may be described by a single word or phrase.

The Australian Government's policy on access and equity recommends that all Government bodies acknowledge that we live in a multicultural society and that there is an obligation to ensure their programs and services are accessible by all eligible Australians, responsive to their needs, and deliver equitable outcomes for them, regardless of their cultural and linguistic backgrounds.<sup>3</sup> The purpose of the policy is to provide all Australians with the opportunity to achieve their potential and fully participate in the social, economic and cultural life of Australia.

**Community** – a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research.

**Community member** – a member of a community.

**Consumer** – patients and potential patients, carers, and people who use health care services.

Collectively, 'consumers' and 'community members' may be referred to as 'the public'.

The Australian Commission on Safety and Quality in Health Care definition<sup>4</sup>: members of the public who use, or are potential users of health care services - patients, consumers, families, carers and other support people.

**Consumer representative**<sup>5</sup> – someone who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person may be nominated by, and may be accountable to, an organisation of consumers. This consumer representative however may have a narrower view as they are speaking on behalf of their organisation and not necessarily that of the wider community.

A consumer representative may be appropriately trained or may undergo training and be supported to advocate for consumer-centred health care.

**Health and medical research** – research with a human health focus.

**Research**<sup>6</sup> – an original investigation undertaken to gain knowledge, understanding and insight.

**Research process** – the planning, funding and conduct of an individual piece of research in addition to implementation of research findings and publication of research findings.

**Researcher** – a person who conducts research.

3 *Multicultural Access and Equity Policy Guide*, Commonwealth of Australia Department of Social Services, Canberra, 2015

4 [www.safetyandquality.gov.au/wp-content/uploads/2014/04/FAQ-Standard-2-Partnering-with-consumers.pdf](http://www.safetyandquality.gov.au/wp-content/uploads/2014/04/FAQ-Standard-2-Partnering-with-consumers.pdf)

5 Definition from [www.chf.org.au/about-consumer-representation.php](http://www.chf.org.au/about-consumer-representation.php)

6 Definition from the *Australian Code for the Responsible Conduct of Research* (2007) [www.nhmrc.gov.au/guidelines-publications/r39](http://www.nhmrc.gov.au/guidelines-publications/r39)

**Research institution** – a place where research is conducted.

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

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# Why is consumer and community involvement important?

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## Consumer and community involvement in health

The World Health Organization and United Nations Children's Fund (UNICEF) Declaration of Alma-Ata<sup>7</sup> states:

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

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 value to the decision making processes surrounding planning, policy development and service delivery in health. Shared decision making is recognised as being important to quality health care, 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 decisions.<sup>8,9</sup>

## Consumer and community involvement in research

NHMRC recognises that involving consumers and community members can add value to health and medical research and have a right and responsibility to do so. The Australian Code for the Responsible Conduct of Research (2007),<sup>10</sup> the primary guidance for institutions and researchers in responsible research practices, states:

*Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.*

In addition, NHMRC encourages researchers to consider the benefits of actively engaging consumers in their proposed research, when they apply to NHMRC for research funding.<sup>11</sup>

Research informs health care decisions and research institutions, researchers, consumers and community members should work collaboratively to support, facilitate and value the contribution that consumers and community members make to research, and its development, conduct and communication.

As beneficiaries of advances in health care, consumers and community members 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.

7 World Health Organization and UNICEF 1978. Primary Health Care: Report of the International Conference on Primary Health Care. Alma-Ata, USSR. 6-12 September, 1978. Geneva: WHO. <http://whqlibdoc.who.int/publications/9241800011.pdf>

8 Refer: [www.safetyandquality.gov.au/our-work/shared-decision-making/](http://www.safetyandquality.gov.au/our-work/shared-decision-making/), accessed 20 March 2014

9 Refer: [www.nhmrc.gov.au/health-topics/shared-decision-making](http://www.nhmrc.gov.au/health-topics/shared-decision-making)

10 Refer: [www.nhmrc.gov.au/guidelines-publications/r39](http://www.nhmrc.gov.au/guidelines-publications/r39)

11 Refer: [www.nhmrc.gov.au/book/nhmrc-funding-rules-2016](http://www.nhmrc.gov.au/book/nhmrc-funding-rules-2016)

Effective consumer and community involvement benefits many stakeholders including the public and researchers.

**Further information:** Consumers and community members can also be involved in health and medical research as a research participant e.g., in clinical trials, or as a member of an ethics committee. The Statement does not specifically cover these types of participation. Guidance on how consumer organisations, consumers and community members can be involved in these ways is available at the following web links:

For information on recruitment into, and participation in clinical trials research – go to [Australianclinicaltrials.gov.au]

For information on involvement in research institutions as a member of a Human Research Ethics Committee – go to [www.nhmrc.gov.au/guidelines-publications/e72]

For information on involvement in research institutions as a member of an Animal Ethics Committee – go to [www.nhmrc.gov.au/guidelines-publications/r39]

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## Levels of consumer and community involvement

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Consumer and community involvement at a particular research institution or for any research activity will depend on the purpose of the involvement, the resources available and the type and subject of the research.

Consumers and community members can be, and are, involved at various levels of research, at various stages of the research cycle and in the institutions in which research is conducted, including but not limited to:

- as a member of the institution's governing board
- as a member of a strategic research advisory group advising on research priorities
- as a chief investigator on a research project or grant application
- providing their perspective on specific research programs or projects over the course of the research cycle
- providing their perspective on the translation of research into patient care, and
- being provided public information on research being conducted.

A number of different models have been developed by various consumer and community organisations and researchers to describe levels of involvement. Some of these have been included as appendices to this Statement:

- Appendix 2 contains a range of models that illustrate different levels of involvement
- Appendix 3 provides additional information on ways consumers and community members can be involved in the research cycle, and
- Appendix 4 provides examples of organisations that have worked to implement the 2002 Statement and what can be achieved.

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## Putting the Statement into practice

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This section includes information about practical ways the Statement can be implemented by research institutions, researchers, consumers and community members.

### The Statement and research institutions

Research institutions should commit to the involvement of consumers and community members in the research process and:

- have a policy on consumer and community involvement in research, defining possible roles that consumers and community members may play, and their level of involvement
- expect the involvement of consumers and community members in all stages of the research cycle
- minimise barriers to meaningful consumer and community involvement
- build capacity of researchers, consumers and community members through training, mentoring and support
- fully justify the level of involvement of consumers and community members, and
- ensure consumer and community members' time and expertise is valued and appropriately remunerated or otherwise acknowledged.

This commitment might involve, but is not limited to:

- developing strategies to implement their policies on consumer and community involvement, including in partnership with consumers 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 stakeholder groups for training, support and guidance
- providing accessible and easy to understand information about the institution's research activities, and
- outlining processes for consumer and community involvement by including planned budgeted strategies in research projects.

Research institutions should have planned budget strategies and allocate funds to support, implement and acknowledge consumer and community involvement. This might include budgeting for:

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

## The Statement and researchers

Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research – refer to Appendix 3.

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 can include consumers and/or community members.

Researchers should have planned, budgeted strategies to support, implement and acknowledge appropriate consumer and community involvement in the research process.

Researchers may consider the relative value of these activities in order to achieve the highest level of consumer and community involvement with available resources.

## The Statement and consumer and community members

Consumers and community members should advise research institutions and researchers on their consumer and community perspectives and lived experiences.

When asked to be involved, consumers and community members:

- adhere to confidentiality requirements
- respect all stakeholders
- support the agreed parameters of the research project, and
- seek appropriate input from other consumers, community members and relevant organisations as required.

Consumers and community members may need skills, information and support in order to add value to the development, conduct and communication of research.

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.

## Implementation issues that may need to be considered

Some examples to enable meaningful consumer and community involvement:

- 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 contribute
- use accessible language that avoids the use of certain expressions, words, acronyms or jargon that might be considered to exclude particular groups of people
- treat everyone – consumers, community members, researchers and other stakeholders – with courtesy, respect and integrity

- work in partnership to develop the appropriate involvement activities, and
- keep everyone informed and involved by sharing information willingly and in language that everyone understands.

Some examples of barriers to meaningful consumer and community involvement:

- poor attitudes, tokenism, feeling of isolation, and strong organisational cultures
- power imbalances (real or perceived) between researchers and consumer and community members
- technical language and research processes
- home and family commitments
- costs of involvement
- uncertainties about responsibility for consumer and community member involvement
- managing illness while being actively involved
- lack of training and support, and
- involvement too late.

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## Appendix 1: Overview of revision of the Statement

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NHMRC developed the current Statement and its predecessor because many consumers, community members and researchers recognised that involving consumers and community members can add value to health and medical research and that they have a right and responsibility to do so.

NHMRC and the Consumer Health Forum of Australia Ltd (CHF) jointly developed the initial 2002 **Statement on Consumer and Community Participation in Health and Medical Research** and companion **Summary Statement**<sup>12</sup> following the 1999 **Health and Medical Research Strategic Review**, chaired by Mr Peter Wills AC. A **Model Framework** and companion **Resource Pack** were published in 2004.<sup>13</sup>

NHMRC and CHF conducted a survey and other activities, including a national workshop in 2011, to inform the revision of the 2002 Statement. A Working Committee consisting of the following members was established in 2012 to consider revisions to the 2002 Statement:

### **Mr Mitch Messer**

(Chair)

Mr Messer is the CEO of Clan WA and was the consumer representative on the NHMRC Research Committee for the 2009-2012 triennium. He is a former Chair of CHF, a Trustee of the Australian Cystic Fibrosis Research Trust and member of the Executive Committee of AREST CF. He is also Chair of the Community Engagement Committee and a Council Member of the Perth South Primary Health Network.

### **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 led 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.

<sup>12</sup> Available at: [www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34](http://www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34)

<sup>13</sup> Available at: [www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34](http://www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34)

### **Ms Anne McKenzie AM**

Ms McKenzie is the Head of the WA Consumer and Community Health Research Network. Her role is to support and enhance consumer and community involvement across the WA Health Translation Network. She is an experienced and respected consumer advocate serving on key national 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 is also a Board member of Health Consumers NSW. Mrs Potter has a strong understanding of the consumer issues relevant to this work and strong links with community networks.

The Statement, while retaining the broad content of the 2002 Statement, is simpler, more readable and accessible and focuses on high level elements. It reflects developments in the area of consumer and community involvement in health care and health and medical research. The Statement was developed 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, closing on 19 September 2014.

NHMRC took account of the 32 submissions received during public consultation in revising the Statement.

NHMRC's Community and Consumer Advisory Group reviewed the final draft of the Statement in May 2016 and advised that revision of the Statement is completed. Membership included:

Ms Karen Carey – Chair	Mr Demos Krouskos
The Hon Fran Bailey	Ms Meagan Lawson
Ms Sandra Bethell	Ms Anne McKenzie AM
The Hon Dr Hendy Cowan AO	Ms Lesley Murphy
Ms Alison Copley	Ms Kay Oke
Ms Rebecca Davies	Mr Glenn Rees
Mr Todd Harper	Mr John Stubbs
Mr David Jack	Dr Moira Watson

The NHMRC Research Committee considered the revised Statement at its meeting on 23-24 June 2016. At its 13-14 July 2016 meeting NHMRC Council recommended that the NHMRC CEO publicly release the revised Statement.

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## Appendix 2: Levels of consumer and community involvement

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Following are models that different organisations use to describe levels of involvement.

1. *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](http://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf)

Cancer Australia describe five different types of involvement for consumers:

- Partner
- Expert
- Adviser
- Advocate, and
- Personal engagement.

2. The ladder of involvement adapted by the University of Western Australia and the Telethon Kids Institute:

[www.involvingpeopleinresearch.org.au/images/docs/fact\\_sheet\\_series.pdf](http://www.involvingpeopleinresearch.org.au/images/docs/fact_sheet_series.pdf)

3. *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, and
- ethical research aiming to be of practical value to Aboriginal and Torres Strait Islander people and their service providers.

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

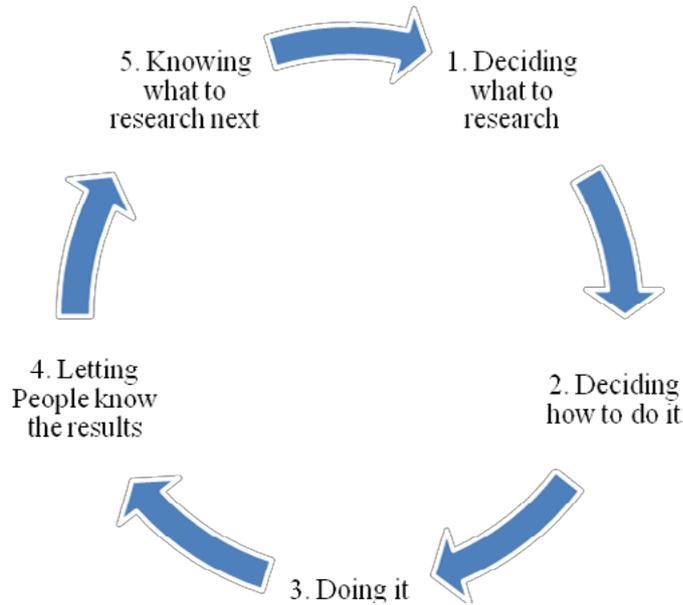
- **Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research** which contains guidelines for ethical health research on Aboriginal and Torres Strait Islander people, and in accordance with guidance from Aboriginal people is written around a framework of Aboriginal and Torres Strait Islander values and principles.  
[www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/e52.pdf](http://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](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e65.pdf)

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## Appendix 3: The research cycle

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- Research usually follows a cycle as illustrated below<sup>14</sup>:



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, and
- Discuss the evaluation of the involvement roles with the consumers and community members.

<sup>14</sup> Based on the 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, and
- 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.

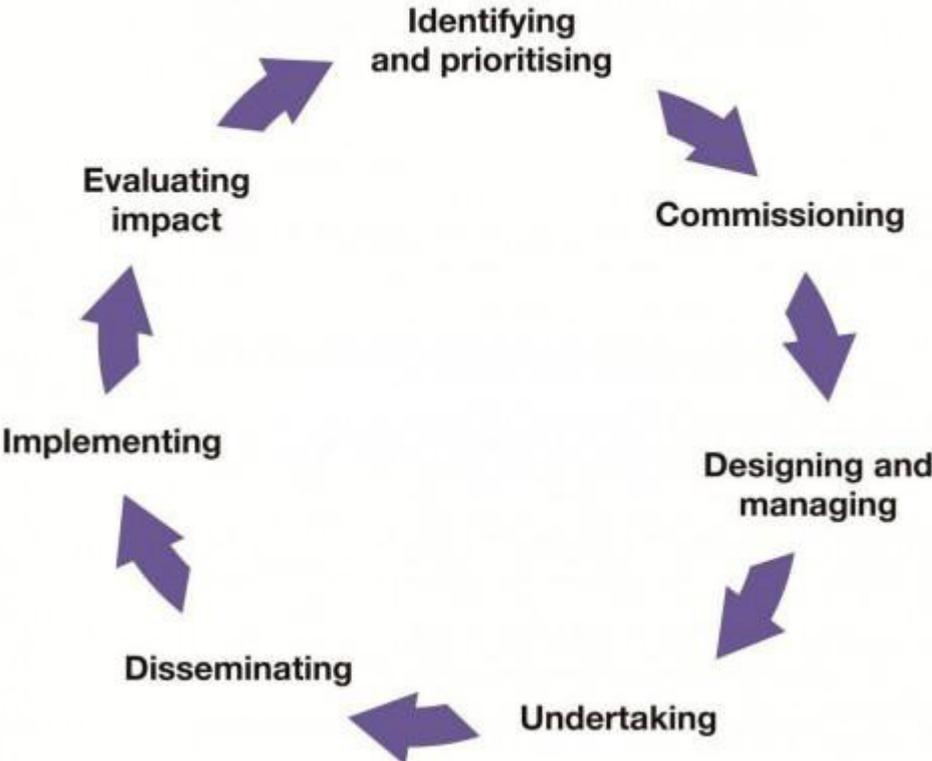
## 4. Letting people know the results:

- 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, and
- Approach recognised consumer organisations for their members' research priorities.

Another example of a research cycle is the UK INVOLVE Research Continuum<sup>15</sup>:



15 Refer [www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/](http://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/)

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## Appendix 4: Useful resources

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### 4.1 From NHMRC

2002. Statement on Consumer and Community Participation in Health and Medical Research: [www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34](http://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](http://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](http://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](http://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](http://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](http://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](http://www.nhmrc.gov.au/guidelines/publications/hp19-hp26)

2007. The Australian Code for the Responsible Conduct of Research: [www.nhmrc.gov.au/guidelines/publications/r39](http://www.nhmrc.gov.au/guidelines/publications/r39)

2007 –updated May 2015. National Statement on Ethical Conduct in Human Research: [www.nhmrc.gov.au/guidelines/publications/e72](http://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](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r47.pdf)

### 4.2 Consumer and community organisations involved in research

#### **Australian Organisations**

- Cancer Voices  
Cancer Voices NSW (CVN) 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. Four peer reviewed papers describe this successful Program, including how it implements the Statement: [www.cancervoices.org.au](http://www.cancervoices.org.au) and [www.cancervoicesaustralia.org](http://www.cancervoicesaustralia.org)

- Consumers Health Forum of Australia, 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](http://www.chf.org.au)
- Health Consumers NSW: [www.hcnsw.org.au/](http://www.hcnsw.org.au/)
- Health Consumers Queensland: [www.hcq.org.au/](http://www.hcq.org.au/)
- The Health Consumers' Council of WA: [www.hconc.org.au](http://www.hconc.org.au)
- Health Issues Centre, Victoria: [www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)
- Health Consumers Alliance Inc of South Australia: [www.hcasa.asn.au/](http://www.hcasa.asn.au/)
- Health Care Consumers' Association of the ACT: [www.hcca.org.au/](http://www.hcca.org.au/)
- 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/](http://www.iap2.org.au/)
- Involving People in Research  
The WA Consumer and Community Health Research Network was established in 2012 to support consumers, community members and researchers working together to increase and enhance participation in research. The Network's website includes a range of resources and information for researchers, consumers and community members: [www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)
- The Lowitja Institute  
The Lowitja Institute is 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: [www.lowitja.org.au/](http://www.lowitja.org.au/)

### 4.3 From international and overseas organisations

- CES4Health  
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: [www.CES4Health.info](http://www.CES4Health.info)
- Cochrane Consumer Network  
The Cochrane Collaboration invites consumers to work collaboratively with health care providers and researchers in over 50 areas of disease-based health care to ensure that evidence on the effects of health care 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 health care. It encourages consumers throughout the world to give their perspectives and help set priorities for health care: <http://consumers.cochrane.org/>
- Community-Campus Partnerships for Health (CCPH)  
CCPH is a non-profit organisation that promotes health equity and social justice through partnerships between communities and academic institutions: [www.ccph.info/](http://www.ccph.info/)
- IAP2  
International Association for Public Participation's spectrum of public participation: [www.iap2.org/associations/4748/files/IAP2%20Spectrum\\_vertical.pdf](http://www.iap2.org/associations/4748/files/IAP2%20Spectrum_vertical.pdf)

- INVOLVE UK

INVOLVE is a national advisory group in England that supports greater public involvement in the National Health Service, public health and social care research in the UK. 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: [www.invo.org.uk](http://www.invo.org.uk) and [www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/](http://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/)

- TwoCan Associates

TwoCan Associates and Association of Medical Research Charities route map for involvement in research 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: [www.twocanassociates.co.uk/routemap/](http://www.twocanassociates.co.uk/routemap/)