



Review of the *Statement on Consumer and Community Involvement in Health and Medical Research 2016*

Position Paper

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Rationale

The Statement on *Consumer and Community Involvement in Health and Medical Research* (the Statement), co-authored by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF), was published in 2016 with the aim of guiding research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research.

The Statement articulates why consumer and community involvement in health and medical research is important and the benefits it brings to the research process, the different levels and types of consumer and community involvement, and discusses a series of implementation issues.

A revision of the Statement is needed to maintain its relevance and currency. Since 2016 a variety of information addressing implementation issues has been produced and made available in a variety of formats – examples include the [NHMRC Toolkit for consumer and community involvement in health and medical research](#) and the Western Australian Health Translation Network handbook [Involving consumers in health and medical research](#) and the Department of Health and Aged Care [Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund](#). With the increasing availability of practical implementation toolkits and other resources, published by a variety of organisations, it is proposed to remove implementation-focused information from a revised Statement.

Revising the Statement provides an opportunity to streamline and refocus it as a high-level national statement. It is not intended to be tied to specific detail but rather offer guidance on actions and concepts that promote and strengthen consumer and community involvement. Publication of a revised Statement will also provide opportunities to further raise awareness of, and promote, the importance of consumer and community involvement across the research cycle now and into the future.

This consultation paper is seeking views from consumers and community members, researchers, research institutions and funders about what should be included in the revised Statement.

For the purpose of this paper, we acknowledge that the distinction between terms is about a difference in perspective. The people who are referred to using the terms ‘community’, ‘community member’, ‘consumer’, ‘stakeholder’, ‘patient’ are as diverse as the Australian population in terms of gender, sexual orientation, age, socio economic status, physical abilities and religious beliefs.

The current definitions from the Statement will be maintained for this consultation paper, being:

Consumer - patients and potential patients, carers and people who use health care services

Consumer Representative - 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 for, 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.

Scope

It is envisaged that the revised Statement will be a high-level document, similar in design and content to the [Australian code for responsible conduct of research](#), that sets out overarching principles and responsibilities for all stakeholders in the consumer and community involvement ecosystem. The revised Statement is expected to focus on consumer and community involvement in health and medical research across all stages of the research cycle.

The key elements of a revised Statement could be:

- an overall values statement to inform the principles of consumer and community involvement
- a list of principles for consumer and community involvement applicable to all parties
- a list of roles and responsibilities for consumers and community members
- a list of roles and responsibilities for researchers
- a list of roles and responsibilities for research institutions
- a list of roles and responsibilities for funders
- a glossary

The principles and roles and responsibilities should avoid focussing on specific issues that would be addressed in an implementation context as this would tie the revised Statement to processes that will become outdated, or be replaced, within a relatively short period. That said, we invite stakeholder insights on areas where implementation of better practice consumer and community involvement in research could be enhanced and supported. These matters may then be operationalised once the revised Statement has been finalised and published.

Stakeholder Engagement and Consultation

NHMRC will engage with stakeholders across the consumer and community involvement space. This will include (but is not limited to) consumers and consumer advocates and representatives, community members, researchers and funders. Input and comment is being sought on the current 2016 Statement and on the content for the revised Statement.

There is a wealth of information available through material published by Australian and international organisations. This paper presents some examples, drawn from existing documents published by national and international organisations, of the kinds of principles, roles and responsibilities that could be included in the revised Statement. These are intended as starting points to promote further discussion and do not represent a fixed position on the part of NHMRC and CHF.

Discussion questions:

- What parts of the current Statement have or have not worked well?
- Why is consumer and community involvement in research valuable? Why does it matter to you?
- What issues should be considered once the revised Consumer Statement has been finalised and published?

Value statement

A value statement is important as it is a brief, high-level statement that underpins and acknowledges the spirit and purpose of consumer and community involvement in the research cycle. The value statement will help to embed the aspirations of the principles into better practice.

Discussion questions:

- The values that underpin the 2016 Statement are 'shared understanding, respect and commitment' (*2016 NHMRC-CHF Consumer Statement*). How might this be strengthened and improved in the revised Consumer Statement?
- Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement? What others would you like to see, and why?
- What overarching values are essential to include in the value statement of the revised Consumer Statement?

Better Practice Principles for Consumer and Community Involvement in Research

The following is a list of principles taken and adapted from existing documentation. They are provided as an example of the kinds of principles that could be included in the revised Statement. All principles included in this section should be broad in scope rather than directed at implementation.

- Consumers and community members should be involved at all stages of research (source: *MRFF Principles*)
- Consumers and community members should be in partnership with researchers (source: *MRFF Principles*)
- Consumers and community members should be involved with broad diversity and equity (source: *MRFF Principles*)

- Mutually respectful relationships (source: *UK Standards for Public Involvement: Better public involvement for better health and social care research*)
- Respect for lived experience and community expertise (source: *Principles of Community Engagement – CDC US Publication*)
- Honesty in the development, undertaking and reporting of research, including presenting information truthfully and accurately in proposing, conducting and reporting research. (source: *Australian Code for the Responsible Conduct of Research*)
- Respect for research participants, the wider community and the environment (source: *Australian Code for the Responsible Conduct of Research*).

Discussion questions:

- What do you regard as the most important principles that should be included in the revised Consumer Statement?

Roles, expectations and responsibilities of consumers and community members

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- 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 (source: *2016 NHMRC-CHF Statement*).
- Consumers and community members can be involved at various levels of research activity and the institutions in which research is conducted. 'Levels of research activity' include planning and co-deciding, governance, developing research design and questions, recruitment, seeking funding, conducting the research, communicating the outcomes and evaluation (*2016 NHMRC-CHF Statement*).
- Consumers and community members should advise research institutions and researchers on their consumer and community perspectives and lived experiences (*2016 NHMRC-CHF Statement*).
- Consumers and community members may need skills, information and support in order to add value to the development, conduct and communication of research (*2016 NHMRC-CHF Statement*).

Discussion questions:

- What roles and responsibilities for consumers and communities should be included in the revised Consumer Statement?

Roles and responsibilities of researchers

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- 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 (source: *2016 NHMRC-CHF Statement*).
- **Champions:** researchers elect to champion the benefits of consumer engagement. Key leaders with experience in consumer involvement advocate to improve the level of understanding among peers. (*National Framework for Consumer Involvement in Cancer Control*)
- **Combined professional development:** researchers and consumers are encouraged to undertake professional development together to learn from each other's knowledge and experience. (*National Framework for Consumer Involvement in Cancer Control*)
- **Equality:** consumers are considered equal members of the group or team (*National Framework for Consumer Involvement in Cancer Control*)
- Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research (*2016 NHMRC-CHF Statement*).

Discussion questions:

- What roles and responsibilities for researchers should be included in the revised Consumer Statement?
- How should researchers involve consumers and community representatives in their research?
- Should involvement be an expectation of research and is there an ethical imperative to do so?

Roles and responsibilities of research institutions

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- 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 (source: *2016 NHMRC-CHF Statement*).
- Research institutions should commit to the involvement of consumers and community members in various levels of research activity (source: *2016 NHMRC-CHF Statement*).

- Governance: governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective consumer participation (source: *National Framework for Consumer Involvement in Cancer Control*)
- Seek feedback from researchers and consumer and community members involved in research and evaluate processes and outcomes (source: *NIHR Cambridge Public and Patient Involvement Public Engagement Strategy 2021/2022*)
- Education and training (source: *National Framework for Consumer Involvement in Cancer Control*)

Discussion question:

- What roles and responsibilities for research institutions should be included in the revised Consumer Statement?

Roles and responsibilities of funders

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- Governance: governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective consumer participation (source: *National Framework for Consumer Involvement in Cancer Control*)
- Policy and Processes: Through policy guidance and other processes, set expectations for how people with lived experience (PWLE) and consumers should be involved in research projects. (Adapted from: *Lived Experience Involvement in Research Funding: Taking a more systematic approach*)
- Research Funding Programs: Research funders can involve consumers in reviewing funding applications, setting priorities, identifying research topics, designing and developing programs, and supporting funded projects (Adapted from: *Lived Experience Involvement in Research Funding: Taking a more systematic approach*)

Discussion question:

- What roles and responsibilities for funders should be included in the revised Consumer Statement?
- Should funders of research mandate the involvement of consumer and community representatives in the research they fund?