

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

Background

In March 2024, The National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia Ltd (CHF) commenced a review of the [2016 Statement on Consumer and Community Involvement in Health and Medical Research](#) (the Statement).

The Statement aims to support consumer and community involvement across all types and levels of health and medical research. The below responses, were provided by Research Australia in response to the Position Paper. The responses were provided via an electronic survey on 12 June 2024.

Response to the Survey

What parts of the current Statement have or have not worked well?

Overall, the Statement has worked well in creating an expectation that consumer and community involvement in research has a role and can be useful. With greater acceptance of this position over time, the Statement now needs to make it clear that consumer and community involvement in research is a requirement.

Why is consumer and community involvement in research valuable?

Consumer and community involvement in research is valuable for benefits it brings to the public as listed on page 4 of the Statement. It improves the quality of research and helps ensure it is fit for purpose and addressing real need.

Why does consumer and community involvement in research matter to you?

Research Australia values consumer and community involvement because it leads to better research and ultimately to better health outcomes.

What overarching values are essential to include in the value statement of the revised Consumer Statement, and why?

Research Australia submits the following values are essential for all participants (consumers, consumer representatives, researchers) involved in health and medical research.

Integrity

All participants should act with integrity.

Respect for others and their views, opinions and beliefs

All participants should be prepared to listen to and consider the views, opinions and beliefs of others. They should also be willing to engage in respectful dialogue and discussion, recognising that they may not always agree.

The values that underpin the 2016 Statement are 'shared understanding, respect and commitment.' How might this be strengthened and improved in the revised Consumer Statement?

Shared understanding: While Research Australia accepts a shared understanding is essential to any collaboration between the participants in research, we don't believe it can be stated as a value. A shared understanding is something that achieved by participants in the research. The dialogue engaged in by all the participants (researchers and consumers) can lead to a shared understanding. This includes not necessarily agreeing a shared understanding.

Respect: see above

Commitment: Research Australia similarly questions whether 'commitment' is a value. Research Australia accepts it is important all participants should commit to making the research as high quality as possible and relevant, and put this objective ahead of any other interests.

Research Australia submits that in addition to values, the Statement should articulate a set of principles which research participants are asked to abide by. These could include agreeing to work with other participants to develop a shared understanding of the research and its objectives, and a commitment to making the research high quality and relevant.

Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

Research Australia suggests that these are better characterised as 'principles' than values and should be included in a section of the Statement which outlines principles which all participants are asked to commit to. (See our response to the next question.)

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

Research Australia submits the Statement should include a set of principles, immediately after the values, which participants are expected to commit to.

The principles should articulate and guide *how* participants are expected to contribute to the research (ways of working). Research Australia has already suggested two principles in our earlier response:

- a) Work with other participants to develop a shared understanding of the research and its objectives; and
- b) Commit to making the research high quality and relevant.

The Discussion paper asks 'Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement?' Research Australia suggests that rather than being values these could be framed as principles in the Statement.

Research Australia supports the inclusion of the principles outlined on pages 4 and 5 of the Position Paper.

What roles and responsibilities for consumers and community members should be included in the revised Consumer Statement?

The roles of consumers and community members will vary depending on their own experience and expertise, the nature of the research and the stage at which they are involved (initial conception and design, proposal development, governance, analysis and publication). Responsibilities of consumer and community members include recognising and articulating the scope of their own lived experience, where it informs their contribution and where it is not relevant- i.e. recognising boundaries of their experience and expertise. This includes assisting researchers to identify where the perspectives and experience of other consumer and community participants can be relevant and necessary.

We also direct the review to the response of Response by Deakin University's Faculty of Health to the Position Paper Questions in relation to the rights of consumers and community representatives. Research Australia supports the call for the Statement to include the rights of consumer and community representatives.

What roles and responsibilities for researchers should be included in the revised Consumer Statement?

The existing roles and responsibilities for researchers outlined in the current Statement remain relevant and should be retained. The Statement should also articulate the role for researchers to facilitate and support consumer and community engagement, and to support individual consumer and community representatives to participate fully.

Should involvement of consumers and community members be an expectation of research?

- Yes
- No
- Not sure

Provide reasons for your response below.

It should be a default expectation, with an obligation on the research funder, research institution or researcher to explain why it is **not** required in any specific scheme or research project; the 'if not, why not?' approach.

Is there an ethical imperative to involve consumers and community representatives in research?

- Yes
- No
- Not sure

Provide reasons for your response below.

The National Statement on Ethical Conduct in Human Research makes several references to the consumers, including an obligation to include consumers in HREC and the following: *'Researchers also have a responsibility to engage appropriately with communities and/or consumers that are relevant to their research and to positively engage with ethics review, governance and monitoring processes.'* (page 97, Chapter 5.3)

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

Research institutions should be required to provide resources, training and support to researchers to effectively engage consumers and community members in research.

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

Research funders must recognise that effective engagement of consumers and community members in research requires time and resources, and adequate funding and time should be provided for these activities.

Research funders should also commit to assessing the quality and extent of consumer and community participation in research proposals as part of their assessment of proposals for funding.

Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

- Yes
- No
- Not sure

Provide reasons for your response below.

Involvement of consumer and community representatives should be a default expectation, with an obligation on the research funder to explain why it is not required in any specific scheme or research project; the 'if not, why not?' approach.

How should researchers involve consumers and community representatives in their research?

As the revised statement will remain a 'high level overarching statement', it is important that researchers are provided with a range of resources and guides that support implementation. The NHMRC has a role to play in facilitating the provision of these resources and guides, including through supporting existing centres of expertise to develop and disseminate resources, guides and training. There is also an opportunity to include consumer and community involvement in health as part of research education and training as part of any teaching curriculum within our tertiary and research institutions.

What issues should be considered once the revised Consumer Statement has been finalised and published?

The revised Consumer Statement should be widely and publicly disseminated, together with links to resources, training and guides that support its implementation.

END