**Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research – Position Paper Questions**

We are encouraging all interested stakeholders to provide a written submission to the questions in the NHMRC Consumer Statement Review Position Paper via NHMRC’s Consultation Hub. These questions will also be discussed in an open forum at Australia-wide workshops in the first half of 2024.

You may enter your responses directly using the online survey. If you provide an email address, you can save your progress and return to the survey as many times as you wish while it is open.

This document has been developed for individuals and organisations who would prefer to prepare their responses offline, for entering on NHMRC’s Consultation Hub once complete. It contains the discussion questions in the order that they appear in the online survey.

Please note that none of the questions below are mandatory, and that there is no word or character limit for each question in the online survey. You are welcome to provide a response to as many or as few questions as you wish. You will also be asked some questions about you or your organisation when you complete the online survey.

Please ensure that you have read the Position Paper (available for download on the Overview page of the survey) prior to answering the questions.

**The current Statement and importance of consumer and community involvement in research**

The current (2016) statement is available for download from NHMRC’s website at: <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

* What parts of the current Statement have or have not worked well?
* Why is consumer and community involvement in research valuable?
* Why does consumer and community involvement in research matter to you?

**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.

* What overarching values are essential to include in the value statement of the revised Consumer Statement, and why?
* 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?
* Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

**Better practice principles for consumer and community involvement in research**

The Position Paper provides some examples of broad principles that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other principles you would like to see included.

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

**Roles and responsibilities**

The Consumer Statement Review Position Paper provides some examples of roles and responsibilities **of consumers and community members, researchers, research institutions and research funders** that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other roles and responsibilities you would like to see included.

* What roles and responsibilities for **consumers and community members** should be included in the revised Consumer Statement?
* What roles and responsibilities for **researchers** should be included in the revised Consumer Statement?
* Should involvement of consumers and community members be an expectation of research?

Yes [ ]

No [ ]

Not sure [ ]

Provide reasons for your response below.

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

Yes [ ]

No [ ]

Not sure [ ]

Provide reasons for your response below.

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

Yes [ ]

No [ ]

Not sure [ ]

Provide reasons for your response below.

**Implementing the revised Statement**

The revised Statement is intended to be a high-level, overarching document that does not focus on issues related to implementation of consumer and community involvement in health and medical research. However, we acknowledge that you may like to share your views on how the revised Statement may be implemented. Responses to the questions on this page may be used to develop implementation guidance once the revised Statement is published.

* How should researchers involve consumers and community representatives in their research?
* What issues should be considered once the revised Consumer Statement has been finalised and published?