Australian Government
National Health and Medical Research Council

NHMRC

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

About your Organisation

What is the name of your organisation?

Council of Deans of Nursing and Midwifery (Australia and New Zealand)

Discussion questions

Please note that none of the questions below are mandatory, and that there is no word or character limit for each question. You are welcome to provide a response to as many or as few questions as you wish.

Expectation of Consumer and Community Involvement in health and medical research

While the Statement does not mandate consumer and community involvement, it sets high expectations. The goal is for consumer and community involvement to become a routine and integral part of every level, stage and type of health and medical research.

- Does the Statement set clear and suitable expectations that consumers and community will be involved in all stages of research?

  Yes ☒
  No ☐

  Would you like to make further comments?

Comment: The purpose clearly articulates the importance of consumer and community involvement, highlighting its transformative potential in research. However, the statement could further strengthen the role of consumers in research by using language that better reflects the important contribution of their lived experience and their role as fully engaged partners rather than "invited participants". We refer the NHMRC to the International Association for Public Participation (IAP2) 2015 for further suggestions.

Values and Principles of Consumer and Community Involvement

The Statement outlines the values and principles that are the foundation for effective consumer and community involvement.

- Does the Statement clearly explain the key values and principles that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

Values

Comment: The values are generally supported but see also our above response re "purpose". Also consider adding a value related to *adaptability*, emphasising the need for researchers to be flexible in their approaches to effectively engaging diverse consumer groups. We also suggest strengthening the existing values to include consideration of consumer input and enablement in research.

Principles of Consumer and Community Involvement

- **Principle 1: Involvement at All Stages**

Comment: This principle appropriately emphasises the importance of involving consumers. However, it could be further strengthened as follows, by:

  - including the concept of co-design, encouraging research that is consumer-led. [See for example: Chauhan, A., Leefe, J., Shé, É. N., & Harrison, R. (2021). Optimising co-design with ethnic minority consumers. *International journal for equity in health*, *20*(1), 240.]
  - acknowledging responsibility towards co-design with specific cultural groups; and/or
  - including a specific statement about co-design with Aboriginal and Torres Strait Islanders. [See for example: Tamwoy, N., Rosas, S., Davis, S., Farthing, A., Houghton, C., Johnston, H., ... & Bat, M. (2022). Co-design with Aboriginal and Torres Strait Islander communities: a journey. *Australian Journal of Rural Health*, *30*(6), 816-822; or Anderson, K., Gall, A., Butler, T., Ngampromwongse, K., Hector, D., Turnbull, S., ... & Garvey, G. (2022). Development of key principles and best practices for co-design in health with First Nations Australians. *International journal of environmental research and public health*, *20*(1), 147; or Gerrard, J., Godwin, S., Whiteley, K., Charles, J., Sadler, S., & Chuter, V. (2025). Co-design in healthcare with and for First Nations Peoples of the land now known as Australia: a narrative review. *International Journal for Equity in Health*, *24*(1), 2.]

- **Principle 2: Mutual respect**

Comment:

  - Highlight the notion that consumers' lived experiences are a valuable contribution to research. Recognition of lived experience can empower consumers and communities to engage with research and, when suitably considered provide valuable insights in the research process.
  - Clearly define terms such as 'engagement' and "mutual respect" and highlight the benefits to consumers and the community in moving from involvement to engagement – as it adds breadth and depth to research/outcomes.
  - Include the importance of authentic relationships as a foundation in research. [See for example: Bull, J. R. (2010). Research with Aboriginal peoples: Authentic relationships as a precursor to ethical research. Journal of Empirical Research on Human Research Ethics, 5(4), 13-22; or Sherriff, S. L., Miller, H., Tong, A., Williamson, A., Muthayya, S., Redman, S., ... & Haynes, A. (2019). Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study. Evidence & Policy, 15(3), 371-392.]

Strengthening the above aspects of consumer and community involvement positively impacts the capacity of consumers and carers to have a voice in health research for policy, planning and evaluation purposes - to the benefit of all involved. It can also bring a richness to research and health system approaches that may otherwise be lacking. For example, lived experience leaders have been pivotal in person-centred care, recovery and harm reduction movements. It is important to capture these views in research.

- **Principle 3: Working in partnership for mutual benefit**

Comment: Provide guidance on what constitutes effective partnerships, including expectations for communication, and roles/responsibilities of each party. This clarity can help prevent misunderstandings. Greater explanation of the mutual benefit is also needed. For example, it would be helpful if there were explanation and discussion about how the proposed research benefits the consumer or community involved. Partnership also requires enabling people to 'be at the table' through research funding models – see also response to "Funding and capacity building".

- **Principle 4: Equitable Inclusion**

Comment: This principle highlights the importance of diversity, which is essential for capturing a wide range of perspectives. It would be helpful here to provide some examples of how people might be 'diverse', such as race, ethnicity, culture, cultural heritage, preferred language, religion and the like. Equitable inclusion should also include - and refer to - use of professional interpreters where relevant.

- **Principle 5: Transparency, accountability, and integrity in the conduct of research involving consumers and communities**

Comment: Emphasise the importance of openness and transparency in research as crucial for building trust among consumers and communities.

- **Principle 6: Safety of Consumers and Communities**

Comment: We suggest that this principle elaborates on what specific safety measures should be implemented. Safety can be quite diverse – from clinical safety, to training in cultural competence for researchers and/or the development of supportive environments for participation.

Roles and Responsibilities for Consumer and Community Involvement

Many of the roles and responsibilities are shared between consumers, communities, consumer organisations, researchers, institutions, and funders, with different individuals and groups responsible for different aspects. Table 1 of the Statement outlines how these responsibilities can be shared.

- Does the Statement clearly explain the **shared roles and responsibilities** of all involved to ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

Comment: The emphasis on shared responsibilities is important for fostering collaboration. It would be helpful to provide specific examples of how responsibilities might vary across different types of research (e.g., clinical trials vs. public health research).

- Does the Statement clearly explain the roles and responsibilities of **consumers, communities, and consumer organisations** that ensure effective consumer and community involvement?

  Yes ☐
  No ☐

  Would you like to make further comments?

- Does the Statement clearly explain the roles and responsibilities of **Researchers** that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

Comment: The outlined roles are clear and comprehensive. Consider adding expectations for researchers to provide regular updates and feedback to consumers involved in the research, enhancing transparency and trust.

- Does the Statement clearly explain the roles and responsibilities of **Research Institutions** that ensure effective consumer and community involvement?

  Yes ☐
  No ☐

  Would you like to make further comments?

- Does the Statement clearly explain the roles and responsibilities of **Research Funders** that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

Comment: The statement recognises the need for funding to support consumer involvement, which is vital. We recommend that this also include recognition of the need for funding in the research development stages to support consumer involvement/engagement in research planning, proposal -writing and related activities.

Implementing the Statement

The 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. It instead creates a strong expectation of consumer and community involvement in all health and medical research and provides high-level guidance.

Implementation is the process of putting recommendations into practice. Supporting the effective implementation of consumer and community involvement may include things such as providing additional support or resources.

Responses to the questions below may be used to develop implementation guidance once the revised Statement is published.

- What else is needed to support the effective implementation of consumer and community involvement?

Comment: The overall framework sets a solid foundation for consumer involvement in research. The statement could benefit from a mechanism for ongoing evaluation of the principles and practices outlined, to ensure they remain relevant and effective in real-world applications. See PORLET & IRLET — Saskatchewan Centre for Patient-Oriented Research to assist reviewers and researchers to understand types of engagement.

Additional Comments

- Do you have any additional comments on the Statement?

Overall comment: There is room for the statement to include consumer involvement in research as a more normalised principle. However, in its current form, the statement on consumer and community involvement is a progressive step toward more inclusive health research. By incorporating specific examples, strategies, and mechanisms for evaluation, it can better guide researchers in implementing effective consumer engagement practices. This will ultimately enhance the relevance and impact of health research outcomes.