

Research and Innovation

11 June 2024

Consumer Statement Advisory Committee
National Health and Medical Research Council
16 Marcus Clarke St
Canberra ACT 2601

priorities@nhmrc.gov.au

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

The University of Queensland (UQ) welcomes the opportunity to provide input into the Review of the Statement on Consumer and Community Involvement in Health and Medical Research (the Statement). Across all disciplines, UQ is one of Australia's top research-intensive universities, consistently ranking in the top-50 global universities year-on-year. UQ has extensive expertise in the Health and Medical fields of research across our Schools, Research Centres, Institutes, and Faculties. The University leverages the experience of over 5000 researchers and clinicians at hospitals, clinics, and institutes across Queensland to find solutions to global challenges to human health.

The University recognises the importance of consumer and community involvement in research and values the knowledge and ideas that people with lived experience of diverse cultural, environmental, and socio-economic backgrounds can bring to the research endeavour. The University's key contributions to health and medical research, such as the Gardasil vaccine for cervical cancer, could not have been achieved without the key involvement of consumers and community representatives who actively engaged with the University as part of this landmark research.

As a leading Australian health and medical research institution, we offer the following comments in response to the review of the Statement. We make specific reference to the "roles and responsibilities-related" items outlined in the consultation paper.

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

UQ is committed to embedding consumer and community involvement (CCI) in our research enterprise. This is consistent with our mission *to deliver for the public good through excellence in education, research, and engagement with our communities and partners* (UQ Strategic Plan 2022-2025). This is also aligned with the trajectory of funding requirements, which increasingly require the active involvement of consumers in research. Additionally, we recognise that there is a significant role for research institutions to play in enabling best-practice in CCI.

Research institutions must ensure that consumer and community members working with health research teams are effectively supported. They should also advocate for the inclusion of consumer and community perspectives in all stages of the research process. To advocate for CCI and to support consumers and community members, research institutions have responsibility for:

- building trust and strengthening partnerships between consumers and researchers;
- enhancing capability and capacity for researchers to undertake effective, fit-for-purpose engagement with consumers and community organisations;
- empowering and facilitating consumers and community organisations to meaningfully engage in and co-design research projects; and
- facilitating open communication and networking between researchers and consumer/community members.

Research institutions must also provide appropriate governance structures that incorporate the principles, values, and elements for effective consumer involvement in research. This may include establishment of advisory groups, policies, and resources to support researchers. Institutions should also present clear processes for researchers with respect to appropriate remuneration for consumer and community involvement in research.

If these institutional responsibilities are fulfilled, this will support researchers to offer the necessary supports to consumers including orientation, capacity building, access to resources, psychological support, and onboarding processes. Researchers will also have an appropriate framework to acknowledge and appropriately remunerate the contributions of consumer and community members, and provide recognition and appreciation for their time, effort, and expertise.

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

Research funders have a crucial role in supporting consumer and community members, as well as health research teams, to ensure best-practice CCI. To facilitate this, research funders should provide support through governance, guidance, and funding mechanisms.

Governance responsibilities for research funders would include:

- governance structures that incorporate the principles, values, and elements for effective consumer involvement;
- relevant definitions regarding different types of CCI, including guidance on consumer researchers as chief investigators and/or associate investigators; and
- guidelines on standard remuneration rates for consumer involvement activities.

Guidance for research institutions and researchers would support best-practice, including through:

- training to enhance the capacity of researchers and consumer and community members;
- mechanisms for collecting feedback from consumer and community members about their experiences participating in research projects and, in turn, evaluation and use of this feedback to continuously improve funding policies and support mechanisms;
- clear direction regarding ethical considerations to be made by researchers and ethics committees when involving consumer and community members;
- support for initiatives aimed at building sustainable partnerships between researchers and consumer and community organisations, ensuring that these collaborations can continue beyond the duration of individual research projects;

- recognising that accountability to be active in the knowledge translation activity is charged to both the researchers and the community/consumers in order to ensure that benefits and knowledge exchange pathways are identified;
- recognition programs, ensuring that researchers and the contributions of consumer and community members are appropriately appreciated and acknowledged; and
- advice, including case studies, with respect to how to formulate a budget for CCI in accordance with the recommended NHMRC rates.

Funding for programs to accommodate reasonable CCI expenses would include support for:

- open access publications;
- pre-grant involvement of consumers; and
- consumer involvement in knowledge dissemination and/or translation activities, such as conference registration/expenses/travel, for example.

Research funders such as the NHMRC may also wish to consider mechanisms that enable CCI representatives to better engage with research projects to ensure appropriate equity and responsibility into the funded research. Many CCI representatives are not affiliated with a participating institution. As such, when brought into a funding agreement, they are personally responsible to meet all obligations under the agreement, including liabilities if deemed to be in default. This can lead to significant complexity in the contracting of CCI groups into research projects. The University requests that the NHMRC gives contracting arrangements due consideration as they work to revise and implement the Statement, and we would be happy to provide more detailed commentary in relation to this should that be productive.

Thank you again for the opportunity to comment on the Statement. We look forward to engaging with any further consultation opportunities.

Yours sincerely,



Professor Mark Blows
Deputy Vice-Chancellor (Research and Innovation)