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

Response By Deakin University's Faculty of Health to the Draft Statement

Thank you for the opportunity to respond to the questions regarding the Draft Statement. This submission builds on Deakin University's 2024 contribution and reflects our ongoing belief in, and commitment to, meaningful engagement as a catalyst for transformational change in the health and wellbeing of our communities. We remain dedicated to advancing health and medical research that delivers real impact through genuine collaboration.

It is essential that the final Statement reflects this rapidly evolving field. We note the acknowledgement of the shifting language and the term consumer and community involvement. Our preference is for the use of the terms lived experience or lived expertise and community engagement. We appreciate the challenges in ensuring policy that is flexible and addresses the needs of a wide range of people and perspectives. However, as it stands, some sentiments do not align with best-practice, strengths-based engagement principles, and there is a risk that the Statement may not keep pace with contemporary practice by the time it is published.

To truly drive practice change, the Statement must be brought to life through meaningful action, not just intent. Currently, the responsibility falls too heavily on individual researchers, institutions, and community members, while significant structural, policy, and practice barriers remain unaddressed.

Key priorities for strengthening the Statement:

- A unified approach across funding agencies, standards, and research guidelines.
- Systems, policies, and practices that enable meaningful involvement—including fair and consistent remuneration practices, flexible ethics processes, and recognition of the time, effort, and resources required.
- Funding reform to support genuine engagement.
- Recognition and prevention of tokenism, with support for innovative ways of working.
- Investment in training, support systems, and funding mechanisms that empower all stakeholders and drive real change.
- Commitment to joined-up approaches that minimise duplication and maximise impact.
- Embracing this exciting, emerging field with a focus on continuous improvement and contemporary best practice.

Expectations of Consumer and Community Involvement in health and medical research

While the Statement sets high expectations for consumer and community involvement, it stops short of mandating it—despite strong stakeholder support for a mandate. The NHMRC funding guidelines have already moved toward requiring consumer involvement as a condition of funding. To ensure consistency and clarity, it is recommended that the Statement be aligned with NHMRC guidelines, adopting a uniform approach to consumer and community involvement across the sector.

The introductory paragraphs on terminology and NHMRC grant involvement help set the tone for the Statement. However, the current wording does not fully capture the ongoing progress and the need for deeper integration of lived expertise. While there is positive language about inclusion at all levels, the Statement could more strongly articulate the importance of true co-design and translation, where lived experience is genuinely embedded in scientific discovery. This is more clearly expressed in the Roles and Responsibilities of Consumers section.

Key recommendations for strengthening the Statement:

- Mandate consumer and community involvement, in line with NHMRC funding requirements.
- Ensure consistent expectations and language across all research guidelines and funding bodies.
- Emphasise the need for genuine co-design and translation, not just inclusion.
- Clearly articulate the value of integrating lived expertise throughout the research process.
- Build on the strengths of the Roles and Responsibilities of Consumers section to drive best practice.

Values and Principles of Consumer and Community Involvement

The values

The values outlined in the Statement are fundamental to effective consumer and community involvement. However, including a brief description of each value would enhance their clarity, relevance, and practical application. For example, concepts like mutual benefit or, alternatively, reciprocity would benefit from clearer definitions—especially in contexts such as basic science research, where consumer benefit may not be immediately visible.

We also recommend adding authenticity as a core value to emphasise the importance of genuine, transparent, and meaningful engagement throughout the research process. This is critical to avoiding tokenistic approaches that undermine the effectiveness and impact of consumer and community involvement.

Key suggestions for strengthening the Statement's values:

- Provide concise descriptions for each value to clarify intent and application.
- Clearly define concepts such as mutual benefit and reciprocity, particularly for research areas where the value of consumer and community involvement is less understood.
- Include authenticity as a value to reinforce the need for genuine and transparent engagement.
- Highlight the importance of avoiding tokenism and ensuring all engagement is meaningful and effective.

The principles

The wording of some of the principles runs counter to the Statement encouraging best practice approaches or true partnering. It is important that the onus of responsibility is shared by all and that language is carefully selected throughout the document so as not to inadvertently endorse tokenistic approaches or e.g. the term 'relevant consumers and communities' in Principle 1 and 'most appropriate consumers' on page 6 in the roles and responsibilities section can promote practice that is at the expense of inclusive approaches with people who are rarely engaged.

There is a lack of clarity as to how the Values and Principles intersect. We suggest mapping each value to a corresponding principle to demonstrate how all values are operationalised. Currently, only some values (e.g., **respect, diversity, accountability**) are bolded within the principles, while others like **openness** - which is not listed as a value – are inconsistently highlighted.

Principle 2: Mutual respect

It is essential that the concept of 'expertise' is explicitly recognised in this principle—not just as skills and experience, but inclusive of expertise derived from lived and learned experience. Meaningful practice is only possible when the unique expertise of people with lived experience is valued equally with the expertise of other members of the research team. Without this, research risks being shaped by unchallenged biases and assumptions, limiting its effectiveness and impact.

To truly embody mutual respect, this principle should also acknowledge the need for new ways of working and genuine sharing of power. This shift is critical to fostering authentic partnerships and ensuring that research is both relevant and impactful.

Principle 3: Working in partnership for mutual benefit: This principle could be strengthened by acknowledging that this work is deeply human, relational and grounded in trust. That this takes time to build and needs to be appropriately resourced to be sustained.

Principle 4: Equitable inclusion of diverse consumers and communities
The Statement should clarify that diversity in consumer and community involvement must be tailored to the stage, size, and objectives of each study and the desires and availability of the affected or interested communities. Contextualising diversity efforts ensures that involvement is both practical and impactful, rather than a one-size-fits-all approach.

Greater emphasis is also needed on accessibility responsibilities, particularly digital access for rural and remote communities, older Australians, and people with hearing or vision impairments. Specific strategies to support culturally and racially marginalised groups should be framed as essential, not optional.

The term ‘hard-to-reach’ is not strengths-based and shifts responsibility away from research systems and onto consumers and communities. Instead, the onus should be on funders, institutions, and researchers to build skills and evolve practices to enable safe, trauma-informed, equitable, inclusive research. Training and skill development for researchers are critical to achieving this.

Some key points for principle 4:

- Make culturally safe, trauma-informed engagement with marginalised groups a core requirement, not an optional strategy.
- Replace ‘hard-to-reach’ with language that celebrates diversity, recognises systemic barriers and rewards diverse and progressive methodologies.
- Place responsibility for inclusive research on funders, institutions, and researchers—not communities.
- Prioritise training and skill development for researchers to support equitable and accessible engagement.

Principle 5: Transparency, Accountability, and Integrity in Research Involving Consumers and Communities
All research should meaningfully involve consumers and communities, with roles and methods tailored to the specific context and research questions. Research and funding priority setting processes that are undertaken in genuine partnership with communities and people with lived experience will help ensure resources are directed toward solutions that matter the most and contribute to reducing waste.

Terms like ‘co-design’ are often used without true enactment e.g. where consultation is misrepresented as co-design. To reduce tokenism, it is critical to establish consistent approaches and clear definitions of participation levels and methods. True co-design must be understood, adequately resourced, and implemented with fidelity to harness the full value of participatory methods and avoid perpetuating tokenistic practices.

Key recommendations for strengthening Principle 5:

- Ensure consumer and community involvement is tailored to the context and research questions.
- Prioritise consumers as partners in informing research and funding priorities.
- Provide clear definitions and expectations for terms like ‘co-design’ to prevent tokenism.
- Establish consistent standards for participation and transparency in reporting involvement.
- Resource and support true co-design, recognising the time, effort, and expertise required for meaningful engagement.

Principle 6: Safety of consumers and communities:
The concept of “safety” in research remains too broadly defined. True safety encompasses physical, psychological, cultural, and data/privacy dimensions—each requiring distinct approaches.

The idea of creating “safe enough” spaces for engagement is important, recognising that meaningful participation can be disruptive and that all parties—researchers, community members, and people with lived experience—must feel safe, heard, valued, and respected. Building trusted relationships is essential for effective collaboration and for enabling all voices to contribute equally to the research process.

Additionally, the principle should more strongly articulate the importance of consistent approaches to fair remuneration. Recognising and compensating consumers for their time, expertise, and contributions is a critical component of respectful and equitable involvement. Clear guidance on remuneration practices would help standardise expectations and reinforce the value of consumer involvement across the sector.

Some key points for Principle 6:

- Clearly define safety to include physical, psychological, cultural, and data/privacy aspects.
- Emphasise the creation of “safe enough” spaces that support open, respectful, and equal participation.
- Highlight the importance of building trusted relationships where all voices are genuinely valued.
- Make explicit the need for fair and consistent remuneration for consumers’ time and expertise.
- Provide clear guidance on remuneration practices to ensure consistency and equity across research settings.

Roles and Responsibilities for Consumer and Community Involvement

Rather than creating a separate section for **shared roles and responsibilities**, we suggest it may be more effective to emphasise that successful consumer and community involvement relies on each party – consumers, researchers, institutions and funders – fulfilling their respective roles and responsibilities. This approach reinforces accountability while recognising the interdependence of all involved in achieving effective involvement.

The roles and responsibilities of consumers, communities, and consumer organisations

The opening paragraph could be strengthened to reflect that consumers, communities and consumer organisations should be involved and included in the setting of research and funding priorities.

Consumers are not a homogenous group. While it's important for community members and people with lived experience to be partners in research, it's equally important to acknowledge the limitations of having one or a few speak on behalf of many. Strengthening community connections could more authentically support a "wider community perspective" by enabling more diverse consumer involvement. If the expectation is that a person is representing a wider set of experiences and perspectives, then this needs to be actively resourced and enabled in order to be meaningfully applied in practice.

The roles and responsibilities of researchers
In addition to the existing expectations outlined in the Statement, we believe that researchers also have a responsibility to proactively seek out opportunities to build and continuously improve their skills in consumer and community involvement. This may include engaging in mentoring relationships, participating in training programs or contributing to communities of practice. This commitment to ongoing learning is essential to ensuring best practice and fostering effective consumer and community involvement throughout the research process.

The roles and responsibilities of Research Institutions
To strengthen the impact of the Statement, we recommend further clarity and emphasis on the following areas within the roles and responsibilities of research institutions:

- **Policies and Procedures:** Move beyond a narrow focus on complaint handling by establishing robust consumer feedback systems. Complaint handling should be one element within a broader framework for continuous improvement, which also addresses ethics processes and ensures consistent, transparent remuneration policies.
- **Institutional Culture:** Demonstrate a strong commitment to measuring, reporting, and sharing best practice examples of consumer and community involvement. Foster a culture of learning, transparency, and continuous improvement at every level of the institution.
- **Enabling Systems and Processes:** Recognise consumer and community involvement as a core research enabler that must be adequately resourced. This includes providing recruitment support, clear practice guidance, coordinated onboarding, training, peer support, and learning opportunities. Embedding evaluation and continuous quality improvement is essential to highlight effective engagement and drive ongoing improvement, while also reducing barriers, duplication, and limited reach.

The roles and responsibilities of Research Funders
To strengthen the Statement, we recommend further clarity and emphasis on the critical role research funders play in enabling meaningful consumer and community involvement:

- **Application and Budgeting Requirements:** Ensure grant application templates include targeted questions on consumer and community involvement, alongside a dedicated budget line to support these activities.
- **Enabling Policies and Practices:** Funding rules must not create barriers to best practice. For example, consumers listed as Associate Investigators should remain eligible for payment. Clear, enabling policies, templates, and guidance are essential to support meaningful engagement.
- **Inclusive and Skilled Peer Review:** Equip grant reviewers with training to assess the quality and impact of consumer involvement. Ensure consumers and community members are equal and active participants in all stages of the grant review process.
- **Supportive Funding Cycles:** Re-evaluate funding timelines and processes to allow for genuine engagement throughout the research lifecycle, rather than limiting involvement to early or late stages.
- **Capacity Building and Sector Leadership:** Funders should champion consumer engagement by offering training, resources, and best practice examples—such as webinars tailored to specific grant schemes.
- **Remuneration and Recognition:** While consumer involvement is listed in Table 1, it should also be explicitly included in this section. Clear guidance on remuneration is vital to ensure consistency and reinforce the value of lived expertise.
- **Avoiding Burnout and Tokenism:** Recognise the resource limitations of lived experience groups, particularly in targeted calls (e.g. rare diseases) or where there is an expectation of engagement with culturally and racially marginalised communities and people. Funders must avoid placing undue burden on individuals and ensure engagement is meaningful, not tokenistic.
- **Consistency Across Peer Review:** Embed consumer and community involvement as a consistent criterion across all stages of the peer review process to drive sector-wide change.

Implementing the Statement

While the Statement is intentionally high-level to accommodate the breadth of health and medical research, this limits its practical application. A tiered structure—similar to research reporting frameworks like CONSORT—could enhance usability. A concise overview supported by a detailed, practical guide would help translate principles into consistent, actionable practice.

The Statement calls for “continuous improvement” and “monitoring and evaluation,” yet lacks benchmarks, indicators, or criteria to assess whether consumer involvement is meaningful or tokenistic. Without these, implementation risks inconsistency and limited impact.

Concerns remain around the adequacy of funding—particularly from NHMRC—to support effective implementation. This creates inequities, where some researchers benefit from established consumer networks while others lack access or support. Additionally, there is limited space for reflection and learning to improve both research outcomes and the experience of contributors. Feedback mechanisms are needed to evaluate performance and identify areas for improvement.

We strongly endorse the development of practical supports and unified approaches that bring the principles to life. Clear guidance, tools, and resources are essential to drive consistent implementation, elevate practice, and ensure that consumer and community involvement is embedded meaningfully across the health and medical research sector.

Additional Comments

Both the MRFF and the NHMRC have developed a set of principles for consumer involvement in research. Establishing a single, unified set of principles would promote consistency, reduce duplication and strengthen national alignment in consumer and community involvement practices.

It is noted that discussions about the continued use of the term consumer are ongoing. Some consumers we heard from said they don’t like the term consumer and suggest that it underplays their role. The definition of consumer may also be is too focused on healthcare and treatment rather than prevention. Research advocate has been suggested as one suitable alternative.

Glossary: The Statement uses "engagement," "involvement," and "participation" throughout but the glossary definitions don't align with actual usage in the text. For example, the glossary defines engagement as one-way information sharing, yet the principles frequently use "engagement" when describing two-way involvement activities.

When we have used the term engagement in this submission, we are using it as an umbrella term reflecting a range of ways in which people share their views and expertise to inform, create and lead change. This may be through different methods and at different levels e.g. consultation, participation, collaboration, partnership and leadership.