Draft Statement on Consumer and Community Involvement in Health and Medical Research – Response to Public Consultation

Research Australia is pleased to have the opportunity to respond to the survey on the National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia's (CHF) draft revised Statement on Consumer and Community Involvement in Health and Medical Research (the Statement).

Our response to the survey follows Research Australia's previous response to the 2024 consultation and attendance at the ACT Health and Medical Research Roundtable on 12 August 2025.

About Research Australia

Setup by government following a landmark review in 2000, Research Australia is the national peak body for the health and medical research and innovation sector. Our membership is drawn from the whole pipeline of health and medical research and innovation, from universities and medical research institutes to charities and patient groups, and health care providers and companies commercialising new health technologies. Our priorities include a whole of systems approach to health and medical research and innovation, smarter investment, workforce and advancing prevention. Underpinning these priorities are equitable health outcomes; collaboration; AI and digital health, data and data linkage.

Research Australia offers the following insights and recommendations, drawing upon our expertise and previous work as the collective voice of the health and medical research, development and innovation ecosystem, to inform the Statement.

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

No. While the Statement sets "high expectations" for consumer and community involvement to become a "routine and integral part of every level, stage, and type of health and medical research", Research Australia argues that this is no longer sufficient. Research Australia believe that the 2016 Statement successfully created an expectation of involvement but now needs to shift from a 'would be nice to do' narrative to a 'standard requirement'. We need to enable consumers, community and those with lived experience to be integrated throughout the research pipeline and cycle because it leads to better research and ultimately to better health outcomes.

We advocate for an 'if not, why not?' approach, placing an obligation on the research funder, institution, or researcher to explain any non-involvement in a specific scheme or project. Research Australia emphasises that consumer and community involvement is not just valuable but also an ethical imperative, drawing on the obligations to consumers set out in the National Statement on Ethical Conduct in Human Research: '*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)

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

Partially. Research Australia previously proposed that “Integrity" and "Respect for others and their views, opinions and beliefs" are essential overarching values for all participants in health and medical research. Research Australia recommends that concepts such as accountability, transparency, partnership, equity, diversity, and inclusion are better characterised as principles rather than values.

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

Partially. The Statement outlines several shared roles, including compliance, monitoring and evaluation, planning and conducting research, research governance, resourcing, networking, recruitment, and capacity building. Research Australia submit that the role of the NHMRC and ethics committees should be included and clarified throughout the Statement.

4. Does the Statement clearly explain the roles and responsibilities of Consumers, Communities and Consumer Organisations that ensure effective consumer and community involvement?

Partially. Research Australia recognise that the roles of Consumers, Communities and Consumer Organisations will vary depending on their own experience and expertise, the nature of the research and the stage at which they are involved. We submit that Consumers, Communities and Consumer Organisations should play a role in recognising and articulating the scope of their own lived experience, where it informs their contribution and where it is not relevant i.e. recognising the 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, which is noted in point 2 of the Statement’s roles and responsibilities for this group. Research Australia also strongly advocates for the Statement to explicitly include the rights of consumer and community representatives.

We reiterate that we must shift from a ‘would be nice to do’ narrative for consumer and community involvement in HMR to making it a ‘standard requirement’, recognising that consumers are essential for sharpening the relevance of research and guiding better care. The Statement therefore must ensure the roles and responsibilities of Consumers, Communities and Consumer Organisations enable and clearly promote genuine partnership with lived experience which guarantees voices are respected, valued and amplified.

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

Partially. Research Australia believes that the existing roles and responsibilities for researchers in the Statement are relevant and should be retained. In addition, Research Australia suggest the Statement should also explicitly articulate the researcher's role to facilitate and support consumer and community engagement, and to support individual consumer and community representatives to participate fully. This includes planning for involvement before research commences, allocating budget and time, and treating consumers and communities as valued team members by acknowledging contributions and offering recognition including remuneration, as picked up in point 2 of the Statement. Furthermore, where consumer and community involvement has not taken place, the researcher should also have a joint responsibility with the research institution to report or explain non-involvement in a specific scheme or project.

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

Partially. Research Australia welcomes the Statement's inclusion of the shared role of research institutions in organising and funding training based around combined professional development and cultural competency and sensitivity training. However, this needs to be expanded to include professional development and capacity building in addition to First Nations communities, including people with disability, gender diverse people, those who identify as LGBTQI+, and children and young people, to name a few. A focus on intersectional discrimination in research, as well as health services and access to health equitable outcomes should also form part of the training.

This is crucial to allow researchers to effectively engage consumers and community members in research. Alongside the roles and responsibilities listed relating to policies and procedures on recruitment, remuneration and complaint handling, institutions should build organisational capacity through the creation of templates for ethics applications that include consumer remuneration and provision of budget planning tools. Furthermore, where consumer and community involvement has not taken place, research institutions should also have a joint responsibility with researchers to report or explain non-involvement in a specific scheme or project.

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

Partially. Research Australia stresses research funders must recognise that effective engagement of consumers and community members in research requires time and resources, and adequate funding. Funders should also commit to assessing the quality and extent of consumer and community participation in research proposals as part of their assessment and wider monitoring and evaluation. We strongly advocate for funders to mandate consumer and community involvement using the 'if not, why not?' approach. Furthermore, funders have a crucial role in explicitly including budget allocations for consumer remuneration in research grants, particularly for major bodies like the NHMRC and MRFF.

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

National Recognition Framework

Research Australia recently partnered with the National Centre for Epidemiology and Population Health at the Australian National University with the aim to co-design a national recognition framework (including remuneration) for recognising consumer contributions in health research. The co-designed recognition framework is the first of its kind in Australia. It offers practical tools, guiding questions, and flexible options that can be adopted by research organisations. The framework supports inclusive, transparent, and sustainable engagement, and aligns with both national priorities and international best practice.

The core elements of the framework, including:

- Payment rates: Consensus on AUD $50 per hour for participation in research and AUD $40-50 per hour for collaboration roles.
- Payment methods: Gift cards favoured for convenience and tax implications, with flexibility for consumer choice essential.
- Reimbursement: Universal agreement that all out-of-pocket expenses should be covered, with upfront clarity about coverage.
- Non-financial recognition: Strong value placed on co-authorship, conference presentations, skills development, and additional approaches including referrals and mentorship

The project produced seven overarching recommendations to support national implementation:

- Recognise consumer expertise as a valued contribution to research.
- Establish national guidelines outlining financial and non-financial recognition practices.
- Promote national consistency through shared standards and regular review.
- Encourage funding bodies to allocate dedicated remuneration budgets.
- Support organisational capacity with toolkits, policies, and training.
- Streamline payment processes to reduce administrative burden.
- Advance equity by removing barriers for underrepresented groups.

This report has been submitted separately.

Warm regards,

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Australia

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