Australian Multicultural Health Collaborative

LA TROBE UNIVERSITY

Our cultures
Our languages
Our health

NHMRC Statement on Consumer and Community Involvement in Health and Medical Research

Joint submission by the Australian Multicultural Health Collaborative and La Trobe University

September 2025

About the Collaborative

The Australian Multicultural Health Collaborative (the Collaborative) is the national multicultural health peak body. An initiative of Federation of Ethnic Community Councils Australia, The Australian Multicultural Health Collaborative (the Collaborative) is committed to addressing the health and wellbeing needs of Australia's multicultural communities. Representing a broad coalition of multicultural health consumers, carers, advocates, health services, practitioners, researchers, and organisations, we advocate for equitable healthcare and ensure that the voices of multicultural communities are heard at the highest levels of policy-making, striving to create a more inclusive and culturally responsive health system across Australia.

La Trobe University

Our vision is for La Trobe to be a leader in health, science and education, driven by technology. As a university, we remain focused on achieving impact through research, education and community engagement. We will stay true to our founding mission to expand the lifechanging opportunities afforded by higher education to under-served communities. We are proud that today over 40% of our students are the first in their family to go to university. We are ranked in the top 1% of universities in the world and will stay focused on academic excellence.

Previous Work of the Leads at La Trobe and the Collaborative

Lead for La Trobe

Professor Bianca Brijnath is a Professor of Health Communication in Society at La Trobe University. Her disciplinary training is in medical anthropology and public health and her research expertise is in cultural diversity, dementia, and mental health. Within these disciplinary and contextual boundaries, she has undertaken several studies on dementia prevention, awareness, diagnosis and care, specific to culturally diverse communities in Australia and internationally. She has authored over 150 publications, has produced >70 multilingual films, comics and animations, and generated >$26 million in research income. In recognition of her research, she was inducted into the State Government of Victoria’s Multicultural Honour Roll in 2022.

Lead for The Collaborative

Priyanka Rai brings more than 15 years of experience across healthcare, advocacy, and non-profit leadership. She most recently served at Breakthrough T1D (formerly JDRF), leading global programs to improve healthcare access in underserved regions. Previously, at Painaustralia, she played a central role in developing the National Strategic Action Plan for Pain Management. Her tenure at Dementia Australia demonstrated her strong commitment to community-focused advocacy, where she contributed to national policy reform and led initiatives supporting individuals with complex neurodegenerative conditions. Priyanka holds a Master of Science in International Business and Management and a Bachelor of Business Management.

Introduction and Background

The Collaborative and La Trobe University welcome the opportunity to provide this joint submission to the review of the National Health and Medical Research Council (NHMRC) Statement on Consumer and Community Involvement in Health and Medical Research. Both organisations share a strong commitment to embedding the voices and experiences of Multicultural Australians in all stages of health and medical research - from governance and design through to implementation and translation of findings.

The Collaborative is the national peak body championing the health and wellbeing of Multicultural Australians. Since its establishment, the Collaborative has worked in partnership with government, researchers, service providers, and multicultural communities to highlight systemic barriers to equitable care, co-design culturally responsive solutions, and strengthen consumer voices in national health reform. La Trobe University brings deep expertise in health communication, cultural diversity, dementia, and mental health research, alongside a track record of working with multicultural communities in Australia and internationally. Together, our organisations provide both the community authority and academic rigour required to shape meaningful reforms in this space.

This submission builds on extensive work:

- The Collaborative's 2024-2025 consultations with its Carer, Consumer and Community Advisory Groups, sector leaders, and multicultural health organisations, which identified persistent challenges in data, equity, cultural competence, and systemic engagement.
- La Trobe University's research expertise and consultations with particular focus on dementia, ageing, and culturally diverse populations.
- Joint insights from national roundtables convened by the Department of Health and Aged Care, as well as targeted sector consultations, which have consistently highlighted the need for structural change to embed multicultural inclusion in health and medical research.

These collective efforts have underlined a consistent message: while there is goodwill across the health and research sectors to engage consumers, Multicultural Australians remain underrepresented as partners in research. Too often they are engaged only as participants, not as decision-makers. Without explicit requirements for inclusion, their needs and perspectives risk being marginalised, leading to inequities in evidence, policy, and practice.

By combining our voices in this joint submission, including in our survey responses below, The Collaborative and La Trobe University aim to ensure the revised Statement sets clear expectations, provides practical guidance, and establishes accountability mechanisms that will deliver genuine inclusion for Multicultural Australians across the research system.

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

1. Expectation of Consumer and Community Involvement

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

Response: Yes.

Comment: The Statement sets high expectations, but it should go further in explicitly recognising the need to involve Multicultural Australians as partners in all stages of research - governance, priority-setting, design, conduct, analysis, and translation. Too often, multicultural communities are engaged only as participants rather than decision-makers. Embedding partnership with multicultural communities as a requirement for grant applicants reflects Australia's reality, where more than half the population has a migration background. This will help ensure research outcomes are equitable, relevant, and beneficial to all Australians.

2. Values and Principles of Consumer and Community Involvement

Does the Statement clearly explain the key values and principles?

Response: Yes.

Comment: The values are strong, but should explicitly reflect multicultural realities. We recommend:

- Involvement: Require multicultural representation in governance and advisory roles, supported by training and remuneration.
- Mutual respect: Include cultural respect explicitly, recognising that multicultural communities bring distinct cultural perspectives and knowledge systems.
- Partnerships: Establish genuine, long-term partnerships with multicultural organisations and leaders, not tokenistic or project-based involvement.
- Equity: Link equity to resourcing (interpreters, bilingual facilitators, safe spaces).
- Transparency: Require results to be returned in culturally accessible formats (translations, forums, ethnic media).
- Safety: Recognise that multicultural communities may define safety differently (gender norms, family involvement) and require cultural safety training for researchers and institutions.

3. Roles and Responsibilities

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

Response: Yes.

Comment: Shared roles should emphasise power-sharing and resource equity. Multicultural involvement is meaningful only with dedicated funding (translation, liaison staff, support for multicultural community organisations) and recognition of their equal partnership in setting priorities and governance.

4. Roles and Responsibilities – Consumers, Communities, and Consumer Organisations

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

Response: Yes.

Comment: Multicultural communities should be recognised not only as participants but as co-creators of research. Consumer organisations representing multicultural communities must be explicitly acknowledged as partners bridging lived experience with research. Without structural representation and resourcing, communities risk being excluded.

5. Roles and Responsibilities – Researchers

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

Response: Yes.

Comment: Researchers must embed cultural competence at every stage, including:

- Undertaking cultural responsiveness training.
- Allocating budget/time for translation and accessible materials.
- Co-authoring dissemination with multicultural partners to avoid extractive practices.
- Acknowledging contributions from multicultural communities in outputs.

6. Roles and Responsibilities – Research Institutions

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

Response: Yes.

Comment: Institutions should normalise multicultural consumer involvement through:

- Diversity and equity benchmarks in governance and ethics processes.
- Policies on recruitment, remuneration, and safe engagement.
- Funded training for researchers and community members.

7. Roles and Responsibilities – Research Funders

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

Response: Yes.

Comment: Funders should:

- Require applicants to demonstrate engagement with multicultural communities.
- Provide targeted funds for inclusive practices (translation, multilingual engagement, partnerships).
- Ensure grant systems are accessible to people with low English or digital literacy. Current platforms (e.g. Sapphire) can be exclusionary.

8. Implementation

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

Response: Implementation requires dedicated infrastructure.

Comment: We recommend:

- A national roadmap with minimum standards for multicultural community inclusion.
- Practical guidance, case studies, and toolkits showing effective multicultural involvement.
- Accountability measures requiring reporting on multicultural engagement.
- Resourcing community organisations as equal partners.
- Training in cultural responsiveness for researchers and institutions.
- An evaluation framework to measure outcomes for multicultural communities.

Conclusion and Next Steps

The revised Statement is welcome and timely, but it risks remaining aspirational unless multicultural realities are explicitly embedded. With rapidly ageing multicultural populations and disproportionate burdens of chronic disease and dementia, equity cannot be optional.

The revised NHMRC Statement represents an important opportunity to set stronger expectations for consumer and community involvement across Australia's health and medical research system. For this Statement to have real impact, multicultural perspectives must be explicitly embedded throughout its principles, roles, responsibilities, and implementation framework.

Research projections show that by 2056, one-third of older Australians will be from non-English speaking backgrounds, with dementia prevalence increasing by 67% in these communities compared to 58% among the Australian-born. Without structural reform in data collection, training, funding, and accountability, multicultural Australians will continue to face exclusion.

The Collaborative and La Trobe University stand ready to support NHMRC and Consumers Health Forum (CHF) in this task. Together, we bring:

- Community authority: The Collaborative's national networks of multicultural health organisations, consumer voices, and lived experience expertise.
- Research expertise: La Trobe's leadership in cultural diversity, health communication, dementia, and mental health, with a proven record of co-designing and evaluating culturally responsive research.
- Implementation insight: Practical lessons from national consultations, sector partnerships, and applied research that can inform workable tools, case studies, and evaluation frameworks.

We encourage NHMRC and CHF to treat multicultural inclusion not as an optional feature but as a core requirement of research excellence. This will ensure that the knowledge generated is relevant to all Australians and that the research system actively contributes to reducing, rather than entrenching, health inequities.

We welcome further dialogue with NHMRC and CHF and offer our expertise and networks to help shape practical guidance, build sector capability, and support implementation. With clear expectations, resourcing, and accountability, the revised Statement can become a cornerstone for a research system that is genuinely inclusive, equitable, and responsive to the needs of Australia's diverse communities.

Contacts for further information

Professor Bianca Brijnath School of Humanities and Social Sciences La Trobe University Melbourne, Australia	**Priyanka Rai** Executive Director Australian Multicultural Health Collaborative Canberra, ACT E: priyanka@multiculturalhealth.org.au

Australian
Multicultural
Health
Collaborative

Unit 1, Level 6, 54 Marcus Clarke Street
Canberra City, ACT 2601
t (02) 6282 5755
e admin@multiculturalhealth.org.au
s @cald_health
multiculturalhealth.org.au

FECCA

An initiative of The Federation of Ethnic
Communities' Councils of Australia