ACADEMY OF
THE SOCIAL SCIENCES
IN AUSTRALIA

DRAFT STATEMENT ON CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH AND MEDICAL RESEARCH: SURVEY

SUBMISSION FROM THE ACADEMY OF
THE SOCIAL SCIENCES IN AUSTRALIA

SEPTEMBER 2025

Submission to the Draft Statement on Consumer and Community Involvement in Health and Medical Research

The Academy of the Social Sciences in Australia (the Academy) is an independent, not-for-profit organisation that brings together the multidisciplinary expertise of our nation's leading thinkers to provide practical, evidence-based advice on important social issues facing society.

As the pre-eminent organisation in Australia representing excellence across the social science disciplines, we welcome the opportunity to respond to the Draft Statement on Consumer and Community Involvement in Health and Medical Research (the Statement).

To discuss any matters raised in this submission or our survey response, please contact Dr Honae Cuffe, Policy Director at honae.cuffeh@socialsciences.org.au.

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

The Academy of the Social Sciences in Australia supports the broad contours and intent of the Statement, which sets clear expectations that consumers and community will be involved in all stages of research and lays the foundations for involvement as a key feature of health and medical research. In terms of the suitability of the expectations that consumers and community will be involved in all stages of research, the Academy wishes to draw attention to the absence of Aboriginal and Torres Strait Islander peoples within the Statement.

The National Agreement on Closing the Gap requires systemic and structural transformation of mainstream government agencies and institutions to ensure they are accountable, outcomes-driven, and culturally safe and responsive to the needs of First Nations communities, including through the services and goods they deliver and the research they fund. There are clear implications for health and medical research, decision-making about the findings and data generated through community and consumer involvement, and how research is applied to practice. The current review of the Statement offers the National Health and Medical Research Council (NHMRC) an opportunity to set expectations and develop values, principles and processes that meaningfully involve First Nations communities – rather than treating this as a bolt-on – to transform Australia's research sector.

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

The values and principles themselves are clearly explained; however, we wish to draw attention to the major omission of considerations related to Aboriginal and Torres Strait Islander peoples. A genuinely effective, comprehensive foundation for involvement in research must provide specific clarification about how the values and principles relate to Aboriginal and Torres Strait

Islander peoples. The Academy acknowledges that NHMRC has developed relevant materials and guiding principles for researchers and participants involved in research, including *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders* and *Keeping Research on Track.* However, these principles and guidelines are not referred to, nor is consideration given to how they interact with the Statement. To ensure health and medical research is safe, respectful, inclusive and of benefit to Aboriginal and Torres Strait Islander people and communities, the Academy recommends that the Statement reference the Guidelines for Researchers and Stakeholders and Keeping Research on Track and provide specific clarification about how they interact.

Roles and Responsibilities for Consumer and Community Involvement

The Statement effectively explains the roles and responsibilities of consumers, communities, and consumer organisations. The communication of these roles and responsibilities could be enhanced by further detail and/or tangible examples of how consumers, communities, and consumer organisations will help prioritise, influence and shape research in practice. This is particularly relevant to Principle 3 and how research can be genuinely community-led and determined and how decision making will be shared. These details are critical to recognising lived experience perspective and ensuring consumers, communities, and consumer organisations feel empowered to participate.

The Statement clearly explains the roles and responsibilities of researchers for involving consumers and communities in a variety of ways across different stages in the research project, including data collection and translating findings into services and products. The communication of roles and responsibilities for researchers could be enhanced through specific considerations relating to the involvement of Aboriginal and Torres Strait Islander peoples, including access, use and sharing Indigenous data and traditional knowledge.

In the National Agreement on Closing the Gap Priority, government have committed to improving how they collect and use data about Aboriginal and Torres Strait Islander people and how they share data to enable communities to make informed decisions and serve self-determined purposes. This includes commitments to genuine involvement in how data is collected, used, reported and shared and decision-making that is responsive to the needs of the community, and ultimately leads to more meaningful outcomes across various aspects of life. Indigenous data governance is particularly important in terms of the commercialisation of research findings and the responsibility to safeguard Indigenous knowledge. We also suggest that the Statement make specific reference to intellectual protection, patent law, commercialisation as it relates to Indigenous knowledge.

We therefore recommend that the Statement give explicit consideration to Indigenous data governance. The CARE Principles for Indigenous data governance (Collective Benefit, Authority to Control, Responsibility, and Ethics) reflect the crucial role that data plays in advancing Indigenous innovation and self-determination. The CARE Principles offer a useful framework for recognising and empowering and Torres Strait Islander peoples to access and use their data in the context of health and medical research, and we encourage their inclusion as the Statement is revised and refined.

The Academy also notes that Guidelines for Researchers and Stakeholders and Keeping Research on Track pre-date the CARE Principles and the National Agreement on Closing the Gap and commitments to Indigenous data sovereignty. The Academy therefore also encourages NHMRC to review *Guidelines for Researchers and Stakeholders* and *Keeping Research on Track* in light of progress since towards Indigenous data sovereignty and protecting cultural and intellectual property.

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

Implementation in a way that is effective, inclusive and of benefit to consumers and communities will require guidance with specific clarification about how the Statement relates to Aboriginal and Torres Strait Islander peoples and research involving these communities. This includes guidance on how the Statement interacts with the *Guidelines for Researchers and Stakeholders* and *Keeping Research on Track* and considerations relating to demonstrating how research contributes value to Aboriginal and Torres Strait Islander peoples, shared decision-making processes, and data governance.