



Australian Government

National Health and Medical Research Council



Consumers Health  
Forum of Australia

# DRAFT



## DRAFT Statement on Consumer and Community Involvement in Health and Medical Research



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# Acknowledgements

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We acknowledge the sovereignty of Aboriginal and Torres Strait Islander Peoples as the Traditional Custodians of Country and pay respect to their Elders past, present and future. As Australia's first scientists, Aboriginal and Torres Strait Islander Peoples have practised community-centred approaches to health and knowledge for tens of thousands of years. Their approach shows how research can be safe, respectful, inclusive, and guided by communities.

We acknowledge all those involved in developing this revised *Statement on Consumer and Community Involvement in Health and Medical Research* (the Statement), including the Consumer Statement Advisory Committee (CSAC), the Australian Health Research Alliance (AHRA), the National Health and Medical Research Council (NHMRC)-Medical Research Future Fund (MRFF) Interim Consumer Advisory Network and the NHMRC-MRFF Consumer Advisory Group. We also acknowledge the consumers, carers, and communities who have shared their lived experiences and perspectives to advance health and medical research, and to develop this Statement. Their contributions are an integral part of research progress.

## Purpose

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The Australian Government through the NHMRC, alongside the Consumers Health Forum of Australia (CHF), recognises that involvement of consumers and communities brings significant benefit to health and medical research. Effective involvement aligns the research with consumer and community priorities and needs, making it more impactful.

Consumer and community involvement is not just a theoretical concept—it has practical, transformative outcomes. **Involvement** is sometimes used interchangeably with other terms like consumer and community **participation** or **engagement**. In this Statement, we consider consumer and community **involvement** to be research that is carried out with or by consumers and communities. Effective involvement of consumers and communities improves public trust in research and facilitates the translation of research findings into practice. The benefits of such involvement are clear: it strengthens the research process, makes it more responsive to the needs of the community, and ultimately leads to more effective and relevant health outcomes.

This Statement was developed through consultation with consumers, community members, researchers, research institutions, and research funders. Throughout public consultation, it was clear that the language about consumer involvement is evolving. The term *consumer* is used in this Statement as it remains widely used around Australia. Throughout the public consultation, stakeholders suggested alternative terms such as *people with lived experience*, *the public*, and *patients*. Discussions about the continued use of the term *consumer* are ongoing, and this Statement will be updated if a new term is adopted nationally.

Throughout public consultation, many stakeholders also expressed support for making consumer and community involvement a requirement to receive grant funding. While this Statement does not mandate consumer and community involvement, it sets high expectations. The goal is for consumer and community involvement to become a routine and integral part of every level, stage, and type of health and medical research. The Statement identifies the broad values, principles, roles, and responsibilities that enable this. Any changes to funding requirements will follow the publication of the final Statement, ensuring consumers and communities have a voice in all health and medical research.

# Values

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Our values are **respect, partnership, mutual benefit, equity, inclusion, diversity, transparency, accountability, integrity, and safety.**





# Principles of consumer and community involvement in health and medical research

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This section sets out the principles that are the foundation for effective consumer and community involvement. These principles expand on the values that are listed above.

## **Principle 1: Consumers and communities are involved in all stages, levels, and types of health and medical research**

Consumers and communities bring valuable skills, perspectives, and lived experience to the research process. Their involvement adds value to all aspects: early research planning, conducting the research, translating and communicating the results, evaluation of research, and peer review. There are benefits to involving relevant consumers and communities in research, and an ethical responsibility of researchers, institutions, and funders to do so.<sup>1,2</sup>

## **Principle 2: Mutual respect**

Consumers, communities, and researchers all bring valuable contributions to health and medical research.

**Respect for skills and knowledge** ensures that consumers, communities, and researchers are all treated fairly, their contributions are valued, and everyone works effectively as a team.

**Respect for the lived experience** of consumers and communities can include valuing their experience of living with or caring for someone with a medical condition, the perspective they bring as part of a community, or their life experiences.

## **Principle 3: Working in partnership for mutual benefit**

Shared decision making and understanding should underpin partnership at all levels. Partnerships can involve any combination of consumers, communities, consumer organisations, researchers, institutions, and funders.

Partnerships can occur at the level of an individual research project. A partnership could include all members of a research team, including consumers and communities, having a say in the planning and direction of research and understanding the role each member will play.

Partnerships can also occur in research more broadly. For example, researchers can partner with consumer organisations to recruit appropriate consumers to be involved in their research. Institutions and funders can partner with consumers, communities, and organisations to set priorities and govern research. Ultimately, the goal of these partnerships must be to improve research quality, relevance, translation, and impact, benefitting everyone involved.

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1. [The World Medical Association Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Participants](#)

2. [National Statement on Ethical Conduct in Human Research](#)

#### **Principle 4: Equitable inclusion of diverse consumers and communities**

Inclusion is about building relationships and trust with consumers or communities for whom the research is relevant. Specific strategies to reduce barriers to involvement may be needed for vulnerable or hard-to-reach communities. These can include accessible information formats, such as plain language documents, documents translated into other languages, and ensuring communities are aware of involvement opportunities. Consumers and communities must be provided with appropriate training, support, and remuneration so they can be involved **equitably**.

**Diversity** in research can mean involving consumers and communities from diverse populations. It can also mean ensuring that the consumers and communities involved in the research have a diverse range of perspectives and life experiences.

#### **Principle 5: Transparency, accountability and integrity in the conduct of research involving consumers and communities**

**Openness** in the conduct of research and how consumers and communities are involved is essential. To maintain trust, research outcomes must be reported to the public in a clear and accessible way, with consumers and communities informed of the research progress and involved in its translation. Researchers and institutions can demonstrate **accountability** through ethical conduct, responsible use of grant funding, and open communication throughout the research process.

#### **Principle 6: Safety of consumers and communities**

Consumers and communities may require accommodations and support so that they can safely and effectively contribute to research. Safety measures must reflect the diversity of the consumers and communities involved, and may include cultural safety, informed consent, and wellbeing support.

Addressing power imbalances in research ensures consumers, communities, and researchers can all participate in open and respectful dialogue. By creating an environment where consumers and communities feel valued and supported, researchers can ensure effective involvement and more impactful research.

# Roles and responsibilities

This section describes the key roles and responsibilities of consumers, communities, consumer organisations, researchers, institutions, and funders. Many of these roles and responsibilities are shared, with different individuals and groups responsible for different aspects (see Table 1).

**Table 1.** Shared roles and responsibilities for consumer and community involvement in research.

Shared role	Who is responsible?
Compliance	<b>All members of a research team must:</b> <ul style="list-style-type: none"><li>• comply with relevant policies, procedures, codes of conduct and confidentiality requirements</li><li>• be aware of and declare any biases and interests.</li></ul>
Monitoring and evaluation	<b>Researchers, institutions, and funders</b> have a responsibility to: <ul style="list-style-type: none"><li>• monitor, evaluate, and report on consumer and community involvement in research</li><li>• commit to continuous improvement.</li></ul>
Planning the research	<b>Consumers, communities, consumer organisations, and researchers</b> share in research ideation, design, and planning. <b>Researchers</b> are responsible for involving them in a variety of ways, including contributing to methodology, ethics approval, and designing the research question.
Conducting the research	<b>Consumers, communities, and consumer organisations partner with researchers</b> to undertake research. <b>Researchers</b> are responsible for involving them in a variety of ways, depending on the research project. These may include assisting with analysing and interpreting findings, data collection, producing accessible language documents, and translating the research outcomes into policy and practice.
Research governance	<b>Institutions and funders</b> are responsible for providing consumers and communities with a voice in research governance, such as ensuring consumer and community representation on boards and advisory committees.



<b>Resourcing, networking and recruitment</b>	<p><b>Researchers and their institutions network with consumers, communities and consumer organisations</b> to involve the most appropriate consumers and communities in their research and to build long-term partnerships.</p> <p><b>Institutions and funders</b> ensure adequate resourcing and funding for effective consumer and community involvement.</p>
<b>Capacity building, training and championing</b>	<p><b>Consumers and communities</b> can act as champions through promoting consumer and community involvement in research and mentoring others.</p> <p><b>Consumer organisations</b> can champion and advocate for consumer and community involvement in particular areas of health research.</p> <p><b>Researchers</b> can be appointed by their institutions to champion consumer and community involvement in research. They may mentor and train consumers, community members, and other researchers as part of this role.</p> <p><b>Research institutions</b> organise and fund training for consumers, communities and researchers, including:</p> <ul style="list-style-type: none"> <li>• combined professional development where consumers, communities and researchers share knowledge and learn from each other</li> <li>• cultural competency and sensitivity training when the research impacts diverse or vulnerable populations.</li> </ul> <p><b>Research funders</b> can provide specific grants for training and capacity building of consumers, communities and researchers.</p>

## Roles and responsibilities of consumers, communities, and consumer organisations

Consumers, communities, and consumer organisations can be **involved in all levels, stages, and types** of health and medical research. Ideally, their involvement will start at the planning stage and continue throughout the research cycle. In addition to their shared roles and responsibilities, consumers, communities, and consumer organisations are responsible for:

- Bringing a **lived experience perspective** to help prioritise, influence, and shape research.
- Using their **community knowledge and connections** to bring a wider community perspective to the research, and to **communicate the research outcomes** to those who will be impacted by it.
- Individual consumers and community members can be involved in **peer review** of applications for grant funding.

## Roles and responsibilities of researchers

Researchers **plan, conduct, and disseminate research** in partnership with consumers and communities. In addition to their shared roles and responsibilities, researchers are responsible for:

- Ensuring **consumers and communities are involved** in their research, in line with the values and principles of effective consumer and community involvement.
- Planning for consumer and community involvement before research commences, including allocating budget and time for effective involvement, capacity building, and support.
- Treating consumers and communities as **valued members of the research team**. This can include acknowledging their contributions in publications, involving them in disseminating research outcomes, and offering remuneration for their contributions. Researchers should work with consumers and communities to determine what role they will play and ensure everyone understands their role.
- **Maintaining ethics and integrity**, including complying with ethical standards and regulations, and protecting the rights, privacy, and safety of consumers and communities.

## Roles and responsibilities of research institutions

Research institutions **support consumer and community involvement**. In addition to their shared roles and responsibilities, research institutions are responsible for:

- Facilitating consumer and community involvement through clear **policies and procedures**, including guidance on recruitment, remuneration, and complaint handling.
- **Creating a safe environment** by assisting researchers to accommodate the needs of individual consumers and community members.
- Promoting an **institutional culture** where consumer and community involvement is celebrated and expected in research.

## Roles and responsibilities of research funders

Research funders **set the expectations for consumer and community involvement** in the research they fund. As part of this role, research funders are responsible for:

Ensuring consumers and communities are **involved in the research they fund**. Funders may decide to define the level of consumer and community involvement required in research they fund.

- **Making funding decisions.** Funders can appoint consumers and community members to participate in peer review, priority setting, and designing funding schemes. This allows consumers and communities to have a say in what research is funded.
- **Producing guidance material** for researchers and institutions on how to involve consumers and communities in research, how to budget for consumer and community involvement, and appropriate remuneration.
- **Creating mechanisms** where consumers, communities, and researchers can provide feedback to funders on their expectations of consumer and community involvement, shaping future funding processes and policies, and guidance material.

# Glossary

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**Community:** A group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different communities are likely to have different perspectives and approaches to their involvement in research.

**Community member:** A member of a community.

**Consumer:** Patients and potential patients, carers, and people who use health care services. Collectively, 'consumers' and 'community members' may be referred to as 'the public'.

**Consumer organisation:** Organisations that research and campaign on behalf of consumers on a range of issues including consumer rights. They may also be familiar with health and related social service delivery issues.<sup>3</sup>

**Engagement:** When information and knowledge about research is shared with consumers and the community to better inform them on why, how, where, and by whom research is conducted.<sup>4</sup>

**Health and medical research:** Research with a human health focus.

**Involvement:** When consumers and community representatives actively work with researchers and research institutions to help shape decisions about health research priorities, policy, and practice.<sup>4</sup>

**Levels of research:** The extent of, and ways in which consumers and communities are involved in the research cycle. These can range from providing input to selected aspects of the research, to sharing in decision-making, to leading and driving the research with support from researchers.<sup>5</sup>

**Lived experience:** Knowledge based on someone's perspective, personal identities, and history, beyond their professional or educational experience.<sup>6</sup>

**Participation:** Where an individual voluntarily takes part in a research project after giving informed consent.<sup>4</sup>

**Research:** The concept of research is broad and includes the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies, inventions and understandings. This could include synthesis and analysis of previous research to the extent that it is new and creative.<sup>7</sup>

**Research funder:** An individual or organisation who funds research.

**Research institution:** Includes universities, independent research institutes, hospitals or any other organisation that conducts research. May refer to one or multiple institutions.<sup>7</sup>

**Research translation:** Activities that use the results of research to inform, for example, the next stage of research, new research or research re-design, public policy, health-related systems and practice, or support the commercialisation of research discoveries, for the improvement of individual and population health.<sup>8</sup>

**Researcher:** Person (or persons) who conducts, or assists with the conduct of, research.<sup>7</sup>

**Stages of research:** The steps that a research team undertakes when conducting research. These include identifying the research topic, designing the research, conducting the research, communicating the results, and implementing and evaluating the research.<sup>9</sup>

**Types of research:** The broad categories of health and medical research. These include Basic Science, Clinical Medicine and Science, Health Services, and Public Health research. Each type of research focuses on different aspects of human health and disease.<sup>10</sup>

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3. Definition from [NHMRC Guidelines for Guidelines - Consumer Involvement](#)

4. Definition from [Involve Australia - Guidelines for Community Involvement in Genomic Research](#)

5. Definition adapted from [NHMRC Guidelines for Guidelines - Consumer Involvement](#) and [IAP2 Public Participation Spectrum](#)

6. Definition from US Department of Health and Human Services - [What is lived experience?](#)

7. Definition from the [Australian Code for the Responsible Conduct of Research \(2018\)](#)

8. Definition from [NHMRC Research Translation Strategy 2022-25](#)

9. Definition adapted from [NHMRC Consumer Statement Review Environmental Scan](#) and [2016 Statement on Consumer and Community Involvement in Health and Medical Research](#)

10. Definition adapted from [Australian standard research classifications and research keywords](#)



