Recommendations for health and medical research institutes to support community involvement in research

Involve Australia, a community-led project coordinated by Australian Genomics, presents these recommendations for health and medical research institutes to support community involvement in research. Involve Australia is informed by an expert working group which includes patient advocates, genetic patient support and advocacy group leaders, and researchers. It aims to give the public a stronger voice and to inspire and enable people to have meaningful involvement in all stages of genomic research.

This project surveyed the Australian public on their perceptions of health research, interviewed community members, researchers, community involvement program coordinators and institute leads, and reviewed existing community involvement guidelines in 2022 and 2023. The recommendations were devised using the collective knowledge of the working group alongside the data collected.

1206 members of the public participated in our health research survey

14 experts interviewed
- Program coordinators
- Community members
- Researchers
- Institute lead

32 publications reviewed

10 expert working group members

26 working group meetings

36 responses to consultation
- Genetic researchers
- Patient/ community members
- Patient support/ advocacy groups

5 domains

17 recommendations

18 endorsements
- Research organisations
- Patient support/ advocacy groups

Guidelines for Community Involvement in Genomic Research
Led by community
Coordinated by Australian Genomics

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Community involvement, defined as when community members actively work with researchers and research organisations to help shape decisions about research priorities, policy, and practice, is becoming a requirement for health and medical researchers. Australia's largest medical research funding body, the National Health and Medical Research Council (NHMRC), highlights community involvement as a required criteria on all funding applications. The Medical Research Future Fund (MRFF) released their 'Principles for consumer involvement in research funded by the Medical Research Future Fund' in 2023, detailing how community members should be involved in MRFF-funded research.

The recommendations presented here aim to provide health and medical research institutes with guidance on how to improve their community involvement processes, and support researchers and community to work collaboratively in a more effective and inclusive way. Many researchers want to involve community members in their projects, but come across several institutional, organisational and/or funding barriers that can limit their efforts.

Including community members in research means research priorities and outcomes are more likely to align with community needs, wants, and expectations. Projects need to reflect patients' views so they can be more readily adopted and translated into clinical care and practice. This also lays a foundation for research that is more acceptable to the public.

Community members are experts in their lived experience. They are well positioned to convey what needs to be done to improve the patient healthcare journey and outcomes as they have experienced the healthcare system themselves.

Involve Australia published the *'Guidelines for Community Involvement in Genomic Research'* at the end of 2023, alongside accompanying documents which aim to assist researchers in their endeavour to involve community members in public-funded research. These guidelines have been endorsed by a number of patient support and advocacy groups, research organisations and institutes.

The recommendations presented here are a companion document, outlining how institutes can enable better community involvement. In our view the guidelines, and the recommendations within this document, are relevant for researchers of all disciplines, not just genomics.

We believe adhering to Involve Australia's *Guidelines for Community Involvement in Genomic Research* at your institute will best support community involvement practices.

Recommendations to health and medical research institutes

1. Set the **tone from the top**. Leaders of institutes, including all governing boards and committees, should **champion, model and prioritise** community involvement practices.

2. Include community involvement in the institute's **strategic plan** to prioritise it in standard research practice.

3. Create a mechanism for **seed funding** to embed community involvement early in projects, prior to the submission of grant applications. This allows projects to be **co-designed with community**.

4. Provide appropriate resourcing such as **dedicated staff** to support researchers and community members in their involvement practices. Institute-wide community involvement programs should be **well-funded** by institutes.

5. Facilitate **ongoing relationship building** between researchers and the community by creating **opportunities for connection**.

6. Create and support **training opportunities** for researchers and community members to develop skills for **partnering in research**. Joint training sessions allow for a **collaborative learning environment** where all types of knowledge, including experiential, is valued.

7. Create **streamlined** and **accessible** pathways for institute-wide processes such as community member orientation and payment. This reduces the **administrative burden** on researchers and community members.

8. **Evaluate and report** on community involvement practices and processes alongside other academic metrics of success.