


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

Involve Australia, a community-led project coordinated by Australian Genomics, presents these recommendations for health and medical research funders 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.





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 funders with strategies 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, aiming to outline how funders can enable better community involvement. In our view the guidelines, and the recommendations presented in 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* in your research funding organisation will best support community involvement practices.

Recommendations to health and medical research funders

1. Involve community members in **setting targeted grant opportunities** and **prioritising grant opportunities**.
2. Offer a **stream of funding** that promotes **community-led research**. This will lead to research that is more relevant to communities.
3. Require **community involvement in all grant opportunities** and ensure it has significant weighting. Criteria to assess community involvement should be developed with consumers.
4. Offer a **stream of funding** that allows researchers to start building long term relationships with communities, such as capacity building grants.
5. Create a category for “**consumer investigators**” in grant applications and include a **budget line item** for remuneration. Review grant applications to ensure that appropriate funds are requested for the **payment of consumers and community members**. Payment acknowledges their contributions and shows their **expertise is valued**.
6. Involve community members in the review of grant applications to ensure involvement is **effective, meaningful, and not tokenistic**. Significant weighting should be given to community review of applications.
7. Provide **payment** for consumer and community involvement **evaluators** (who are usually consumers) for their review of grant applications.
8. Provide grant application **feedback** to researchers on how community involvement strategies can be **improved** upon if not appropriate for the study.
9. **Evaluate and report on funding provided** for consumer and community involvement in annual reports and other official documents.