

CASE STUDY



Co-producing guidelines for genomic research with community members

Involve Australia, Australian Genomics

The work and its impact

Involve Australia is a community-led project that aims to improve consumer and community involvement in genomic research. Genomic research spans from basic science to the use and integration of DNA sequencing technology in the health system and beyond.

Sometimes researchers will study medical conditions without ever meeting patients with lived experience of them. Involve Australia aimed to bridge this gap by developing the Guidelines for Community Involvement in Genomic Research (the Guidelines)¹. They provide practical guidance for researchers on how to involve community members effectively, leading to community members being valued and forming an integral part of the project. Community members were involved in developing the Guidelines in several ways, including:

- a **working group**, which brought together community members and researchers to write the Guidelines
- a **public consultation** to ask the community what they think about being involved in research
- **interviews** with community members to identify what helps them take part in research, and what the barriers are.

The Guidelines in practice

The Guidelines were published in December 2023. The Guidelines have been downloaded more than 350 times and have been endorsed by 23 research and community organisations. They have also attracted interest from genomic researchers in Canada and Japan. Importantly, they have been accessed by researchers and community members in both the genomics field and other areas of health and medical research.



23 endorsements



International interest



More than 350 downloads

An evaluation study is underway to assess how the Guidelines have been used since they were published. The focus groups conducted as part of the study found that community members involved in research where the Guidelines were used felt valued and listened to and researchers found it useful to have a resource guiding their work, especially when they were new to community involvement. Study findings also suggest that both researchers and community members appreciated the voice and perspectives of the community used within the Guidelines.

What is genomics?



Genomics is the study of many or all of someone's genes (their genome). Unlike genetics, which looks at individual genes, genomics examines many genes at a time and how they interact with each other and the environment. Genomics can help diagnose genetic conditions that are caused by multiple genes or where it is unknown which gene is causing the condition. Genomics also makes possible practices that are ethically complex, such as human cloning and genetic discrimination, and therefore require community involvement in decision making.

¹[Involve Australia - public involvement in genomic research — Australian Genomics](#)



"I particularly like the way the Guidelines have been written from the voice of the community, and as well as providing easy to follow recommendations, the provision of clear examples and additional resources is really helpful. I think this will be a great resource for the genomics (and beyond) research community."

Dr Lisa Melton
University of Sydney

Head of Research, Sanfilippo Children's Foundation (2020-2024)

