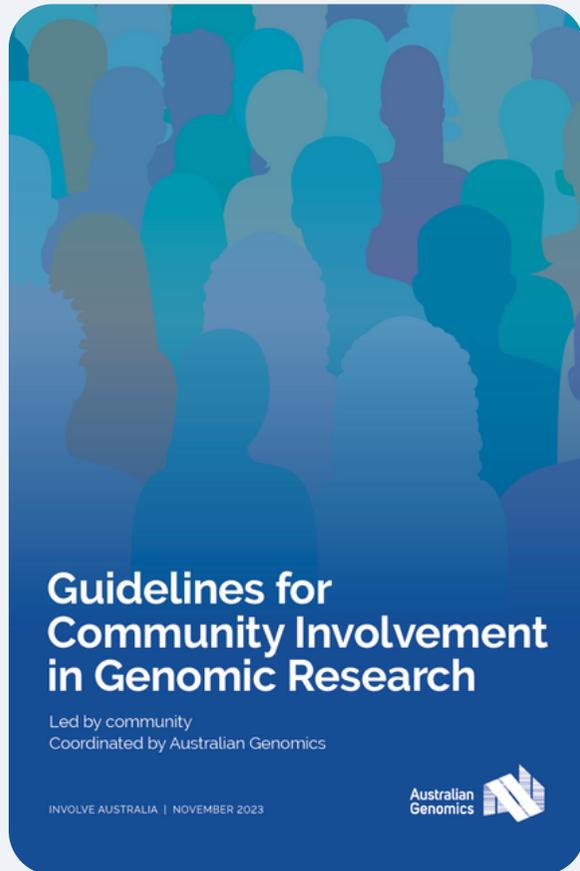


Guiding Questions for Researchers

A supporting document for the **Guidelines for Community Involvement in Genomic Research**



Involve Australia's Guidelines for Community Involvement in Genomic Research aim to provide genomic researchers in Australia with practical information for involving community members effectively and meaningfully in research projects.

Genomic research brings with it complex ethical, legal and social implications, which benefits from the lens of lived experience to facilitate equitable and responsible implementation.

Here, we provide genomic researchers with a set of questions for each recommendation to guide their community involvement processes.

As every research project is unique, implementation of these recommendations and questions should be tailored to meet the needs of your project and the community members involved.

These guidelines have been written from the voice of the community.

We use terms 'us' and 'we' to refer to community members and 'you' to refer to researchers.



Access the guidelines:
australiangenomics.org.au/involve-australia



Building relationships

1.1 Connect with us.

- Have you reached out to us and groups that you haven't connected with before?
- What relationships does your institute already have? Can you leverage these?
- What community involvement structures (for example, community advisory group, research buddy) best suits your project?
- Are you connecting with us even if you do not yet have a project in mind?

1.2 Initiate and maintain a meaningful and respectful partnership with us.

- Have you accounted for the time it takes to foster and grow relationships?
- Is there a power dynamic? What are appropriate avenues that you can take to address this?
- Are there suitable training opportunities available for us and researchers involved in the project?

1.3 Involve us as early as possible, we can contribute to all parts of the research and can be invaluable in the early stages.

- How can we assist in the early stages of your project, for example priority setting?
- How can we be involved in all stages of your research, including grant writing? Have you asked us how we would like to be involved?

1.4 Diversity and inclusion when involving community members is essential for equitable health outcomes. Listening to diverse voices enables research to benefit a greater number of communities.

- Do we provide a relevant perspective?
- How will you create and support an inclusive and diverse team who will bring different perspectives to the project?

1.5 Communication is a two-way process that is integral to effective research. Developing a communication plan with input from us, for participants and the broader community will promote well informed and acceptable research.

- Have you discussed with us our communication preferences early in our interactions?
- Are you involving us in discussions about the best way to connect and communicate with participants and the broader community?

1.6 Discuss with us how we would like to be identified within a project. This will help foster mutual respect.

- Have you asked us how we would like to be identified in meetings and project communications/reports/documents?



Setting expectations

2.1 Discuss with us whether we will represent ourselves, a specific community or organisation. Making this clear will determine whether we are the right fit, and inform involvement design.

- Are you seeking perspectives from a broad range of community members?
- If so, have you discussed with us how we can best assist to provide community perspectives that are useful to the project?

2.2 Every community member is different and will require different approaches to support involvement. Discuss with us how we would like to contribute.

- What ways can you make our involvement more accessible?
- Have you discussed with us how you can support our individual needs so we can meaningfully contribute to the project?

2.3 We are experts in our lived experience but may not be familiar with genomics. Take the time to provide contextual information on the project and genomics more generally if needed.

- Are you providing us with relevant background information that will increase our understanding and help inform our contributions to the project?
- Have you provided us with a lay summary of the research project?

2.4 Co-create a shared core goal(s) for the project. This will allow us to work together with a clear objective and help shape our role(s) within the project.

- Is the research team (including us) working together to develop a shared goal(s)?
- How will we all work towards the shared goal(s)?



Valuing community members

3.1 Valuing our time is essential, therefore an appropriate payment should always be offered. Providing payment allows for a more diverse community member workforce.

- Have you included our payments in your budget?
- Do you have a plan in place for payments (for example, administrative processes)?
- Are the administrative processes for payment accessible and streamlined?

3.2 We may choose to get involved because of lived experience, and we will draw on these experiences to inform our contributions. Approaching our involvement with respect and in a non-judgemental way can provide a safe, inclusive environment.

- Is the team environment safe, respectful and inclusive?
- Have you planned regular check-ins with us?

3.3 Acknowledging the contributions we make demonstrates our value as members of the research team. Discuss with us how we would like our efforts acknowledged.

- Other than payment, have you discussed with us additional ways to acknowledge the contributions of community members (for example, associate investigators)?



Evaluating and reporting on your community involvement processes

4.1 Community involvement practices and impact of involvement should be evaluated throughout the project. This encourages project teams to reflect on and adapt involvement processes.

- Are you thinking about appropriate evaluation processes early in project design?
- Are there other colleagues with evaluation experience who can assist?
- Are you asking us what we think successful community involvement looks like? How can this be captured (for example, interviews, informal conversations, surveys of both community members and researchers)?

4.2 Report publicly on how we were involved as community members to demonstrate to researchers and the public the value and impact of our involvement in genomic research.

- Are your community involvement processes transparent?
- How will you report on the community involvement in the project (for example, newsletters to broader community, publications/reports, [GRIPP2](#), [STARDIT](#))?



Translating your research outcomes into real-world impact

5.1 Translation of research findings into real-world changes can directly benefit the community. Draw on our lived experience for translation that meets the needs of our communities.

- Are you involving us in discussions about translation?
- Are these conversations about translation occurring throughout the various stages of the project?
- Are you discussing with us how to harness our voices in advocacy and lobbying to support project outcomes?

5.2 We may have a strong network with our communities. Include us in conversations about sharing research findings with those that it will impact.

- Are you discussing with us ways to share information with the relevant communities?
- Are you summarising your work in plain language to make it accessible and easily understood?