



# Guidelines for Community Involvement in Genomic Research

Led by community  
Coordinated by Australian Genomics

INVOLVE AUSTRALIA | NOVEMBER 2023

Australian  
Genomics





## Acknowledgement of Country

With our deepest respect, Involve Australia acknowledges Aboriginal and Torres Strait Islander people as the first peoples and the traditional custodians of the land that we work on. We recognise that the sovereignty of this land has never been ceded and was not peacefully settled. We also acknowledge the resilience and resistance of Elders past and present.

Involve Australia acknowledges there is still much work to be done to ensure the involvement of Aboriginal and Torres Strait Islander peoples and other under-represented groups in research. We commit to involving people in research that impacts them.

## The story of the artwork

Community gathering placed in the middle of the artwork representing Australian Genomics and Aboriginal community working together, supporting one another, sharing culture and education.

DNA symbols placed through the design represent Australian Genomics promoting genomic testing, expertise and care to better support the community.

The top left circle represents knowledge. The top right circle represents the health and wellbeing support. The bottom right circle with the footprints represents the journey. The smaller elements as the background represent the Aboriginal culture, our countries, people and our native animals.

## About the artist

My name is Alkina Edwards. From my mother's side I am a Yorta Yorta, Wemba Wemba, Mutthi Mutthi, Wiradjuri woman. From my father's side I am a Bundjalung, Wakka Wakka woman.

I am from the Echuca community Yorta Yorta country and have just recently moved to the Shepparton area with my partner.

I am a community woman who has been brought up with strong cultural beliefs and values and have been creating art since I was a little girl. Art to me is everything. It is my dreaming and my identity.

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Acknowledgement of Country .....	2
A note on terminology .....	5
Executive summary .....	6
Recommendations .....	9
Introduction .....	12
1. Building relationships .....	14
2. Setting expectations .....	30
3. Valuing community members .....	36
4. Evaluating and reporting on your community involvement process .....	44
5. Translating your research outcomes into real-world impact .....	50
Final word .....	54
Glossary .....	55
References .....	56
Appendix 1 .....	62
Appendix 2 .....	63



## Acknowledgements

Involve Australia would like to acknowledge and thank everyone who contributed to this document. To the community members, program coordinators, researchers and institute leads who took part in the interviews, your insights and expertise have been invaluable in shaping the guidelines. Involve Australia is very grateful for your willingness to share your knowledge and experiences with us.

Involve Australia is extremely grateful to all who took part in both the primary consultation and the additional community member review of the guidelines and would like to thank them for the time and effort they put into providing a response. The detailed and constructive feedback provided was exceedingly useful in refining the final version of the guidelines.

We would also like to thank all the survey participants for their valuable insights.

## Involve Australia

Involve Australia, a community-led project coordinated by Australian Genomics, 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.

Involve Australia's vision is to have responsible community involvement practices standardised and incorporated into every part of genomic research. This will enable the field to progress in an inclusive, equitable, and ethical manner.

# A note on terminology

Several terms are used to refer to community members, including 'consumer', 'patient', 'public', and 'stakeholder'. These terms all have slightly different meanings but are often used interchangeably. The National Health and Medical Research Council (NHMRC) suggests the terms 'consumer' and 'community' in their [Statement on consumer and community involvement in health and medical research](#).

These guidelines use the term 'community member', where **community** is defined as a group of people sharing a common interest (for example, cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research (NMHRC, 2016).

When first involving community members on a research team, we recommend asking what terminology they prefer. Other potential terms include advisor, ambassador, co-researcher, leader, patient, patient advocate, or family advocate.

When using the word 'community member' or any other terms, ensure the labels for the communities are co-created and co-defined, and that people self-identify as members.

While it may be confusing initially, it is important to understand the differences between community involvement, engagement, and participation. This will allow researchers to accurately identify the role of community members in the research project, and can enable researchers to recognise when each method of inclusion is most appropriate for the different stages of their project. Clearly defined roles also allow for more accurate reporting.

The definitions below have been adapted from the Australian Clinical Trials Alliance (ACTA) & Clinical Trials: Impact and Quality (CT: IQ) ['Consumer Involvement and Engagement Toolkit'](#)

**Involvement** is when community members actively work with researchers and research organisations to help shape decisions about health research priorities, policy, and practice.

**Engagement** is 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.

**Participation** is where an individual voluntarily takes part in a research project after giving informed consent. Examples of participation include:

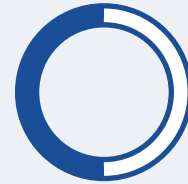
- completing a questionnaire or attending a discussion group as part of a research study
- providing data or tissue that is analysed as part of a research study
- being recruited to take part in a clinical trial.

## Executive summary

In recent years there has been increasing demand for community involvement in health research projects. This is consistent with, and in recognition of, the international and Australian evidence demonstrating the value of and need for community involvement. The research field is also being influenced by community advocates and researchers. As clinical genomic practice is relatively new, genomic researchers have a unique opportunity and responsibility to include community perspectives in research design, conduct, translation, and evaluation.

The value of community involvement is further recognised by funders who support research that includes a community perspective. It is essential that both researchers' and community members' priorities align. Not only is including the community voice best practice, but it is also more ethical and leads to better research outcomes.

It is imperative that a broad cross section of people is included in research to represent the wide range of community perspectives. This includes but is not limited to people with disability, and people from the LGBTQIA+, Aboriginal and Torres Strait Islander, and culturally, linguistically and/or ethnically diverse communities.



**51%** of respondents are living with a health condition

4% of respondents with a health condition are involved in research



According to Involve Australia's 2022 survey, 51 per cent (n=591) of Australians report having a chronic health condition, similar to data seen in the [2021 census](#). However, community members who have lived experience of a health condition, and who partner on genomic research projects suggest they are over-extended across several projects. The increasing requirement by funding bodies for community member partners has only increased this workload. Community members also report their involvement can feel tokenistic if not done in a meaningful way with researchers.

**“They explain what they’re doing when you meet with them, and that’s about the end of it, until they say, ‘Uh-oh, I’ve got to have something signed tomorrow!’ and you never hear anything ... You just feel like you’re just there because you have to be there.”**

— Community Member 3

A key outcome of the Involve Australia project is the development of these guidelines for genomic researchers in Australia on how best to involve community members effectively and meaningfully in research. Genomic research brings with it complex ethical, legal, and social implications, such as high levels of unmet need for people living with genetic conditions, including access to therapies and treatments such as precision medicine and gene therapy, and palliative care. Each of these areas will benefit from the lens of lived experience in the equitable and responsible implementation of research.

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 easily 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.

**“I found it so motivating to know who would be the potential end-user of something that’ll probably be decades away, but it was still, why do it otherwise? It’s not a cell in a dish, it’s a person.”**

— Program Coordinator (institute) 4

The 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.



## KEY FINDINGS

- **Members of the public often do not know they can be involved in health research, and they sometimes find researchers and research itself confronting.**
- **Members of the public like to remain informed about research findings.**
- **Existing relationships with community members can lead to more effective community involvement.**
- **Adequate resourcing (for example, dedicated personnel and funding) and institutional support enable effective community involvement.**
- **Researchers are more likely to involve community members if they see that their colleagues have positive experiences involving community themselves.**
- **There is limited reporting and evaluation of community involvement practices.**
- **Researchers want to involve community members but often do not know how.**

**“Research is the foundation of good policy. And so if we [community members] wanted to make changes to policy, and changes that are meaningful to people, we have to start with research.”**

— Community Member 1

Data was collated to form key recommendations for genomic researchers to improve their community involvement processes. Each recommendation has background information, practical strategies, and useful resources sourced through a review of existing guidelines.



# Recommendations

An important element of this project was to capture the voice of the community. Involve Australia drew from community experience and expertise to develop these guidelines. Therefore, these guidelines have been written *from the voice of the community to researchers*.

We use terms '**us**' and '**we**' to refer to community members and '**you**' to refer to researchers. As these guidelines are community-led, writing them from the voice of the community is an important distinction from existing guidelines.

Involve Australia also wants you to hear the voice of the community as you read through the guidelines.

The recommendations provide a blueprint for community involvement. However, we understand that every research project is unique. Implementation of these guidelines should be tailored to meet the needs of your project and the community members involved.

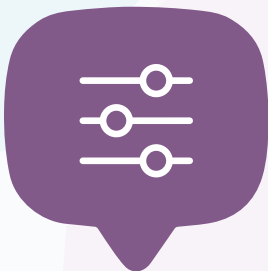


# RECOMMENDATIONS



## 1. Building relationships

- 1.1** Connect with us.
- 1.2** Initiate and maintain a meaningful and respectful partnership with us.
- 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.
- 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.
- 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.
- 1.6** Discuss with us how we would like to be identified within a project. This will help foster mutual respect.



## 2. Setting expectations

- 2.1** Discuss with us whether we will represent ourselves or a specific community. Making this clear will determine whether we are the right fit and inform our involvement in the project design.
- 2.2** Every community member is different and will require different approaches to support involvement. Discuss with us how we would like to contribute.
- 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.
- 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.



### 3. 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.
- 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.
- 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.



### 4. Evaluating and reporting on your community involvement process

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



### 5. 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.
- 5.2 We may have a strong network with our communities. Include us in conversations about sharing research findings with those who will be impacted by them.

# Introduction

Involve Australia's vision is to have responsible community involvement practices standardised and incorporated into every part of genomic research. This will enable the field to progress in an inclusive, equitable, and ethical manner.

The first step in achieving this vision is the creation of guidelines for genomic researchers to use when involving community members in research. It is important for researchers to listen to the expert voice of the community to undertake meaningful and translatable research with community interests at the forefront.

## What is the community involvement spectrum?

Community involvement can take many forms. The community involvement spectrum is a useful way to visualise the different levels of involvement and to decide (preferably alongside community members) what works best for the project and the community members involved. The level of involvement can also help dictate the payment community members receive.



**"I had some women with me who'd had breast cancer and the researchers who had been doing all this basic science research into breast cancer said, 'Oh, that's actually the first time we've ever met somebody with breast cancer and it really makes a difference to us to know that actually this is the person at the other end that we're helping' and it just blew my mind that they were doing all this work in this space but had never actually met a breast cancer patient."**

— Program Coordinator (patient group) 1

### Why were these guidelines developed?

The guidelines aim to encourage genomic researchers in Australia to involve us, 'community members', effectively and meaningfully in research projects. Many researchers want to involve us in their projects, but sometimes lack the knowledge about how to include us in a meaningful way that adds value.

Including community members in your research can influence the delivery of research outcomes so they are more community-focused and translatable. This means research is more acceptable to the public. It is particularly important in genomics, where the application of testing in clinical practice is relatively new. Genomic research has a unique opportunity and responsibility to include our perspectives into research design, conduct, translation and evaluation.

Guideline consultation feedback suggests that Involve Australia mandate community involvement in genomic research. Community involvement may be mandated in health research in the future, however Involve Australia notes that this is not the current reality of the genomic research landscape. To suggest mandating community involvement at the beginning of all genomics projects would be a significant leap for researchers, institutes, and funding bodies, and there is no existing structure to enforce this. Involve Australia strongly believes that community members have a right to be involved in all projects about them, however these guidelines aim to assist genomic researchers in taking the next step to progress community involvement.

### How were community members involved in the development of these guidelines?

Working Group members ([Appendix 1](#)) met monthly to discuss study documents, data collection and analysis ([Appendix 2](#)). Capturing the voice of the community was critical to developing these guidelines, which were informed by:

- the Involve Australia Working Group
- a review of existing Australian-based community involvement guidelines
- a large public perceptions of health research survey
- interviews with community members, researchers, community involvement program coordinators and institute leads, and
- the public consultation of these guidelines.

Although the guidelines have been written for genomic researchers, they are relevant for community members as well as all healthcare researchers. We encourage their use in other fields. We hope they encourage researchers to take the first step towards a more inclusive future.



# 1. Building relationships



## 1.1 Connect with us

The public is interested in research. However they are not always aware that they can get involved. Think broadly about where you can connect with us to reach the people who are most relevant to your research.

Partnering with us can be time-consuming and may be challenging for many researchers. However connecting with us can lead to fruitful long-term relationships. Community involvement training for researchers is key in learning how to best connect and work with us. Refer to [Recommendation 1.2](#) for community involvement training.

Speaking with patients, families and/or their carers can be a great opportunity to conceptualise meaningful and needs-based project ideas. This can be a good avenue for clinician researchers to begin connecting with people who are relevant to their field of research. However, be mindful of only reaching out to community that you already know as this could lead to limited representation and/or diversity. Refer to [Recommendation 1.4](#) on diversity.

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**“It’s more a case of them [researchers] not really realising how they can draw on their own networks, they’re usually a part of a wider team or a wider network that have got direct contact with consumers.”**

— Program Coordinator (institute) 2

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There are many different structures of community involvement. The [Consumer and Community Involvement Program](#) has provided examples that you may find useful:

- ▶ **Research Buddies** are community members who can provide a link between researchers and the community as some researchers have little or no contact with people impacted by the condition they are studying. This is a less formal partnership. Research Buddies and researchers may meet to discuss various aspects of the research, from aims to results and new ideas.
- ▶ **Consumer and Community Researchers** have been trained to work with researchers to conduct all or part of the research project. They might be involved in developing methodological approaches, data collection, co-facilitating focus groups or data analysis. This method can be very useful for working with specific groups such as Aboriginal or Torres Strait Islander peoples or culturally, linguistically and/or ethnically diverse communities.

Although not common practice in genomic research, community-led research is important and becoming more essential. As defined by the [Medical Research Future Fund \(MRFF\)](#), community-led research is “driven by meaningful [community] involvement and partnerships, to incorporate priorities, needs, values and experiences to deliver fit-for-purpose outcomes that can be adopted by consumers, carers, healthcare professionals and other end-users.”

Community-led research is now being recognised and supported by the [NHMRC and the MRFF](#), making it important for you, as genomic researchers, to understand and support this movement. As highlighted through the Involve Australia consultation, connecting with community members and patient support and advocacy groups and asking us what our research ideas and priorities are, is fundamental to this type of research.



## SUGGESTIONS

- ▶ Ask your institution or organisation if they have a community involvement program or links to relevant community members.
- ▶ To make initial connections, try leveraging existing relationships.
- ▶ If you are a clinician researcher, your patients and their carers can be a valuable resource when looking for community perspectives. This may, however, cause concern about power imbalances. Refer to [Recommendation 1.2](#) for more information regarding this.
- ▶ Think about how you will approach community member recruitment, for example: will there be an invitation process, or an expression of interest required?
- ▶ Having more than one community member can help reduce the pressure on that one person and provide a wider perspective. It can also increase the confidence of any community members involved by having a team member in a similar position.
- ▶ Connect with relevant patient support and advocacy groups. Building relationships with these groups will require time. These groups generally have strong links with the community and can be a good conduit to community members who might be interested in being involved in your project.
- ▶ It can also be useful to connect with peak bodies. These groups can add a different perspective as they often have a policy focus and represent a broader community.
- ▶ There are many of us that may not be linked to a patient support and advocacy group, however we may be active on social media or in citizen science groups. You can connect with us through these platforms.
- ▶ If the public is the focus of your research, social media can also be used to connect with the members of the public who may be interested in being involved as a community member on a research project. Other pathways include advertising in places community members frequent for example, community/health hubs, places of worship, local markets, schools.



- ▶ To decide the community involvement structure that best suits the research project, consider the following:
  - What is the budget for community involvement?
  - What is the timeframe of the project?
  - What is the size of the population you are researching? For example, if you are looking at a rare disease community, there might only be a few individuals willing to be involved in research. However, if the project is investigating a common disease such as diabetes you may want to involve multiple people from the community and employ a community engagement strategy.

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

Investing time in your relationships with community members before, during and after research projects ensures we feel valued and promotes more effective collaboration.

Much like the relationships that you build with your research colleagues to foster a good working collaboration, similar efforts should be made with community members. It is important to ensure our opinions and experiences are respected and we feel like equally valued members of the team.

Developing and investing in long-term relationships with community members and patient support and advocacy groups can create trusted, valued interactions with one another. This has multiple benefits, such as a better understanding of each other's perspectives and values, and avenues for involvement. This leads to mutual respect which encourages future interactions and partnerships.

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**"I just love that over time I've gotten to know particular researchers and they've seen my value because I've been involved with them. And you just get this wonderful two-way relationship where you can call on them when you need support ... and then the trust builds and then I am invited to be an investigator and we're just at the very planning stages. We haven't applied for funding, but let's meet and chat and flesh out our idea."**

— Community Member 1

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We may feel intimidated or uncomfortable in group meetings, which may hinder our ability to speak up. Developing confidence and mutual trust can take more time than anticipated.

Researchers can undergo training to develop skills in community involvement. This should be prioritised before involvement begins, however it can be useful at any stage. Educating researchers about good community involvement practices will allow for a positive experience for both researchers and community members. If suitable, we can benefit from training opportunities as well. This not only benefits the current project but also increases our knowledge and capability for future projects.



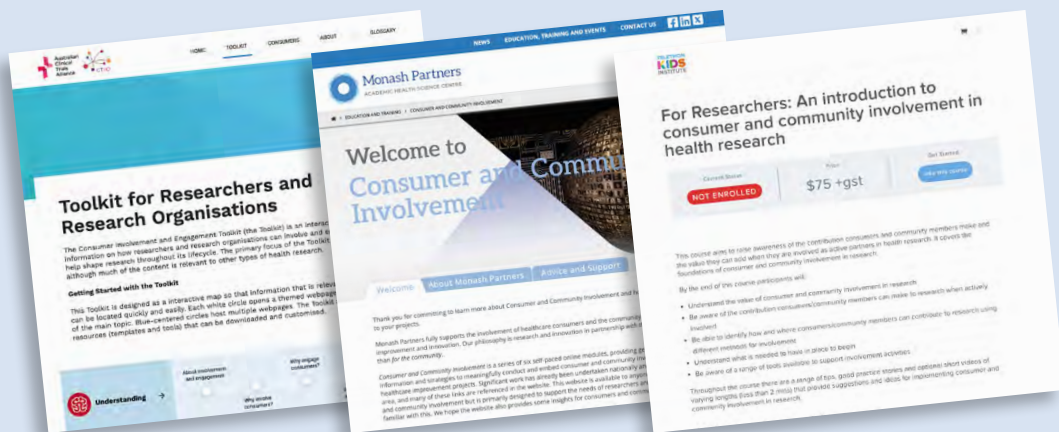
## SUGGESTIONS

- ▶ **Power dynamic:**
  - If you are a clinician-researcher asking your patients to get involved in research, you should be mindful of the unequal power dynamic in clinician-patient relationships. Ways to equalise this may include informal meetings outside the clinic or research environment and explicitly acknowledging the presence of a power dynamic prior to discussions on patient experiences. Refer to Monash Partners '[Managing power dynamics and imbalances](#)'.
  - This power dynamic may also exist for researchers. You may also like to employ the above suggestions to equalise this.
- ▶ Allow for informal conversations to build our confidence in the research setting. It is important to maintain relationships with us throughout the project and beyond. Regular one-on-one meetings are an effective way to do this, even informally.

**“The important thing is for the project lead to really engage with the consumer. When they’ve got meetings and papers [that] are sent out you should follow up before the meeting and ask ‘Have you had a chance to look through the papers? Are you clear about what we’re discussing, is there anything I can help you with in the meantime?’”**

— Program Coordinator (patient group) 1

- ▶ Talk to your institute or organisation about training opportunities for researchers. If this is not available, see here for training courses:
  - [ACTA and CT:IQ's Consumer Involvement and Engagement Toolkit for Researchers](#)
  - [Monash Partners Consumer and Community Involvement Training](#)
  - [Telethon Kids Institute Introduction to consumer and community involvement in health research for researchers](#)



- ▶ Training specifically for community members and researchers on working together can foster positive working relationships, help improve ways of working and promote mutual understanding of expectations.
- ▶ Discuss with us whether we would like more structured training on becoming involved in research and what model of training would suit us best. Freely available resources for community member training include the [Telethon Kids Institute Introduction to consumer and community involvement in health research](#).

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**“We [researchers] should be trained in what best practice is and how best to work with consumers.”**

— Researcher 2

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### 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

Input from the community as early as possible in your research is recognised as extremely important, however you should still engage us if the project is already established. Community involvement is relevant and benefits all stages of a research project.

Early engagement can ensure research projects are informed by what is most important to the community, who are the ultimate beneficiaries of health research. Funding bodies are now strongly encouraging community involvement and are placing more weight on it when assessing grant applications.

Even if a particular stage requires less input from us, for example, bioinformatics processes, keeping us well informed throughout the project allows us to remain engaged and maintain a clear understanding of the overall project. This will also assist us in understanding how and when our input is most needed.

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**“In some cases, whether at NHMRC, MRFF, Cancer Australia, in some of the funding rounds, it seems to be it [community involvement] is mandatory.”**

— Program Coordinator (institute) 3

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## SUGGESTIONS

Here are some examples of how we can participate in the various stages of research:

### ► Priority setting:

- Use established methods for involving us in setting research priorities (for example, [James Lind Alliance Priority Setting Partnerships](#)).

*Example project:* Australian Genomics, in collaboration with patient support and advocacy groups, identified and responded to a need for patients and the community to have access to reliable and evidence-based resources on genomics and its implications. The [GenomicsInfo](#) website features a whole range of plain English genomic materials, including Genomics

in the Community developed resources and others shared from research and medical organisations. The website has been met with very positive feedback from many different stakeholder groups. Clinicians have been sharing the website with their patients and patient support and advocacy groups.



*Example project:* Queensland Genomics' Community Advisory Group (CAG) provided advice to the Queensland Genomics program and its projects in an advisory capacity. The CAG was also resourced to develop and lead community-focused activities. These community focused activities were self-nominated areas of interest and activities that aligned with the CAG strategy. The structure, functions and key outcomes of this CAG were outlined in a [publication](#) to provide insights for the other initiatives seeking to undertake community involvement in genomic research and healthcare.

### ► Grant writing:

- Prior to beginning grant applications, engage with us about our perspectives on the project. Ethics approval and/or funding is not required to start having these conversations. We can add a different and important perspective to grant applications including translation, impact, community engagement and involvement strategies, and real-world evidence. Given the time-limited nature of research, community members are often engaged too late in grant writing. Funding agencies are increasingly asking for evidence of community involvement to inform grant application scoring.

**“If [researchers] can see the benefits in involving consumers in [research] outcomes but also [in] making their grant applications more competitive. Those will be big drivers.”**

— Program Coordinator (institute) 5

➤ **Method development:**

- We can provide a perspective on methodology that will encourage community acceptability of the project, which may increase the likelihood of participation and acceptance of outcomes.

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*Example project:* On the [Mackenzie's Mission](#) project, gene selection meetings were attended by a community investigator and the gene list was reviewed by a Community Reference Group to ensure their voices were heard on this ethically challenging topic.

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➤ **Planning participant recruitment strategies:**

- Recruitment pathways and strategies can be co-created with us.
- We can offer advice on practical barriers to recruitment and data collection methods.
- Language used and recruitment promotion (for example, previous participant stories demonstrating the value of being involved in research) can be created in collaboration with us.

“You are involved in things like recruitment and certainly I think having consumers involved at the recruitment stage is really critical. I've just been involved in a project quite last minute and they're trying to recruit children six to 17 years of age, but they're not putting a nurse on after hours. So it's school hours and you have to withdraw your children from school on five separate occasions, and I'm like, I wish I was there earlier.”

— Community Member 1

➤ **Dissemination:**

- We can provide insights on how to share research results with relevant communities in a way that can encourage community acceptance.
- We will likely have some understanding of how members of our community like to receive information. Discuss with us ways (for example, video, social media) to inform the community of research projects and their findings, limitations, and recommendations.

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*Example project:* The '[Your Blood, Your Story](#)' animation was created by QIMR Berghofer for Aboriginal and Torres Strait Islander people to share information about genetics.

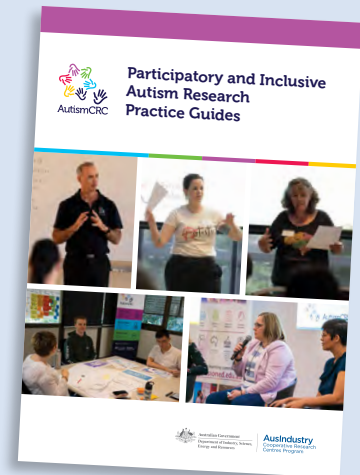
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➤ **Translation:**

- This is a key element in the research process that we can take part in. For example, we have played a significant advocacy role when engaging with government.

*Example project:* The significant work carried out by the Mito Foundation to advocate for the passing of [Maeve's Law](#) highlights the impact community members can have on research translation.

- It is also important to acknowledge our feedback and suggestions. Regularly engage and consult with us throughout the research process and incorporate our feedback where appropriate.
- The '[Participatory and Inclusive Autism Research Practice Guide](#)' includes a useful resource on the different ways we partake in various stages of research (pg. 8).
- The [International Association for Public Participation \(IAP2\) spectrum](#) of public participation contains explanations and examples of different levels of community involvement.
- Monash Partners provide a useful [summary table](#) on the ways we can be involved in each stage of the research process.



**“We would love it if more [involvement occurred] at the start of projects.”**

— Program Coordinator (patient group) 1

#### 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

Researchers and community members have called for the inclusion of diverse communities in research. This need for change has been outlined in a [2022 publication](#) by the American Society of Human Genetics. The Australian population is multicultural and diverse. Twenty-eight per cent of the Australian population was born overseas, according to the [2021 census](#). It is essential that research benefits all communities as it is funded by the public.

Historical medical research abuse and negative healthcare experiences have resulted in a lack of trust between researchers and underrepresented communities (for example, Aboriginal and Torres Strait peoples, people with disability). For the genetics field in particular, early theories of inheritance and evolution were used to discriminate against certain groups of people. Rebuilding trust between researchers and underrepresented communities is vital. Empowering these communities to be involved in genomic research can prevent further gaps in health outcomes.

Currently, most genomic studies are undertaken on populations with [European ancestry](#), meaning underrepresented, diverse populations will receive less benefit from genomics as it is implemented into clinical care.

Underrepresented populations may have different experiences of the healthcare system that can lead to poorer health outcomes. Providing space for their voice in research can have a positive impact on their communities. These groups are also underrepresented in patient support and advocacy groups, so using multiple avenues for recruitment is essential as discussed in [Recommendation 1.1](#).

Community members surveyed by Involve Australia who were involved in a research project are more likely to hold an undergraduate or post graduate degree (69%), more likely to be of Australian ethnicity (73%) and to have paid employment (54%) with 50 per cent earning over \$100,000 (household income), meaning they are in a privileged position to be involved. Although they may have a genetic or rare disease, these individuals will usually be better placed to navigate the healthcare system than for, example, someone with a genetic or rare disease who is culturally, linguistically, and/or ethnically diverse or someone with an intellectual disability.



## RESOURCES

Please note these guidelines do not go into detail on involving and conducting research with specific groups of people, such as Aboriginal and Torres Strait Islander Peoples.

Please see existing resources for specific guidance on how to involve Aboriginal and Torres Strait Islander Peoples in research in a culturally safe and responsible manner:

- ▶ [Genomic Partnerships: Guidelines for genomic research with Aboriginal and Torres Strait Islander peoples of Queensland](#)
- ▶ [Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities](#)
- ▶ [Researching Indigenous Health: A Practical Guide or Researchers](#)





## SUGGESTIONS

- Build relationships and be conscious that diverse community members may have had previously poor experiences with the healthcare system and/or research. Take particular care to make them feel safe, valued and welcome in the research space.
- Building relationships with diverse communities is a long-term commitment. When conducting research with a particular community, collaborate with or where possible empower researchers from that community to lead the project and decide on priorities.
- Allow space to hear negative experiences (this includes all community members). Although these experiences can inform stronger research outcomes, expressing this may be emotional. It is important to keep our wellbeing in mind, which may include debriefing afterwards. Refer to [Recommendation 3.2](#) on using a trauma-informed approach for more information.
- Be mindful of whether the community member(s) on the research team can speak for the community you are researching, and their role(s) or association with that community. Please refer to [Recommendation 2.1](#) on representing communities.
- Consider our cultural differences, language barriers, and/or disabilities. Additional support may be required for our involvement in the project. The best way to establish these needs is to communicate with community members.
- Speak with us one-on-one to discuss any additional support required to be involved in the project. This should happen during initial interactions when bringing us onboard, as it is a critical part of establishing trust and equity from the outset.

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**“We all live in a diverse community and there is no one size fits all approach, not even for a group or a community. So, I think that is just that. Seeing people as individuals. That’s just a fantastic reminder for all of us to not be so set on putting people into a [particular] bucket.”**

— Program Coordinator (institute) 5

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## RESOURCES

Additional resources for working with specific communities are described below:

People living with intellectual disability are another specific group you may wish to engage in your research. The University of New South Wales Disability Innovation Institute have developed the guidelines '[Doing Research Inclusively: Co-production in Action](#)' to help researchers involve people with disability in their work more meaningfully.

The Australian Clinical Trials Alliance have developed [a set of recommendations](#) for the involvement and participation of people from culturally and linguistically diverse backgrounds in clinical trials. Although clinical trials-focused, you may find these useful for other areas of research.

Stronger Futures have developed the '[Know our story](#)' initiative to inspire, encourage and support clinical and population health researchers to work in partnership with communities of refugee and migrant backgrounds. There are several written resources and an animation, with plans to update and develop more resources over time.



### 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

Communication plays a vital role in research, including how a project is perceived by community members, participants, and the broader community. Having a clear plan for all aspects of communication with the community ensures consistency in messaging and allows for open dialogue between researchers and the community.

Co-designing the communication strategy, which involves community members in writing, reviewing and implementing communications, will ensure it is more effective.

Early in the project, consider how to communicate each aspect of the project to the research participants and broader community, including disseminating findings. We can be very helpful in this area as we may have ideas about how to best communicate within our communities.



Involving community members in communication strategies creates a pathway for connection between researchers and the broader community. Community members can enable better communication between researchers and participants.



## SUGGESTIONS

Your communication strategy will need to address three key audiences:

### Community member/s

- ▶ Consider how to engage community members and how you will present the project to us. Discuss with us how we would like to receive information and the frequency of communication. We can provide valuable input at the earliest stages of project development as noted in [Recommendation 1.3](#).
- ▶ When a community member has agreed to be involved in the project, identify a key contact person for us in the investigator team. They can talk to us about project-related and administrative matters (for example, payment, document and building access) or discuss any questions or concerns. Provide us with this information at the start of the collaboration.
- ▶ Include in your communication strategy detailed information such as a co-designed Terms of Reference for any formalised group – which should include information about meeting occurrences, primary modes of communication (for example, email, teleconferencing), conflict resolution strategies and relevant codes of conduct.
- ▶ Healthy Trajectories have a '[Research Partnership Feedback Communication Checklist](#)' which details how researchers can support two-way feedback and communication with community members at different stages of the research process.

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### Participants

- ▶ Develop project key messages with our input. Key messages are short statements, often one or two sentences, that capture the essence of a research project or program. This ensures project information will be expressed in an understandable manner and be of interest to the community. These key messages support consistent communication within and beyond the project and can inform participant-facing materials such as consent and patient information forms.
- ▶ Use our expertise to devise a communication strategy with potential participants. This may include communicating how the project is progressing, appropriate methods for return of results, and modes of communication for sharing research findings.

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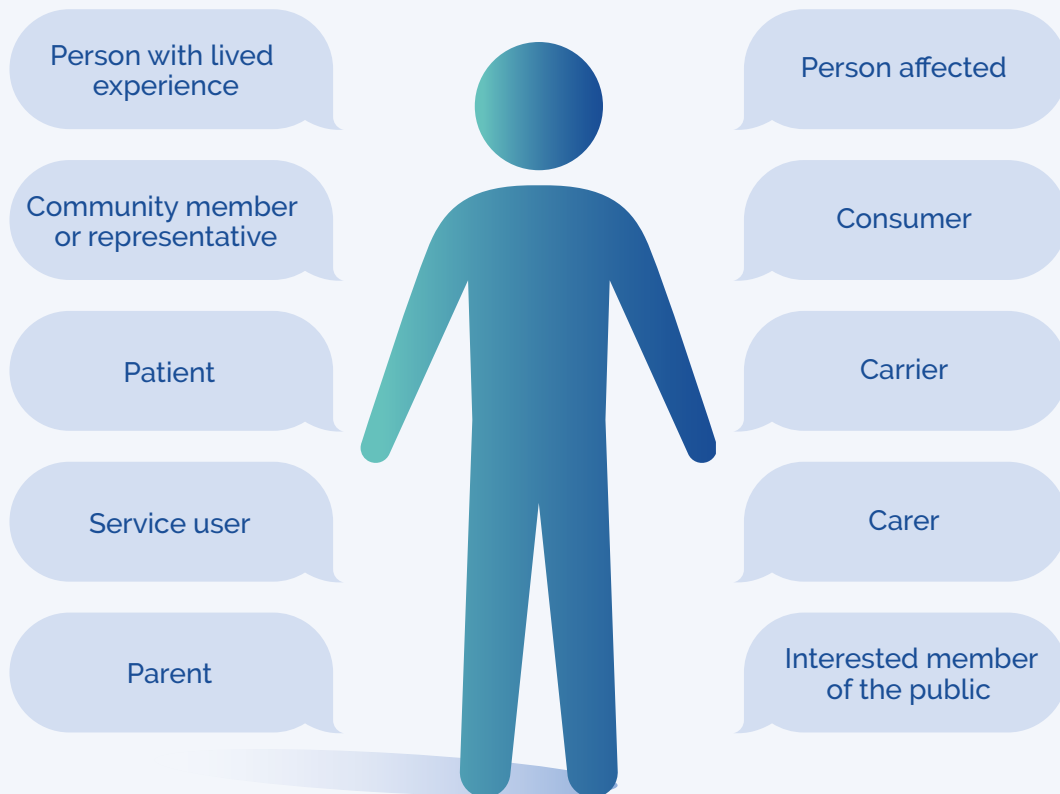
### Broader community

- ▶ Our expertise can be harnessed to raise awareness of the project to the broader community. Our guidance can also inform effective methods to disseminate research findings at the conclusion of the project (for example, involvement in the development of plain language summaries). This can ensure acceptance of the research project and translatable outcomes.

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

Terminology can be a challenging part of research. Every community member is unique and will have individual identification preferences. Discussing these will allow for positive relationship-building and foster mutual respect.

### People may choose to identify as ...



#### SUGGESTIONS

- Early in your interactions with us, ask how we would prefer to be introduced (in meetings, presentations etc). Later in the project, ask how we would like to be referred to in publications and other forms of acknowledgement.
- When using the word 'community member' or any other terms, ensure the labels for the communities are co-created and co-defined, and that community members self-identify as members.





## 2. 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

An individual cannot always be expected to provide the perspective of their entire community, given the diverse presentation and lived experience of people with genetic conditions. Every community member brings their unique experiences, even if they are affected by the same genetic or rare condition. Getting a 'representative' community perspective may not always be possible.

A decision needs to be made, preferably in collaboration with us, on what is an appropriate strategy for community involvement and/or engagement.

If you would like us to provide a representative community perspective, as opposed to representing ourselves as an individual, be clear about how community perspectives should be collected. An example of this can be attending or holding community meetings to collect broader perspectives. Also provide an appropriate timeline and necessary resources to undertake this.



### SUGGESTIONS

- ▶ If you would like us to provide a community perspective, this will usually require a more formal method of involving community members. It is best to check with your Human Research Ethics Committee (HREC) whether approval for this method is needed.
- ▶ Develop, with our input, your planned method of involving people. This may need to be considered in project budgeting.
- ▶ If we are involved in a patient support and/or advocacy group, we may be able to provide broader views from our community if given enough time and resources to collect this information.

**“The researchers themselves have to, before they start a venture into consumer and community involvement, get an understanding of what [representation] they want from the person or the people.”**

— Program Coordinator (institute) 3

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

Involvement of one community member will look different to involvement with another. Given the spectrum of conditions that can be identified with genomic testing, this is an important consideration for projects in genomics. Individualising involvement approaches based on our needs encourages involvement that is not tokenistic and respects individuals' different workloads, capacity and availability.



### SUGGESTIONS

- ▶ Talk to us about how we would like to or are able to contribute to the project. This includes:
  - Preferred communication method.
  - Timing, frequency, structure and location of meetings (for example, meetings during working hours may be challenging for us to attend).
  - An expectation of the workload/time required outside of meetings.
  - Timeframes and methods for providing feedback.
  - Ask if providing plain language summaries of documents would be useful. It may also be useful to ask how best to deliver these summaries (for example, written, video, Easy English, Easy Read).

## 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

Our lived experience can encompass our professional, volunteer, and personal experience which we can draw upon in our community involvement role. This might sometimes include prior experience in genomics. However, this may not be true for the majority of us. Genomics is a forever evolving, complex field, and we may not have an expert understanding of the science when we join a project. It is important to ask us whether we need more information on genomics, that is specific to the project, rather than assuming we do or do not know things.

As community members on a research project, we may feel intimidated. Twenty-six per cent of Australians surveyed by Involve Australia stated they lacked confidence to be involved in health research. It is important to consider this dynamic during team meetings.

Providing information on topics relevant to the project will build our confidence and competence to help ensure our opinions are well-informed. This will ultimately benefit the project and its outcomes.



# 26%

of Australians surveyed stated they lacked confidence to be involved in research





## SUGGESTIONS

- As early as possible do a formal induction as well as a learning and support assessment of all members of the research team, including community members and researchers. This can help identify areas where additional support is required. We may feel uncomfortable asking for additional support in a group setting, so these discussions may be better in a one-on-one meeting.
- Provide us with an information session on some key concepts prior to first meeting with the research team. Review the project proposal with us and provide context around the project in plain language, ensuring everyone understands the scope of the project and what it is aiming to achieve. As community members, it is important to consider the 'why' of the project and understand how this research will help patients.
- Ask how community members would like to receive this information, assuring it is provided in accessible format if required.
- Ask us if we would like to have further discussions or additional materials provided to supplement the information session. Refer to [GenomicsInfo](#) for plain language genomic resources or Syndromes Without A Name Australia's Easy English resource – [What is A Gene Test](#).
- When thinking about what contextual information should be provided, it is important to balance scientific information with what is relevant to a community member who has lived experience (for example, how will research impact future patients?).

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**“We're talking about incredibly complex information but, actually, do we need to go back to what is a cell, what is DNA, or do we need a focus on people making decisions about healthcare and about their children and their family? And yes, we can rattle off these things because that's how we learnt to describe genetics, but actually, is that helpful?”**

— Researcher 2

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- Avoid using jargon and acronyms wherever possible. Provide us with a glossary of commonly used acronyms and terminology.
- During, or after meetings (if more appropriate), ask if explanations about the research are appropriate or if further clarification is required. This can also encourage us to ask more questions during the meeting when we feel unsure.
- It might be helpful to reach out to us in an informal one-on-one setting to ask if we have any concerns about our involvement in the project. Be mindful that some community members may not feel comfortable disclosing their concerns or asking questions in a group setting.

## 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

Aligning expectations of both researchers and community members can support a better working relationship and more effective communication over the course of a project. Expectations can include clarification of roles and expectations of research project outcomes. Sixty-one per cent of individuals want to be involved in research for altruistic reasons, such as wanting to contribute to improving the health of future generations and believing that research should be informed by community views.

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**“It’s all about giving back.”**

— Program Coordinator (patient group) 1

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Harness this drive to improve the lives of others and promote a collaborative team environment by devising shared research goals with our input. This not only increases community acceptability and relevance of the research, but also allows us to feel like genuine partners in the project. Work together towards a shared goal.

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**“You’ve got to feel like you’re all working towards the same goal and you kind of reinforce what that goal is, so that when it’s really challenging ... you come back to why you’re doing it at the end of the day.”**

— Researcher 2

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However, there may be other reasons (for example, personal) for our involvement. Providing us with an opportunity to discuss our motivations for involvement can help align both research and personal goals.

Awareness of other’s assigned tasks and contributions is essential. Considering how each person’s role will impact the bigger picture is a way to promote team cohesion.

Research projects should also be flexible, as community member responsibilities and priorities may change over time. Refer to [Recommendation 4.1](#) on evaluating community involvement processes.

The nature of research also means that timelines may be delayed, and therefore the application of findings into practice may also be delayed. This should be communicated with us, so our expectations are realistic. It is always best to be honest and transparent. We should be made aware of timeline changes, and our opinions sought as to managing patient and community expectations or supporting translation.



## SUGGESTIONS

- Ideally, goals should be discussed prior to grant applications being submitted. This means relationship building early on. Refer to [Recommendation 2.4](#) on shared goals.
- If the goals of researchers and community members do not align, it is acceptable to decide not to include a particular community member. We may also decide that we are not the best fit for the project after learning more about the project and what is involved. Therefore, it is helpful to have these discussions early in the project.
- Have a clear 'why' that all team members agree on.
- Early in the project, clearly define team member tasks. Tasks and timelines may also change throughout the project. Refer to [Recommendation 4.1](#) on evaluating community member roles for ways to address these changes.

"It wasn't even that there was a scientific method in terms of recruiting these people. It was just catch up for a coffee. Of course, you ask those 'interview' questions, but at the end of the day it was really about assessing that personality fit."

— Program Coordinator (institute) 5



### 3. 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

Community members provide researchers with insights that allow for meaningful and effective research, and as such our role in research should be valued and respected. Payment can be a factor that encourages participation and shows contribution is valued.

The term payment is used in this document to cover all possible terms used to describe paying community members for their contributions.

**“I do firmly believe that consumers require remuneration for involvement. Especially when you are not just being involved, but you are helping devise their consumer engagement strategy. So you're really performing a service for the research team. Not only that, but obviously there are costs associated with childcare, and other things.”**

— Community Member 1

By being involved in research projects we are providing our expertise - our lived experience - therefore, our time should be valued, just as it is with paid researchers.

Without offering payment, the risk is that research is only informed by the limited group of community members who have surplus time and energy, can take time off work, or have assistance with caring responsibilities. By offering payment for our contribution, you are removing some of these barriers, enabling a more diverse community member workforce.

Some community members may not take up the offer of payment, some may choose to donate it back to the project, institution or a charity of their choosing. The important thing is that it is offered.

It can be difficult to find a funding source prior to a grant application being awarded. Community involvement can be included as a line item in many grant applications, however you may also wish to speak to your institute about models for paying community members in the absence of grant funding.

While it's important to pay community members for their involvement, you do not need funding to begin having conversations and building positive relationships with us.



## SUGGESTIONS

- ▶ When planning research budgets, in the early stages of your project, factor in costs for community involvement. These costs should also be reflected in grant applications. This can include costs for paying community advisory group members, reimbursement of participants, or the costs of holding community engagement events.
- ▶ Speak to your institute as they may already have a payment policy in place that can be adopted. Different institutes/organisations will suggest different rates of payment. Some institutes/organisations do not offer payment or have a policy. We understand that you will be directed by the institute/organisation's guidance.
- ▶ You may be bound by institutional policies; however, if possible, ask us what our preferences are. For example, this could be an honorarium, a payment, or a voucher. We might have different preferences regarding how we would like to be paid for our time. If there is flexibility, discuss with us what our payment preferences are.
- ▶ Sometimes the terminology used to describe payment may have tax or benefit implications for the community member. The terms honoraria/honorarium are used frequently and have tax advantages. The [Australian Tax Office](#) states: "honorary rewards for voluntary services are not assessable income and related expenses are not deductible".
- ▶ Different states and territories may also have different payment suggestions. If your research institute/organisation does not have a relevant community member reimbursement policy and payment is to be offered, there are several models available to use:
  - [Australian Genomics payment policy](#)
  - [Health Consumers QLD remuneration of consumers statement](#)
  - [Healthy Trajectories budgeting tool](#)
  - [Health Consumers NSW remuneration and reimbursement of consumers](#)
  - [Victorian Comprehensive Cancer Centre Alliance paying consumers](#)
- ▶ Payment processes should be transparent and should be conveyed to us prior to the project commencing. This will allow us to make an informed decision about whether we want to be involved in the project.
- ▶ The process for payment should also be inclusive and accessible. However, this may be limited by institute/organisation policies. Attempt to streamline processes for payment where possible to reduce the administrative burden (for example, simple, straightforward payment forms).

### 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

While we bring lived experience skills and knowledge, this may also include challenging or even disempowering experiences (for example, prolonged diagnostic journeys). Approaching these discussions with interest, respect, and transparency works to create an environment that is safe and welcoming.

In some cases, you may want to take a trauma-informed approach, which is "based upon principles of safety, choice, collaboration, empowerment, and trustworthiness" when working with us. This approach means understanding, recognising, and responding to trauma, and seeking to prevent re-traumatisation.

These principles are often used in [healthcare](#), however they should also be applied across all elements of community involvement in research.

[As described by the Blue Knot Foundation](#) "The word 'trauma' describes events and experiences which are so stressful that they are overwhelming, and the impacts of these experiences. The impacts depend on several factors. Certain life situations can make trauma more common, for example people with disability of all ages experience and witness trauma more often than people without disability."

In a healthcare context, people with a genetic condition may face many traumatic events due to poor healthcare experiences. These can have a cumulative impact and erode trust.

Due to our lived experience, we may have a more personal connection than researchers to potentially challenging stories shared by participants. Responses from the Involve Australia survey indicate that 17 per cent of people find research confronting, 26 per cent lack the confidence to become involved in research and 13 per cent believe researchers are unapproachable. Keep these factors in mind when involving us.

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**"It's about being aware of [the fact that] genomics conversations can be very emotionally triggering."**

— Researcher 2

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You should aim to check in with us periodically through the project. We may not always wish to share our stories publicly and the desire to share stories may change with time. This also may change depending on the forum. For example, we may feel comfortable sharing in a closed meeting but not during a presentation. These decisions should be respected.

We can develop burnout for a variety of reasons, including changes in health. You should be mindful of the impact a chronic or progressive disease may have on a community member and our capacity to be involved at different times. Refer to [Recommendation 2.2](#) on individualised involvement approaches for more information.



## SUGGESTIONS

- Taking a trauma-informed approach may look like:
  - Ensuring that everyone has a chance to be heard without judgement.
  - Creating a safe space and building trust.
  - Respecting confidentiality.
  - Warning in advance if a potentially triggering topic is to be discussed.
- The NSW Centre for Genetics Education has a webpage on '[Trauma-Informed Care](#)'. Key strategies to enable this are provided by [GeneEQUAL](#).
- Let us know where we can go for support should involvement cause us emotional distress.
- Dedicate a team member who we can speak to for extra support. Think about the most suitable person for this role for example, genetic counsellors.

**"I think it was great having those two [in our Community Advisory Group] - a genetic counsellor that worked in clinic and a genetic counsellor that worked in research, and they really advocated for the consumers as well."**

— Program Coordinator (institute) 5

- Think about upskilling in trauma-informed approaches. There are no certified courses for trauma-informed community involvement in research specifically, however [Phoenix Australia](#) and the [Mental Health Coordinating Council](#) offer online courses that might be of interest.
- Dedicate time to check in with us and have a conversation about changes in capacity.
- Resources that may be useful for practising responsible community involvement with people with intellectual disability can be found on the [GeneEQUAL](#) website. These resources do have a clinical focus however the information can be translated to the research space.
- For more in-depth information on trauma-informed care, see the NSW Health '[Integrated Trauma-Informed Care Framework: My story, my health, my future](#)'.



### 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

Just as you would acknowledge research colleagues, it is important to also acknowledge our contribution to projects. This is a critical element of working with community members.

There are a wide variety of ways to acknowledge our contributions for example, inviting us to co-present at conferences or acknowledging us in annual reports.

Another important way of acknowledging our contributions is asking for our input on manuscripts, conference posters, public-facing documents, or other forms of reporting. This can demonstrate our value and legitimise our contributions to the project.

On the other hand, being an author on an academic paper is not always as meaningful to us as it may be to a researcher. If contributing to a manuscript is not appropriate or not something we are comfortable with, our contributions can still be addressed in the manuscript 'acknowledgements' section (not just as 'community group members' but with individual's names, if preferred) or in other, more relevant ways. It is important to ask us how we would like to be acknowledged on all the public platforms that you present project findings, noting we may have different preferences depending on the platform.

It is important that it is made clear that we have been heard and our voices are reflected in the outcomes of the project. Be transparent, indicate where our contributions have been used and where they have made a difference and had an impact on the project. Conversely, acknowledge when our ideas will not be used and explain why, whether this be for practical resourcing or scope reasons.

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**"You just get a sense of they've got to tick the box. You get a nice meal, you get invited to the meeting ... You sit round with butcher's paper and your round tables. Then you see the outcome and there's not been anything that you've said in there."**

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— Community Member 2

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## SUGGESTIONS

- Discuss with us how we would like to be acknowledged. This can include a discussion about how we would like to be addressed in documented outcomes such as reports, papers or presentations, which may differ from how we would like to be addressed in personal interactions, for example in working group meetings.
- It is important to have these discussions early on in our interactions. If such discussions are left until the end of the project, we may think that our contributions will not be appropriately acknowledged, and this could undermine the trusting relationships that have been built.
- Community member input into presentations or co-presenting can be very effective and a great way to highlight the benefits of community involvement.
- Acknowledge the work we have contributed when the project is concluded. This can foster a positive relationship in the long term.

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**“We just released a new resource ... that's all about recognition and acknowledgement ... You, the organisation recognising the contributions of a consumer, the impact, the influence. And if none of that happened, having a conversation [about] ‘What did you all learn?’”**

— Program Coordinator (institute) 4

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- Given that virtual meetings are now common, you may like to consider inviting us to tour the research institute, laboratories, and workplace. This will give us an opportunity to meet other staff and have our contributions recognised in-person.
- Launch events are also a great opportunity to highlight our contributions to research projects.
- Other ways to acknowledge community members' contributions include verbal acknowledgements in meetings and presentations, listing us on annual reports, websites, and other project reports. Discuss with us where and how we would like to be acknowledged.
- When community members contribute to academic publications, some considerations may include:
  - We may not be familiar with academic publications and dissemination - take the time to develop our skills/understanding in these areas.
  - Use of the [Contribution Roles Taxonomy \(CRediT\) author statement](#), which states various ways a person can contribute to academic publications, including conceptualisation, methodology, provision of resources etc.
  - Community members may not have an institute/organisation affiliation. Instead, you may like to include be acknowledged as a working group member or Community Advisory Group member for the research project. Before assigning an affiliation, it is important to ask us if we think this is appropriate.

- Using [Standardised Data on Initiatives \(STARDIT\)](#) to report on who did which tasks, how we were involved and any impacts of outcomes on the project or the wider community. Refer to [Recommendation 4.2](#) on reporting community involvement processes for more information.
- If an academic publication is inaccessible to the public (for example, behind a pay wall), ensure that the publication is shared with community members involved in the project.



## 4. Evaluating and reporting on your community involvement process



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

Involve Australia's literature review suggested that researchers' community involvement practices should be evaluated. It is usually suggested that evaluation is split into two types:

1. Evaluation of community involvement process (i.e., process-based)
2. Evaluation of community involvement impact on the project (i.e., outcome-based)

Evaluations must provide the space for all parties to provide honest feedback on the involvement activities. This is an opportunity to learn and improve on your community involvement processes. Asking us what we think should be assessed throughout a project can help form an appropriate evaluation strategy.

As addressed in [Recommendation 2.4](#), it is important to define our roles and tasks on a project. However, it is noted that the work being asked of us may change over time. This may be due to change in project direction or a better understanding of skill sets. It is important to re-evaluate our roles to ensure they align with any changes in the project scope.

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##### Evaluation of community involvement process

- The purpose of this evaluation is to ensure researchers are valuing our input throughout the research process, and that involvement practices are appropriate.
- ACTA and CT:IQ highlight that there should be a continuous process throughout a project, that all team members partake in. It can allow for improvements to be made sooner rather than later and can promote better research outcomes.
- This practice also ensures better involvement practices in future research projects.
- This can also promote more effective communication between community members and researchers and address barriers to involvement.

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##### Evaluation of community involvement impact

- This can be more difficult and may need an individualised approach project-to-project.
- As found in Involve Australia's program coordinator and researcher interviews, a key factor that encourages researchers to include community members in their projects is learning from their peers' experiences. By assessing the positive impacts of community involvement, researchers can contribute to the building of an evidence base and encourage community involvement practices among other researchers. Refer to [Recommendation 4.2](#) on reporting community involvement practices for more information.
- Many guidelines state the benefits of community involvement. By conducting these evaluations, our impact on research processes and outcomes, can continue to be highlighted.



## SUGGESTIONS

- Evaluation strategies can be co-designed with us early on in a project.
- Evaluation can be undertaken internally or externally. How evaluation occurs should be discussed with us. If an external evaluation is preferred, then this will need to be considered as part of the project budget.
- If several community members are responding to evaluation questions, comments can be anonymised, to allow us to comfortably share our opinions.
- Evaluation may involve providing all members of the research team with a survey to determine their thoughts on various aspects of involvement. Surveys may be developed with more general questions, or with specific questions for community members or researchers.
- Continuous evaluation throughout the research project should incorporate feedback on expectations of roles and the actual activities and tasks we are asked to complete.
  - Periodic evaluation can ensure we are not being asked too much or too little. We generally want to offer all the help we can, but we often have multiple commitments (for example, being a community member on multiple other research projects, caring for a loved one who may have a genetic or rare disease or our own health and wellbeing) that can impact our capacity to contribute.
  - Make it known upfront (for example, on a Terms of Reference) that community member roles may change throughout the project.
  - These check-ins are also useful to determine if involvement approaches are still appropriate for different stages of the project life cycle.
  - These periodic check-ins do not always need to be a formal process. It may involve a chat between us and an appointed person.



## RESOURCES

Additional evaluation resources and information can be found in the following guidelines:

[Health Consumers QLD's A Guide for Health Staff – Partnering with Consumers \(pg. 31\)](#)

This resource details three levels of evaluation that can be undertaken to assess community involvement processes and why evaluations should be conducted.

[Telethon Kids Institute and University of WA – Planning for Consumer and Community Participation in Health and Medical Research \(pg. 75 and 76\)](#)

This resource provides an example evaluation form aiming to seek feedback from a 'Community Conversation' event held at the Telethon Kids Institute. It includes questions about whether the event met community member expectations, if topics that are relevant to the community were covered, and ways that the event could be improved.

[WA Health Translation Network for Australian Health Research Alliance and National Consumer and Community Involvement Initiative – Involving Consumers in Health and Medical Research \(pg. 47 and 48, Resources 27 and 28\)](#)

Resource 27 provides a set of questions that you can ask community members, researchers and other project members at the end of the involvement or project. Questions allow you to measure the involvement experience.

Resource 28 provides a set of questions that can help all parties of a research team to reflect on the outcomes of the involvement or project.

[AutismCRE – Participatory and Inclusive Autism Research Practice Guides \(pg. 45-50\)](#)

This section of the resource describes how autism researchers can evaluate their community engagement strategies and at what stages of the research process did they engage community. This includes four different templates to guide how to conduct an evaluation (for example, questions for a semi-structured evaluation interview on pg. 48).



## 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

Many projects already involve community representation. However, the lack of a standardised approach to reporting this involvement in academic publications and other formats means there is no strong evidence base on the impact of our involvement.

Reporting on community involvement processes demonstrates to other researchers the benefits of including us and makes it easier for others to engage with us more effectively by learning from each other's experiences. The transparency of your involvement processes shows other researchers how they can responsibly and effectively involve community members.

Involve Australia and the Global Alliance for Genomics and Health's (GA4GH's) Regulatory and Ethics Working Group suggest the use of '[Standardised Data on Initiatives](#)' (STARDIT) reporting tool. For example, you can view more information on Involve Australia's community involvement process in our [STARDIT report](#).

There are other tools to report on involvement, including:

- [Guidance for Reporting Involvement of Patients and the Public 2 \(GRIPP2\) reporting checklists](#)
- [Public Involvement Impact Assessment Framework \(PiiAF\)](#)



### SUGGESTIONS

- Use one of the suggested forms above (GRIPP2 or STARDIT) when planning community involvement, as they can walk you through various things to consider when involving community members in a project.
  - Academic publications can benefit from the addition of completed GRIPP2 or STARDIT forms, provided as supplementary information or included in the methods section.
  - Community members can also be involved in updating STARDIT reports, including reporting impacts and outcomes. This ensures that the community are empowered alongside researchers to be involved in such reporting.
- It is also worthwhile considering non-academic reporting avenues where appropriate. Community members may have suggestions about where the public and/or patient support and advocacy groups go to find information.







## 5. 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

Real-world application or translation of research outcomes focuses on bridging the gap between knowledge gained through research and its use in policy and practice – it is the process of moving research ideas to diagnostic labs and clinics. This is where it can begin to make a difference to the community or public.

Given the breadth of research projects in genomics, from foundational studies to clinical trials, translation outcomes can vary greatly.

**“There is the end user or the end beneficiary of that product or service, [who] has a fundamentally useful view to input at all stages of the development and the design of that product or service.”**

— Program Coordinator (institute) 5

Translation of research findings into useful outcomes for health system users should be addressed in the early stages of project planning. This ensures that you are designing a research project that will make a difference in people's lives. In Involve Australia's survey, 42 per cent of people were interested in translation of research outcomes.

Using our knowledge and experience to aid tangible outcomes for the end users can promote greater community acceptability of research findings. Include us in conversations about translation as we may provide a greater understanding of the real-world implications of findings.

Research does not always lead to an implementable outcome, instead it may inform the next piece of research. Future directions for research can also be informed by our perspectives.



### SUGGESTIONS

- ▶ Discuss translation early on in project planning and seek our perspectives. Communication should continue throughout the project.

*Example project:* Dr Anna Singleton's [EMPOWER-SMS project](#) is a good example of co-design and its impact on real-world use of research findings. Women with or who had breast cancer were asked to evaluate lifestyle-focused support text messages aimed to help women post-treatment. This led to more highly evaluated message templates chosen for the program and edited by community members.

*Example project:* QIMR Berghofer and Queensland Genomics' [IG-HeLP project](#) involved 12 Aboriginal and Torres Strait Islander people from across Queensland (including regional and rural areas) to develop resources to educate and inform

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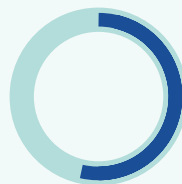
Aboriginal and Torres Strait Islander consumers and health workers on the topics of DNA, genes, genetic health, genetic testing and precision medicine. Resources include the animation '[Your Blood, Your Story](#)', and several brochures for each Queensland region containing custom artwork from a local Indigenous artist.

- ▶ Keep us involved in future conversations on project translations.
- ▶ [STARDIT](#) can also be used to report continuously on project impact and outcomes, even after funding has ceased. Capturing this information helps to highlight translational outcomes so future research can benefit.

## 5.2 We may have a strong network with our communities. Include us in conversations about sharing research findings with those who will be impacted by them

Of all research tasks, the public are most interested in being informed about research outcomes. Dissemination of research findings to relevant communities should be a focus at the conclusion of project, but it can also be useful to share updates during the project.

Researchers should harness our knowledge and our networks to promote research findings to communities that will benefit from this knowledge.



**59%**

of Australians surveyed stated they would like updates on the progress of research

Patient support and advocacy groups are well placed and often experienced in advocacy. These groups can play a significant role in advocating for systemic change. Look to share research outcomes with these groups to aid translation.

The interest in and acceptance of study findings by the relevant communities can have its challenges. If strong and respectful relationship building has been carried out early and throughout the project, this can lead to more impactful research.



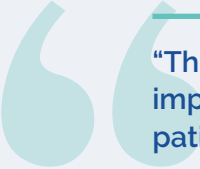
## SUGGESTIONS

- Write a plain language summary (or Easy Read or Easy English summary if we require) of research outcomes for patient support and advocacy group newsletters as an additional avenue of dissemination. Use our knowledge and skills to help write public-facing materials and determine how best to communicate them to the relevant communities.
  - See the article '[Generating Plain Language Summaries of Scientific Publication with Ethical Foundations](#)' for a practical how to guide.
- Share papers and/or reports with community members who have been involved with the project in a timely manner. We too have invested our time into these projects and are interested in the outcomes and what they mean for the communities we represent.
- Co-create [graphic abstracts](#) or infographics with us. These can be a great way for us to share the most important points of the project with the broader community.
- The '[University of NSW Disability Innovation Institute community involvement guidelines](#)' suggest how co-design of dissemination materials may be done. Some of their suggestions include researchers and community members co-presenting at conferences, development of plain language documents to describe findings, making a video of findings etc.
- Ask community members what online communities or networks they interact with as there may be potential opportunities within these to share findings.

## Final word

Involve Australia intends for these guidelines to support responsible and meaningful community involvement practices. This will allow both researchers and community members to be part of projects that will have a lasting impact. By encouraging the standardisation of practices, Involve Australia hopes genomic research will progress in an inclusive, equitable and ethical manner. Sharing community involvement experiences and learning from others will promote more effective community involvement in future.

Involve Australia aims to update and adapt these guidelines as we learn more.



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**“The common theme through all my diverse projects [is] about trying to improve the patient journey. And if you’re doing that without involving the patients, you’re kind of stumbling at the first block.”**

— Researcher 2

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<b>Co-design</b>	the meaningful involvement of research users during the study conception and planning phase of a research project, where 'meaningful involvement' is taken to refer to participation in an explicitly described, defined and auditable role or task necessary to the planning and/or conduct of health research ( <a href="#">Slattery et al 2020</a> ).
<b>Community</b>	a group of people sharing a common interest (for example, cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research ( <a href="#">NHMRC, 2016</a> ).
<b>Community member</b>	a member of a community ( <a href="#">NHMRC, 2016</a> ).
<b>Consumer</b>	patients and potential patients, carers, and people who are the end users of genomic health research ( <a href="#">adapted from ACTA &amp; CT:IQ</a> ).
<b>Engagement</b>	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 ( <a href="#">ACTA &amp; CT:IQ</a> ).
<b>Involvement</b>	when consumers and community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy, and practice ( <a href="#">ACTA &amp; CT:IQ</a> ).
<b>Participation</b>	where an individual voluntarily takes part in a research project after giving informed consent ( <a href="#">ACTA &amp; CT:IQ</a> ).
<b>Public</b>	collectively, 'consumers' and 'community members' may be referred to as 'the public' ( <a href="#">NHMRC, 2016</a> ).
<b>Stakeholder</b>	an individual or group from within or outside research organisations with a key interest in research. This might include members of consumer organisations, professional bodies, government agencies, non-government organisations, industry, or research funders, as well as consumers and community members. Stakeholders can provide support or expertise and may influence decisions about the research and its findings ( <a href="#">NHMRC, 2016</a> ).

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# Appendix 1

## Project Leads



**Monica Ferrie**  
CEO, Genetic Support  
Network of Victoria



**Anne McKenzie AM**  
Adjunct Research Fellow, The  
University of Western Australia



**Sean Murray**  
CEO, Mito Foundation;  
Community Advisory Group,  
Australian Genomics

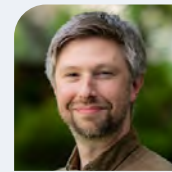
## Working Group Members



**Tiffany Boughtwood**  
Managing Director,  
Australian Genomics



**John Cannings OAM**  
Cancer patient representative;  
Community Advisory Group,  
Australian Genomics



**Jack Nunn**  
Director, Science for All; Public  
Involvement Strategic Lead,  
La Trobe University



**Gregory Pratt**  
Principal Research Fellow, Office  
of Indigenous Engagement,  
Central Queensland University



**Fiona Russo**  
Parent representative;  
Researcher, Centre for  
Resilient Regions, University of  
Southern Queensland

## Project Coordinators



**Keri Finlay**  
Project Coordinator, Involve  
Australia, Australian Genomics



**Isabella Sherburn**  
Project Officer, Involve Australia,  
Australian Genomics

## How were community members involved in the development of these guidelines?

Community members were involved as Involve Australia Working Group members. Members of the working group are primarily involved in health consumer advocacy groups/organisations. Several members are service users themselves. Other working group members are professional researchers.

The tasks of the Involve Australia Working Group were to progress Involve Australia activities by providing input and advice on methods used to conduct the scoping review, involve the public effectively, and how best to evaluate the impact of guidelines, as well as revision of key output documents before they are made available publicly. Working Group members were offered an honorarium for their contributions to the project.

Working group members attended monthly formal working group meetings via videoconferencing. These meetings informed members of project updates and provided time for discussion and feedback on key documents. Key documents were also made available outside meetings for review.

## How were community members involved in each of the data collection methods?

There were three data collection methods:

1. Scoping review
2. Public-facing health research perceptions survey
3. Interviews with community involvement program coordinators, institute leads, researchers who involve community members and community members.

The table below states the various tasks community members undertook for each of the data collection methods.

Method	Working group member tasks
Scoping review	<ul style="list-style-type: none"> <li>• Provided feedback on what types of data should be extracted.</li> <li>• Provided resources for inclusion in review.</li> <li>• Undertook data extraction for cross-checking purposes.</li> </ul>
Health research perceptions survey	<ul style="list-style-type: none"> <li>• Provided feedback on survey questions and data to be collected.</li> <li>• Testing survey.</li> <li>• Assisted with survey data analysis (quantitative and qualitative).</li> <li>• Assisted with recruitment by emailing survey invitations to their networks.</li> </ul>
Interviews	<ul style="list-style-type: none"> <li>• Provided feedback on interview questions.</li> <li>• Assisted with recruitment by emailing interview invitations to their networks.</li> </ul>



## Promoting effective community involvement in genomic research

**Australian  
Genomics**



50 Flemington Road, Parkville, Victoria 3052 Australia

03 9936 6345

[info@australiangenomics.org.au](mailto:info@australiangenomics.org.au)

[australiangenomics.org.au](http://australiangenomics.org.au)