Australian Genomics

GUIDELINES FOR COMMUNITY INVOLVEMENT IN GENOMICS RESEARCH

Led by community

Coordinated by
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.

A note on terminology

There are several terms that are used to refer to community members, including 'consumer', 'patient', 'public', and 'stakeholder'. The National Health & Medical Research Council (NHMRC) (2016) suggests the terms 'consumer' and 'community'.

These guidelines use the term 'community member', where **community** is defined as: *a group of people sharing a common interest (e.g. 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* (NHMRC, 2016).

We suggest that when first involving community members on the research team, you ask them what terminology they prefer.

We suggest that when using the word 'community member', care is always taken to ensure the labels for the communities are co-created, co-defined and that people self-identify as members.

We define a **participant** as *a person who voluntarily partakes in human research after giving informed consent to be the subject of the research (i.e. passive participation).*

Definitions for the terms 'involve' and 'engage' have been taken directly from Australian Clinical Trials Alliance (ACTA) & Clinical Trials: Impact and Quality (CT:IQ).

Involvement: *when consumers and community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy and practice* (ACTA & CT:IQ).

Engagement: *when information and knowledge about research is shared with consumers and the community so that they are better informed on why, how, where and by whom research is conducted* (ACTA & CT:IQ).

Contents

Executive summary

In recent years, there has been an increasing demand for community involvement in health research projects. This need is consistent with and in recognition of the international and Australian evidence confirming the value of community involvement. The research field is being influenced by community advocates and researchers appreciating the of benefits community involvement.

The value is further recognised by funders expecting that research involves community members and supporting research that includes a community perspective. The public are also the ultimate beneficiaries of health research, and their active involvement in research is becoming more common and called-for as a more ethical approach.

According to Involve Australia's 2022 survey, 50% of the Australian public report they have a chronic health condition. However, community members who have lived experience of a health condition that 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.

50% of respondents are living with a health condition

4% of respondents with a health condition are involved in research
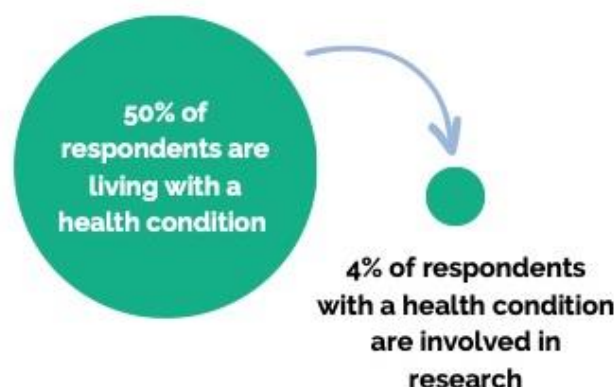
> "They explain what they're doing when you meet with them, and that's about the end of it, until they say, "Uh-oh, I've got to have something signed tomorrow," and you never hear anything... You just feel like you're just there because you have to be there."
>
> **Community Member 3**

Involve Australia, a community-led project coordinated by Australian Genomics, is informed by a diverse working group which includes patient advocates, support group leaders and researchers collaborating to give the public a stronger voice in genomic research and its translation into clinical practice. The project aims to inspire and enable people to be involved meaningfully in all parts of genomic research by bringing together patients, broader community representatives, patient advocacy and support groups, and the clinical and research community.

A key outcome of the Involve Australia project is the development of these guidelines, which aim to provide genomic researchers in Australia with a blueprint for how to involve community members effectively and meaningfully in research projects. As clinical genomic practice is relatively new, genomic researchers have a unique opportunity and responsibility to include community perspectives into research design, conduct, and translation.

Benefits of community involvement in genomic research

Including community members in research supports the delivery of research outcomes that align with community needs and are more likely to be translated into practice. This also lays a foundation for research that is more acceptable to the public.

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

Key findings of the Involve Australia project

This project surveyed the Australian public on their perceptions of health research, interviewed community members, researchers, community involvement program coordinators and institute leads, and reviewed existing community involvement guidelines in 2022 and 2023.

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 of research findings;
- Existing relationships with community members can lead to more effective community involvement;
- Adequate resourcing (e.g. 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;
- Limited reporting and evaluation of community involvement practices, and;
- 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 contextual information, practical strategies to address each recommendation, and useful resources found through 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 they have been written from the voice of the community *to researchers*.

These recommendations provide a framework to work within, 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.

Relationship building

Build respectful relationships with us that allow for an open dialogue.

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

Consider diversity when involving community members. Listening to diverse voices enables research to benefit a greater number of communities.

Communication is a two-way process that is integral to meaningful research. Co-designing a communication plan with us, for participants and the broader community, will promote well informed and acceptable research.

To foster mutual respect, discuss with us how we would like to be identified within a project.

Setting Expectations

Decide whether we will represent ourselves or a specific community. Making this clear will determine whether we are the right fit, and inform involvement design.

Every community member is different and will require different things. Discuss with us how we would like to contribute and what can support our involvement.

We are experts in our lived experience but may not be familiar with genomics. Take the time to improve our knowledge on the project and genomics more generally.

Agree on a shared core goal(s) for the project with our input. This will allow us to work together with a clear objective and help shape our role(s) within the project.

Valuing Community Members

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

We may get involved because of personal experience and will draw on these experiences to inform our contributions. Using a 'trauma-informed' approach can provide inclusive and appropriate support.

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

Evaluating and reporting on your community involvement process

How we are being involved should be evaluated throughout the project. This encourages continuous reflection and adaptation of the involvement process.

Our roles as community members can change over the course of a project. It is important to re-evaluate our roles to ensure it aligns with any changes in scope.

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 genomics research.

Real-world applications of your research

Translation of research findings into real-world changes can directly benefit the community. By drawing on our lived experience we can inform translation so that it meets the needs of the community.

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

Introduction

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

> "I had some women with me who'd had breast cancer and the researchers 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 (PSAG) 1**

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

Why were these guidelines developed?

These guidelines aim to encourage genomic researchers in Australia to involve us, 'community members', effectively and meaningfully in co-designing research projects. We know that researchers want to include us, but sometimes they do not know how.

Including community members in your research supports the delivery of research outcomes that are more community-focussed and translatable. This also lays a foundation for research that is more acceptable to the public. This is particularly important in genomics, where the application of testing into clinical practice is relatively new. We believe genomic research has a unique opportunity and responsibility to include our perspectives into research design, conduct, and translation.

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

Working group members (Appendix I) met monthly to discuss study documents, data collection and analysis (Appendix II). Capturing the voice of the community was critical to developing these guidelines. These guidelines have been informed by the Involve Australia Working Group, a review of existing Australian-based community involvement guidelines, a large public perceptions of health research survey and interviews with community members, researchers, community involvement program coordinators and institute leads.

For more information on Involve Australia's community involvement process, please see our STARDIT report here.

Although these guidelines have been written for genomic researchers, we believe they are relevant for community members as well as all types of healthcare researchers, and we encourage their use in other fields.

We hope that these guidelines encourage researchers to take the first step to a more inclusive future.

> "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**

Relationship building

___

Build respectful relationships with us that allow for an open dialogue.

Developing strong and productive relationships with us is essential for effective community involvement and inspiring research that will have real-world benefits.

The public are interested in research, however they are not all aware that they can get involved. Think broadly about where you can connect with community members.

> "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**

Speaking to patients can also be a great opportunity to conceptualise meaningful and relevant project ideas.

Much like the relationships that you build with your research colleagues to foster a good working environment, similar efforts should be made with community members. Make us feel like valued members of your team and that our opinion and experience is respected and holds the same weight as other team members. This will ensure that we are all treated as equal partners.

> "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."
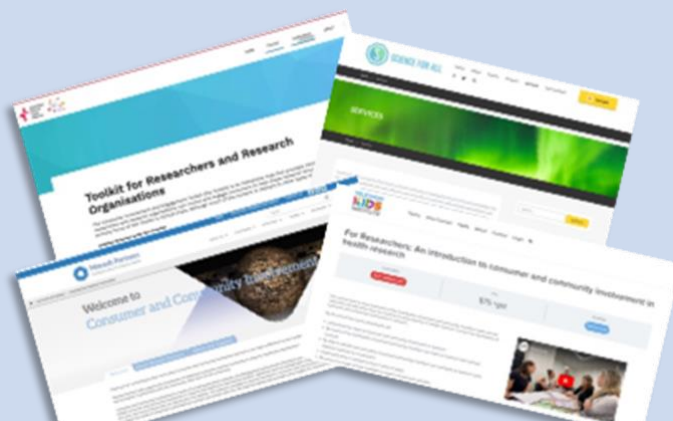>
> **Community Member 1**

Keep in mind that community members 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. Investing time in your relationship with community members before, during and after research projects ensures we feel valued and can promote more effective collaboration.

- Training specifically for both community members and researchers on working together can help build working relationships, help improve ways of working and mutual expectations.

> "We [researchers] should be trained in what best practice is and how best to work with consumers."
>
> **Researcher 2**

- 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.

> "They do take me out for lunch. That makes quite a difference, and that's when we do most of the chatting, personal chatting. But that makes a big difference to me."
>
> **Community Member 3**

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 (PSAG) 1**

- Freely available resources for community member training include:
  - Telethon Kids Introduction to consumer and community involvement in health research
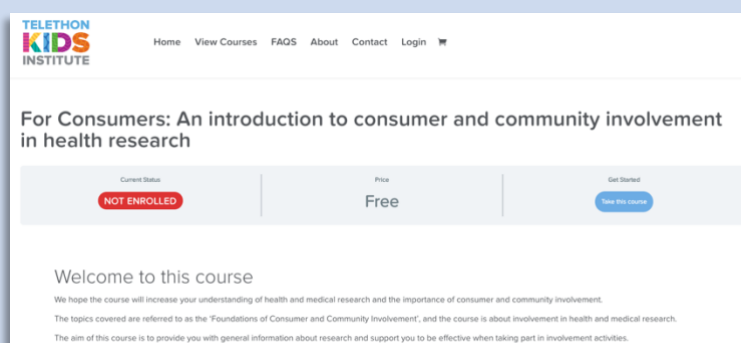
Involve us as early as possible, we can contribute to all parts of the research and can be invaluable in the early stages.

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

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

> "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**

How to do this

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

- Priority setting:
  - o Use established methods for involving community members in setting priorities (e.g. James Lind Alliance Priority Setting Partnerships)
  - o Research is informed by what is important to the community
  - o Make projects more relevant for the community, the ultimate beneficiaries of your research
  - o Make projects more translatable

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 evidenced-based resources on genomics and its implications. The GenomicsInfo website features a whole range of easy-to understand 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 PSAGs.

Genomic information for you and your family

Genomic testing may be used in your medical care if your doctors think there is a chance of you having a genetic condition. Doctors and researchers are learning more about genomics, and how it can help in different medical situations. But it can be hard to find reliable, up-to-date information on genomic testing, and what it might mean for you. This website and the Genomics in the Community project are designed to help you find those answers.

What is Genomics?   Genomic testing   More Resources

- Grant writing: We can add a different and important perspective to grant applications including translation, impact, community engagement 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 demanding 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.

> On the Mackenzie's Mission project, gene selection meetings were attended by community investigators to ensure a community voice was heard on this ethically challenging topic.

- Planning participant recruitment strategies
  - Ideas for recruitment pathways
  - Providing advice on practical barriers to recruitment and data collection methods

> "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**

  - Language used and recruitment promotion (e.g. previous participant stories demonstrating the value of being involved in research)

- Dissemination
  - How to share research results with relevant communities in a way that can encourage community acceptance
  - Methods and modes of dissemination (e.g. video, social media)

Dr. Noc shares short videos explaining relevant health information to the public, breaking down research into understandable pieces.

- Translation is a key element in the research process which community members can take part in. For example, community members have played a significant role in advocacy to government. 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 community members may partake in various stages of research (p 8).
- Monash Partners provide a useful summary table on the ways community members 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 (PSAG) 1

Consider diversity when involving community members. Listening to diverse voices enables research to benefit a greater number of communities.

Groups that are seldom heard 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.

The genomics field is beginning to acknowledge this need for change as outlined in a recent publication by the American Society of Human Genetics.

Currently, community members surveyed by Involve Australia who are 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% 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.

Please note these guidelines do not go into detail on involving and conducting research with 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
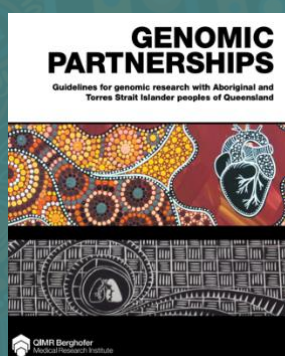
How to do this

- Build relationships and be conscious that diverse community members may have had previously poor experiences with the healthcare system, so take particular care to make them feel safe, valued and welcome in the research space.

- Allow space to hear our negative experiences (this includes non-diverse community members). These experiences can inform stronger research outcomes, however expressing this may be emotional. It is important to keep our wellbeing in mind, which may include debriefing afterwards. See our recommendation 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 see our recommendation on representing communities.

- Consider our cultural differences, language barriers, and disabilities. Additional support may be required for our involvement in the project. The best way to establish these needs is to talk to community members.

"

"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

"

Communication is a two-way process that is integral to meaningful research. Co-designing a communication plan with us, for participants and the broader community will promote well informed and acceptable research.

Communication plays an extremely important role in research, including how a project is perceived by community members, participants, and the broader community. Having a clear communication 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 plan and involving community members in writing and checking planned communications can help ensure it is more effective.

Early in the project, begin to think about how you will 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.

Researcher

Participants

Community members

Broader community
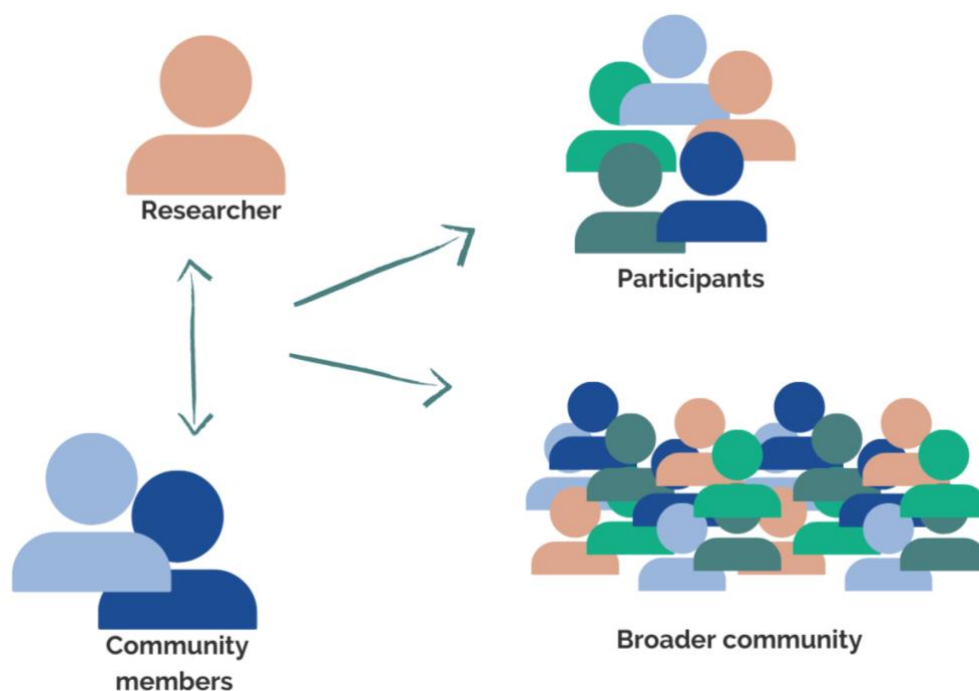
How to do this

Your communication plan will need to address three key audiences:

Community member/s

- Consider how to engage community members and how you will present your project to us. Community members can provide valuable input at the earliest stages of project conceptualisation and development as noted in a previous recommendation.
- When a community member has agreed to be involved in your project, identify a key contact person for us in the investigator team who we can talk to about project-related and administrative matters (e.g., payment, document and building access) and raise questions. Provide us with this information early on.
- Include in your communication plan detailed information such as a Terms of Reference for any formalised group – which should include information about meeting occurrences, primary modes of communication (e.g., email, teleconferencing), conflict resolution strategies and relevant codes of conduct.

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 plan with potential participants. This may include communicating how the project is progressing, appropriate methods for return of results, and modes of communication for sharing of research findings.

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. This can ensure acceptance of the research project and translatable outcomes.

To foster mutual respect, discuss with us how we would like to be identified within a project.

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

Parent

Consumer

Community member or representative

Person affected

Carrier

Patient

Carer

Service user

Interested member of the public

People may choose to identify as....

How to do this

- Early in your interactions with us, ask how we would like 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.

Setting expectations

Decide whether we will represent ourselves or a specific community. Making this clear will determine whether we are the right fit, and inform involvement design.

An individual cannot 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.

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. Also provide an appropriate timeline and necessary resources to undertake this.

How to do this

- If you would like us to provide a community perspective, this will usually require a more formal method of involving community members. This method might require ethics approval. Develop your planned method of involving people with us. 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 of our community if given enough time and resources to collect this information.
- 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.

"

"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

Every community member is different and will require different things. Discuss with us how we would like to contribute and what can support our involvement.

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 allows us to integrate workloads into our lives.

How to do this

- Talk to us about how we would like to or are able to contribute to the project. This includes things like:
    - preferred communication method
    - timing and structure of meetings (e.g. meetings during working hours may be challenging for us to attend)
    - time required to review content prior to meetings
    - timeframes for providing feedback
   - providing plain language summaries of documents where appropriate

We are experts in our lived experience but may not be familiar with genomics. Take the time to improve our knowledge on the project and genomics more generally.

As community members on a research project we may feel intimidated: 26% of Australians surveyed stated they lacked confidence to be involved in research. It is important to consider this dynamic during team meetings.

Genomics is a complex field, and it is likely we will not have an expert understanding of the science when we join a project.

Upskilling us on topics relevant to the project will build our confidence and 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
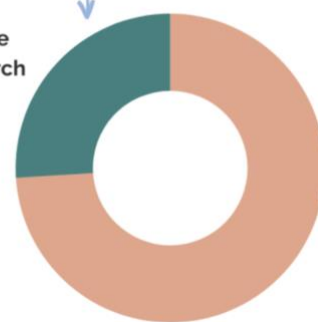
How to do this

- 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 learning and development may be required.

- Provide us with an information session on some key concepts prior to first meeting with the team. Go through the project proposal and provide context around the project in plain language. It is also important to consider, as community members, the 'why' of the project and explain how this research will help patients.

- Ask us if we would like to have further discussions or additional materials provided to supplement this session. See GenomicsInfo for plain language resources.

> "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**

- Avoid using jargon and acronyms wherever possible. Provide us with a glossary of commonly used acronyms and terminology.

- During meetings, check with us if your explanations are appropriate or if we need clarification. This can also encourage us to ask more questions during the meeting when we feel unsure.

- Informal discussions with us outside of meetings can provide an environment for us to ask any questions we may not have felt comfortable to ask during the meeting.

Agree on a shared core goal(s) for the project with our input. 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.

61% 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.

> "It's all about giving back."
>
> **Program Coordinator (PSAG) 1**

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 with us towards a shared goal:

> "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**

However, there may be other reasons (e.g. 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.

> "This was my best experience of consumer engagement because it was a true partnership. We had secretariat, we had professionals and patients around the table."
>
> **Community Member 2**

How to do this

- Ideally, goals should be discussed prior to grant applications being submitted. This means relationship building early on (see <u>our recommendation on shared goals</u>).
- 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 these discussions. Therefore, it is helpful to have these discussions early in the project.

> "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**

- Have a clear 'why' that all team members agree on.
- Early in the project, clearly define team member tasks. Tasks may also change throughout your project. See <u>our recommendation on evaluating community member roles</u> for ways to address these changes.

Valuing community members

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 their role in research should be valued and respected. Their contributions should be considered with the same weight as other researchers.

> 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.
>
> **Community Member 2**

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. Payment can be a factor that encourages participation and shows contribution is valued.

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.

The Australian Tax Office states "honorary rewards for voluntary services are not assessable income and related expenses are not deductible" ATO website which is why these guidelines use the term honoraria/honorarium

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.

How to do this

- Your institute may already have a payment policy in place that you can follow. 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.

- Sometimes the terminology used to describe payment may have tax or benefit implications for the community member. Researchers and institutes/organisations should be mindful of this when organising and offering payment.

- If your institute/organisation does not have a relevant policy but you would still like to offer payment, there are several models you can use. Here are the links to some examples:
    - Australian Genomics
    - Health Consumers QLD
    - NSW Health Consumers
    - VCCC Alliance

- Different states and territories may also have different payment suggestions. You may use these as a guide if your institute/organisation does not have a policy in place.

- We might have different preferences regarding how we would like to be paid. Discuss with us what our payment options are.

- The process for payment should be inclusive and accessible. However, this may be limited by what your institute/organisation can offer. Attempt to streamline processes for payment where possible to reduce the administrative burden (e.g. provision of template invoices)

We may get involved because of personal experience and will draw on these experiences to inform our contributions. Using a 'trauma-informed' approach can provide inclusive and appropriate support.

Good community involvement is supportive. This may include using a 'trauma-informed approach', which is "based upon principles of safety, choice, collaboration, empowerment, and trustworthiness." Key to this is creating welcoming and safe working spaces. These principles should be applied across all elements of community involved research.
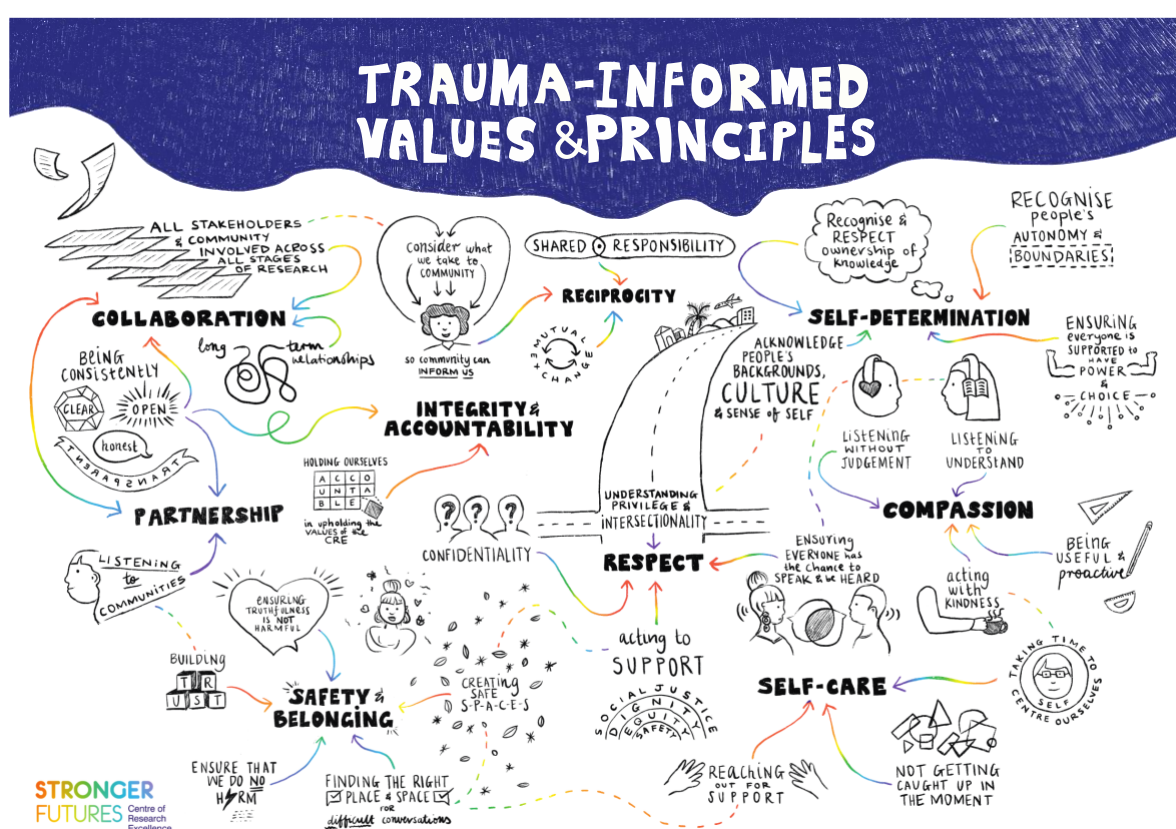
Created by visual artist and CRE Scholar, Rowena Coe for Stronger Futures Centre of Research Excellence

Due to our lived experience, we may have closer proximity than researchers to potentially challenging stories shared by participants. Survey responses indicate that 17% of people find research confronting, 26% lack the confidence to become involved in research and 13% believe researchers are unapproachable. Keep these factors in mind.

> "It's about being aware of [the fact that] genomics conversations can be very emotionally triggering"
>
> **Researcher 2**

You should aim to check in with us periodically through the project. We may not always wish to share our stories and our desire to share our story 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.

We can develop burnout for a variety of reasons, including changes in our 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. See our recommendation on individualised involvement approaches for more information.

How to do this

- 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

- Let us know where we can go for support should our involvement cause us emotional distress.
- Dedicate a team member who we can speak to for extra support. Think about who on your team would be suitable for this role e.g. 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. Although there are no certified courses for trauma-informed community involvement in research specifically, you may find courses from Phoenix Australia and the Mental Health Coordinating Council.
- Dedicate time to check in with us and have a conversation about changes in capacity.

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 your colleagues, it is important to also acknowledge our contribution to projects. This is a critical element of working with community members.

Asking for our input on manuscripts or other forms of reporting can demonstrate our value and legitimise our contributions to the project.

We can also edit and provide feedback on manuscripts and other dissemination materials, so they are written in a way that is understandable to a wider audience.

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 or in other, more relevant ways.

How to do this

- Discuss with us how we would like to be acknowledged.
- 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.

> "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**

- We may not be familiar with academic publications and dissemination - take the time to develop our skills/understanding in this area.
- Other ways to acknowledge community members contributions include payment, verbal acknowledgements in meetings and presentations.

- When community members contribute to papers, some considerations may include:

  o Use of the [CrediT author statement](#), which states various ways someone can contribute to a paper including conceptualisation, methodology, provision of resources etc.

  o Community members may not have an institute/organisation affiliation. Instead, you may like to include us as a working group member or Community Advisory Group member for your project. Before assigning an affiliation, it is important to ask us if we think it is appropriate.

  o 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. See [our recommendation on reporting community involvement processes](#) for more information.

Evaluating and reporting on your community involvement process

How we are being involved should be evaluated throughout the project. This encourages continuous reflection and adaptation of the involvement process.

Involve Australia's literature review suggested that 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)

Evaluation of community involvement process

- The purpose of this evaluation is to ensure we are being valued in the research process, and that your involvement practices are appropriate.
- ACTA and CT:IQ highlight that this 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.
- This can also promote more effective communication and address barriers to involvement.

Evaluation of community involvement impact

- This can be more difficult and may need an individualised approach project-to-project.
- As found in program coordinator and researcher interviews, a key factor that encourages researchers to include community members in their projects is through learning from their peers' experiences. Therefore, evaluation of community involvement impact can contribute to the building of an evidence base, which can encourage community involvement practices. See our recommendation on reporting community involvement practices for more information.
- Many guidelines state the benefits of community involvement. By conducting these evaluations, we can continue to highlight our positive impact on research processes and outcomes.

How to do this

- 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.
- Honest evaluations should not negatively impact researcher-community member relationships. If evaluations are likely to negatively impact relationships, then external evaluation may be more appropriate.
- 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.
- Additional evaluation resources and information can be found in the following guidelines:
  - HCQ's A Guide for Health Staff – Partnering with Consumers (pg. 31 – additional information)
  - Telethon and UWA – Planning for Consumer and Community Participation in Health and Medical Research (pg. 75 and 76 – template evaluation form)
  - WAHTN for AHRA and National CCI Initiative – Involving Consumers in Health and Medical Research (Resources 27 and 28)
  - Den Houting - Participatory and Inclusive Autism Research Practice Guides (templates on pages 46-50)

Our roles as community members can change over the course of a project. It is important to re-evaluate our roles to ensure it aligns with any changes in scope.

As addressed in an earlier [recommendation](#) it is important to define our roles and tasks on a project. However, it is noted that over time the work being asked of us may change. This may be due to change in project direction or a better understanding of skill sets.

How to do this

- Continuous evaluation throughout the project should also 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 want to offer all the help we can, but we often have multiple commitments (e.g., 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.

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 genomics 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). There are many other tools to report on involvement, including:

- o GRIPP2 reporting checklists
- o Public Involvement Impact Assessment Framework (PiiAF)

How to do this

- Use one of the suggested forms above 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.

Real-world applications of your research

Translation of research findings into real-world changes can directly benefit the community. By drawing on our lived experience we can inform translation so that it meets the needs of the community.

Research translation focuses on bridging the gap between knowledge gained through research and its application in policy and practice - it is the process of moving research ideas to diagnostic labs and clinics. Given the breadth of research projects in genomics, from foundational studies to clinical trials, translation outcomes can vary greatly.

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. Forty-two percent of people are interested in translation of research outcomes.

> "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**

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 have 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.
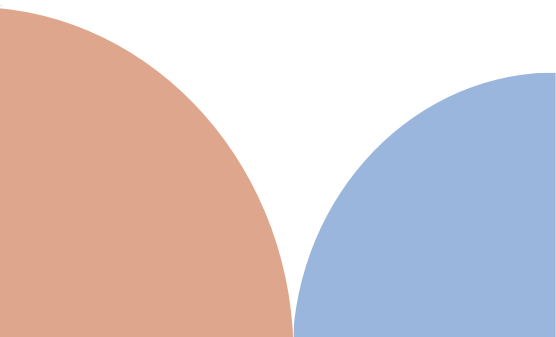
How to do this

- Discuss translation early on in project planning and seek our perspectives. Communication should continue throughout the 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-focussed 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.
- Keep us involved in future conversations on project translation.
- 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.

> "Researchers need to be able to translate their research or their project into something that can be understood by the lay person, by, so that's part of our consumer reps' role really, is to provide the input into [if] this is a suitable thing to be doing or not. But then also, to help translate it into language that other people can understand."
>
> **[Program Coordinator (PSAG) 1**

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

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. Of all research tasks, the public are most interested in being informed about research outcomes.

To promote your work to communities that will benefit from this knowledge and more broadly, researchers should harness our knowledge and our networks.

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 with these groups the outcomes of your research to aid translation.

59% of Australians surveyed stated they would like updates on the progress of research
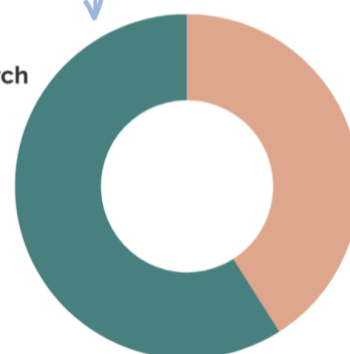
How to do this

- Write lay summaries of research outcomes for patient advocacy and support group newsletters as an additional avenue of dissemination. Use our knowledge and skills to help write these community facing materials and figure out how best to communicate them to the relevant communities.

- The UNSW community involvement guidelines suggest how co-design of dissemination materials may be done. Some of their suggestions include: researchers and community members presenting together 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 hopes these guidelines will support responsible and meaningful community involvement practices, and allow both researchers and community members to be part of projects that will have a lasting impact. By encouraging the standardisation of practices, we hope the field will progress in an inclusive, equitable and ethical manner. Sharing community involvement experiences and learning from others can promote more effective community involvement in future.
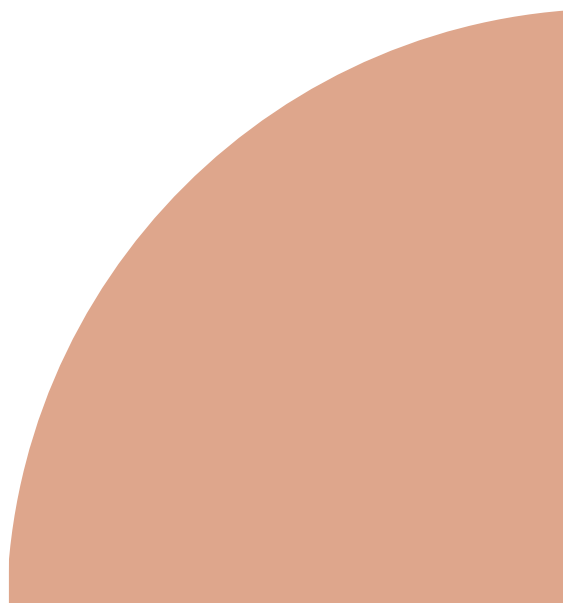
Involve Australia aims to update and adapt these guidelines as new learnings emerge.

> "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**

Appendix I

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

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, Manager of Aboriginal and Torres Strait Islander Health Research, QIMR Berghofer Medical Research Institute

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

Project Coordinators

Keri Finlay, Involve Australia Project Coordinator, Australian Genomics

Isabella Sherburn, Involve Australia Project Officer, Australian Genomics

Appendix II

___

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 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	• Provided feedback on what types of data should be extracted • Provided resources for inclusion in review • Undertook data extraction for cross-checking purposes
Health research perceptions survey	• Provided feedback on survey questions and data to be collected • Testing survey • Assisted with survey data analysis (quantitative and qualitative) • Assisted with recruitment by emailing survey invitations to their networks
Interviews	• Provided feedback on interview questions • Assisted with recruitment by emailing interview invitation to their networks