Involve Australia

Community involvement in genomic research

June 2025

Australian Genomics

Acknowledgement of Country

In the spirit of reconciliation Australian Genomics acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea, and community.

We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Artwork by Yorta Yorta artist, Alkina Edwards, for Australian Genomics.

Involve Australia

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Author Acknowledgement

Project Leads	
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Project Coordinators	
Keri Finlay	Involve Australia Project Coordinator, Australian Genomics
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Executive Summary

Project Overview

Involve Australia, a community-led project coordinated by Australian Genomics, is informed by an expert working group which includes patient advocates, patient support and advocacy 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 support and advocacy groups, and the clinical and research community.

Methods

Development of the Guidelines was informed by a literature review of existing Australian community involvement resources, a survey of the public's perceptions of being involved in health and medical research, stakeholder interviews with researchers and community members involved in research, and working group discussion and analysis of findings. The Guidelines then underwent a public consultation and an additional community member review to ensure the community voice was still at the forefront of the resource. The Guidelines were published in November 2023 and have undergone a pilot with two research projects to assess it use in practice.

Key Outcomes

A key outcome of the Involve Australia project was the development of the Guidelines for Community Involvement in Genomic Research, which aim to provide genomic researchers in Australia with information for involving community members effectively and meaningfully in research projects.

Impacts

The Guidelines, as well as additional resources developed through the project including the AG consumer honorarium policy, are being implemented by AG-supported research projects and others to improve their community involvement processes.

Recommendations

In future, the Guidelines should be revised and improved based on evidence collected through their use in practice. Involve Australia may benefit from expanding its scope beyond genomic research as the Guidelines are relevant more broadly in health and medical research.

Introduction

Involve Australia, a community-led project coordinated by Australian Genomics, is informed by an expert working group which includes patient advocates, patient support and advocacy 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 support and advocacy groups, and the clinical and research community.

A key outcome of the Involve Australia project was the development of the Guidelines for Community Involvement in Genomic Research, which aim to provide genomic researchers in Australia with information for involving community members effectively and meaningfully in research projects. 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 diagnosis, access to treatment, and growth of precision medicine and gene therapies. All of which will benefit from the lens of lived experience to facilitate equitable and responsible implementation.

Aims

- To develop a set of community involvement guidelines for genomic researchers, prioritising the voice of community members.
- To pilot and evaluate the community involvement guidelines to ensure they are implementable and fit for purpose.

Objectives

- Undertake data collection activities to inform the development of the guidelines:
    - Conduct literature review of existing Australian community involvement resources for health and medical researchers
    - Develop and undertake survey of general public’s perceptions of being involved in health research
    - Conduct key informant interviews with community involvement stakeholders
- Draft the Guidelines and hold a public consultation
- Launch the Guidelines
- Conduct surveys and focus groups with projects piloting the Guidelines
- Develop recommendations for improvement of the Guidelines informed by pilot projects

Involve Australia Working Group

Formation of the working group

‘Involve Australia’ was initially conceptualised by a community member and a partnership with Australian Genomics was formed. The two groups collaborated to enlist experienced patient advocates, community involvement experts and researchers to form a working group. A snowball type approach was taken where invitations to participate were distributed to people known to already recruited working group members. Some members of the working group hold ‘dual’ roles, where they are both a researcher and patient advocate.

Working group structure

The Involve Australia Working Group members are listed in Table 1:

Table 1: Working group members	
Project Leads	
Monica Ferrie	CEO, Genetic Support Network Victoria
Anne McKenzie AM	Adjunct Research Fellow, The University of Western Australia; Consumer Advocate, The Kids Institute
Sean Murray	CEO, Mito Foundation; Chair, 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
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Isabella Sherburn	Involve Australia Project Officer, Australian Genomics

Meetings

The first Involve Australia meeting was held in July 2021. Monthly formal working group meetings with project updates and time for discussion and feedback on key documents were held. When monthly working groups were not required, a written update was distributed to the group.

Working group members were emailed meeting agendas one week prior to monthly meetings. Monthly meeting invites were sent at the start of the year for the entire calendar year. Specific tasks that working group members completed will be listed below against specific research processes undertaken throughout this project.

Remuneration

From June 2022 community members on the working group were offered an honorarium upon recommendation by a group member. This led to the development of a broader honoraria policy (downloadable PDF on Involve Australia project webpage) for use across all Australian Genomics projects and has since been adapted for use by external projects.

Guidelines development

The development of the Involve Australia Community Involvement Guidelines for Genomic Researchers applied a co-design, evidence-based approach. Following formation of the working group, data collection activities were outlined and discussed. Throughout the course of the project, activities and timelines were adjusted to ensure the community voice was being prioritised. The final development process is presented in Figure 1.

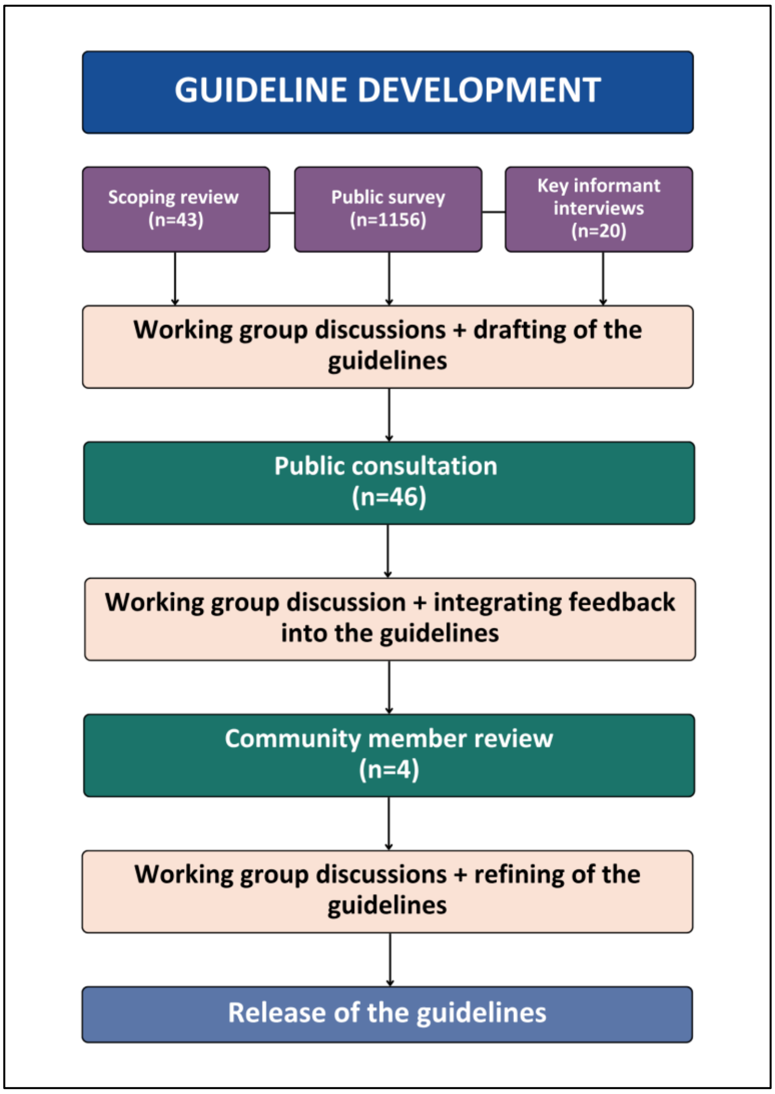


Figure 1: Process of guideline development

Data collection and analysis

Three data collection strategies were used to inform the development of the Guidelines. These included:

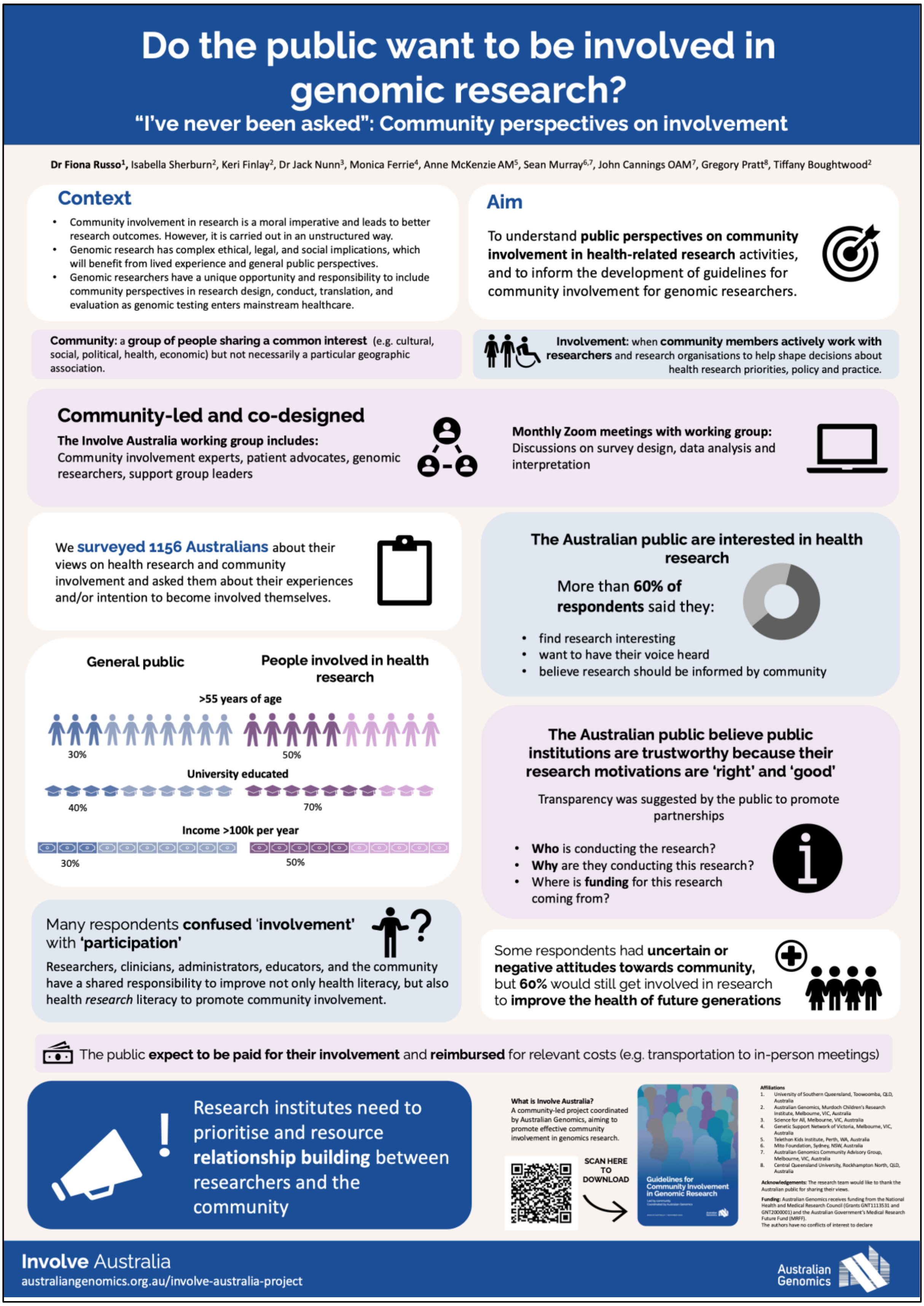
- A scoping literature review to identify existing Australian guidelines on community involvement in research (n=21) and community involvement in international peer-reviewed genomics literature (n=22);
- A survey on the public's perception of community involvement in health research activities (n=1156)
- Key informant interviews (n=20) to identify community involvement processes currently being undertaken, and barriers and enablers to community involvement from the perspectives of community members (n=5), community involvement coordinators (n=6), researchers (n=7) and institute leads (n=2)

Through the **scoping review**, we identified existing Australian community involvement guidelines for health research and determined how communities were involved in guideline development, if and how community involvement activities were reported, and if guidelines covered all relevant content to guide others on implementing community involvement. We also identified current examples of community involvement in international genomics research and determined the current level of community involvement in this research and how involvement is reported.

Four guidelines reported on at least 70% of content expected based on STARDIT. Guidelines often suggested that researchers address the different 'domains' of community involvement (e.g. remuneration, evaluating impact of involvement) but did not always describe how this is undertaken in practice. Guidelines did not provide much detail when reporting their own community involvement processes during guideline development. More detail on these processes were identified in the genomics peer-reviewed literature. Despite this, only two peer-reviewed publications used standardised reporting tools.

A 37-question **public-facing survey** was completed by 1,156 members of the Australian public via Dynata to understand the public's perspectives on community involvement in health-related research activities. Key themes emerging from survey data that impact potential involvement included low community confidence to contribute, a limited understanding of community involvement, roles and recognition, trust and governance of data, perceived trustworthiness of research funders, and factors related to time and personal resources. Despite this, more than 60% of respondents said they find research interesting, want to have their voices heard, and believe research should be informed by community views (Figure 2).

Key informant interviews allowed us to identify current examples of community involvement activities and several barriers and enablers to effective involvement. Enablers found included: involving community members early in a project, shared goals between researchers and community members and researchers' ability to effectively and frequently communicate with community members. Barriers included researcher attitudes to community involvement, and lack of training, funding and institute support, as well as the nature of research itself (Figure 3). Systematic barriers and enablers were also identified and informed the development of the Recommendations to health and medical research funders and institutes.



Do the public want to be involved in genomic research?

"I've never been asked": Community perspectives on involvement

Dr Fiona Russo[1], Isabella Sherburn[2], Keri Finlay[2], Dr Jack Nunn[3], Monica Ferrie[4], Anne McKenzie AM[5], Sean Murray[6,7], John Cannings OAM[7], Gregory Pratt[8], Tiffany Boughtwood[2]

Context

- Community involvement in research is a moral imperative and leads to better research outcomes. However, it is carried out in an unstructured way.
- Genomic research has complex ethical, legal, and social implications, which will benefit from lived experience and general public perspectives.
- Genomic researchers have a unique opportunity and responsibility to include community perspectives in research design, conduct, translation, and evaluation as genomic testing enters mainstream healthcare.

Aim

To understand **public perspectives on community involvement in health-related research** activities, and to inform the development of guidelines for community involvement for genomic researchers.

Community: a **group of people sharing a common interest** (e.g. cultural, social, political, health, economic) but not necessarily a particular geographic association.

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

Community-led and co-designed

The Involve Australia working group includes:
Community involvement experts, patient advocates, genomic researchers, support group leaders

Monthly Zoom meetings with working group:
Discussions on survey design, data analysis and interpretation

We **surveyed 1156 Australians** about their views on health research and community involvement and asked them about their experiences and/or intention to become involved themselves.

The Australian public are interested in health research

More than **60% of respondents** said they:

- find research interesting
- want to have their voice heard
- believe research should be informed by community

	General public	**People involved in health research**
>55 years of age	30%	50%
University educated	40%	70%
Income >100k per year	30%	50%

The Australian public believe public institutions are trustworthy because their research motivations are 'right' and 'good'

Transparency was suggested by the public to promote partnerships

- **Who** is conducting the research?
- **Why** are they conducting this research?
- Where is **funding** for this research coming from?

Many respondents **confused 'involvement'** with **'participation'**

Researchers, clinicians, administrators, educators, and the community have a shared responsibility to improve not only health literacy, but also health *research* literacy to promote community involvement.

Some respondents had **uncertain or negative attitudes towards community,** but **60%** would still get involved in research to **improve the health of future generations**

The public **expect to be paid for their involvement** and **reimbursed** for relevant costs (e.g. transportation to in-person meetings)

Research institutes need to prioritise and resource **relationship building** between researchers and the community

What is Involve Australia?
A community-led project coordinated by Australian Genomics, aiming to promote effective community involvement in genomics research.

SCAN HERE TO DOWNLOAD

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3. Science for All, Melbourne, VIC, Australia
4. Genetic Support Network of Victoria, Melbourne, VIC, Australia
5. Telethon Kids Institute, Perth, WA, Australia
6. Mito Foundation, Sydney, NSW, Australia
7. Australian Genomics Community Advisory Group, Melbourne, VIC, Australia
8. Central Queensland University, Rockhampton North, QLD, Australia

Acknowledgements: The research team would like to thank the Australian public for sharing their views.

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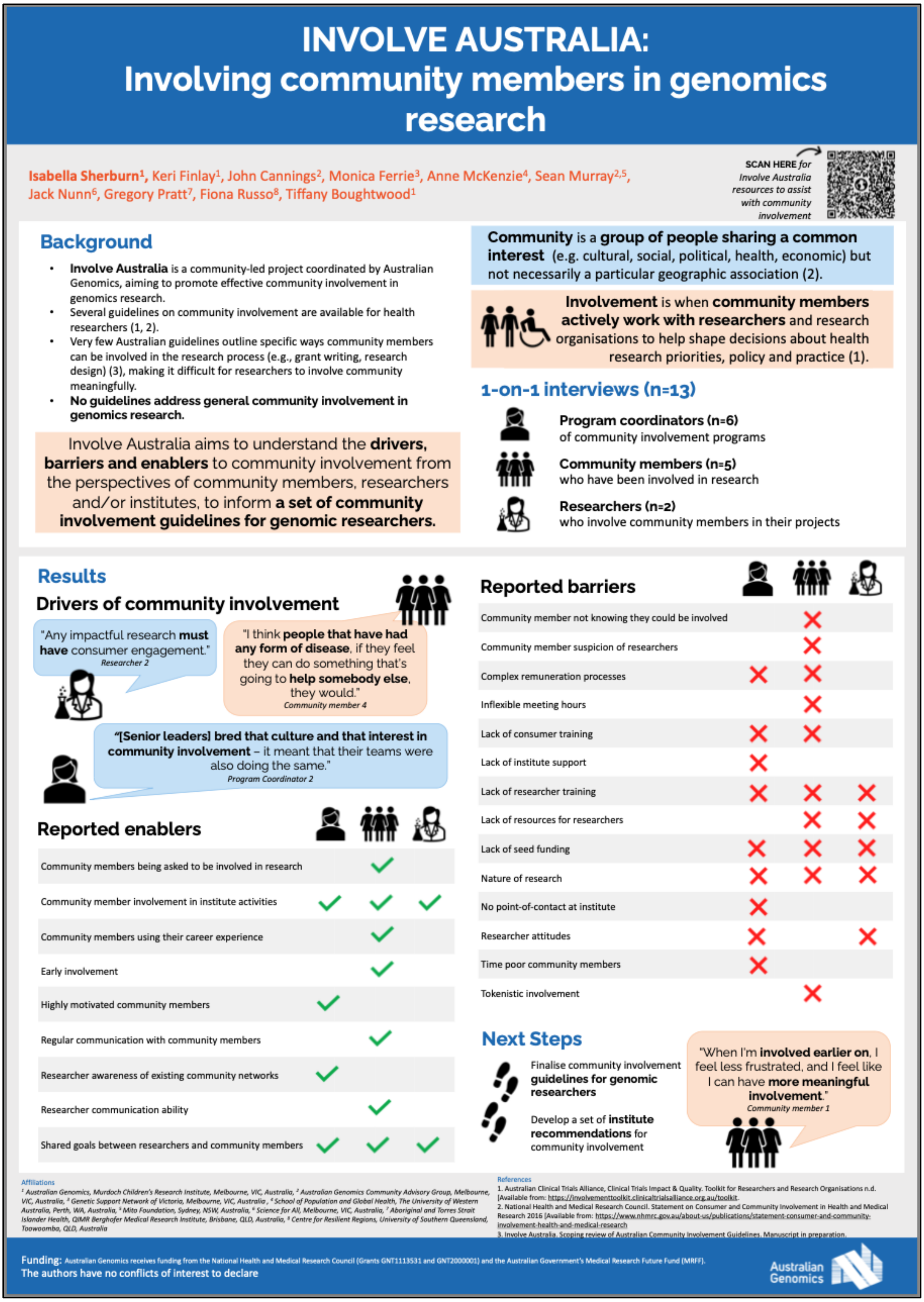
The authors have no conflicts of interest to declare

Involve Australia
australiangenomics.org.au/involve-australia-project

Australian Genomics

Figure 2: Do the public want to be involved in genomic research? Poster at Human Genetics Society of Australasia (August 2024)



INVOLVE AUSTRALIA: Involving community members in genomics research

Isabella Sherburn[1], Keri Finlay[1], John Cannings[2], Monica Ferrie[3], Anne McKenzie[4], Sean Murray[2,5], Jack Nunn[6], Gregory Pratt[7], Fiona Russo[8], Tiffany Boughtwood[1]

SCAN HERE *for Involve Australia resources to assist with community involvement*

Background

- **Involve Australia** is a community-led project coordinated by Australian Genomics, aiming to promote effective community involvement in genomics research.
- Several guidelines on community involvement are available for health researchers (1, 2).
- Very few Australian guidelines outline specific ways community members can be involved in the research process (e.g., grant writing, research design) (3), making it difficult for researchers to involve community meaningfully.
- **No guidelines address general community involvement in genomics research.**

Involve Australia aims to understand the **drivers, barriers and enablers** to community involvement from the perspectives of community members, researchers and/or institutes, to inform **a set of community involvement guidelines for genomic researchers.**

Community is a **group of people sharing a common interest** (e.g. cultural, social, political, health, economic) but not necessarily a particular geographic association (2).

Involvement is when **community members actively work with researchers** and research organisations to help shape decisions about health research priorities, policy and practice (1).

1-on-1 interviews (n=13)

Program coordinators (n=6)
of community involvement programs

Community members (n=5)
who have been involved in research

Researchers (n=2)
who involve community members in their projects

Results

Drivers of community involvement

"Any impactful research **must have** consumer engagement."
Researcher 2

"I think **people that have had any form of disease**, if they feel they can do something that's going to **help somebody else**, they would."
Community member 4

"**[Senior leaders] bred that culture and that interest in community involvement** – it meant that their teams were also doing the same."
Program Coordinator 2

Reported enablers

Community members being asked to be involved in research		✓	
Community member involvement in institute activities	✓	✓	✓
Community members using their career experience		✓	
Early involvement		✓	
Highly motivated community members	✓		
Regular communication with community members		✓	
Researcher awareness of existing community networks	✓		
Researcher communication ability		✓	
Shared goals between researchers and community members	✓	✓	✓

Reported barriers

Community member not knowing they could be involved		✗	
Community member suspicion of researchers		✗	
Complex remuneration processes	✗	✗	
Inflexible meeting hours		✗	
Lack of consumer training	✗	✗	
Lack of institute support	✗		
Lack of researcher training	✗	✗	✗
Lack of resources for researchers		✗	✗
Lack of seed funding	✗	✗	✗
Nature of research	✗	✗	✗
No point-of-contact at institute	✗		
Researcher attitudes	✗		✗
Time poor community members	✗		
Tokenistic involvement		✗	

Next Steps

Finalise community involvement **guidelines for genomic researchers**

Develop a set of **institute recommendations** for community involvement

"When I'm **involved earlier on**, I feel less frustrated, and I feel like I can have **more meaningful involvement**."
Community member 1

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2. National Health and Medical Research Council. Statement on Consumer and Community Involvement in Health and Medical Research 2016 [Available from: https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research
3. Involve Australia. Scoping review of Australian Community Involvement Guidelines. Manuscript in preparation.

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The authors have no conflicts of interest to declare

Australian Genomics

Figure 3: Involve Australia: Involving community members in genomic research. Poster at XXIII International Congress of Genetics (July 2023)

Drafting the Guidelines

As data was collected, key findings were presented to the working group for discussion. This allowed for interpretation and analysis of the findings, and we were able to map key themes which were refined into a set of recommendations for genomic researchers to consider when involving community members in projects.

Key findings that informed the basis of the Guidelines included:

- 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 do not feel they have the confidence to be involved in research.
- 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.

Community member involvement in tasks

Working group member involvement in data collection and analysis activities are described in Table 2 below. Reporting on community involvement in the Involve Australia project via STARDIT can also be found here.

Table 2: Community 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 • Several working group members reviewed manuscript
Public 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
Key informant interviews	• Developed interview questions • Assisted with recruitment by emailing interview invitations to networks
Guideline development	• Conceptualised and refined the recommendations via working group discussions and written feedback • Assisting in refining structure and wording of the Guidelines

Public consultation and community member review

A public consultation was held from May to June 2023 to ensure the Guidelines were meeting the needs of genomic researchers wanting to involve community members as well as speaking to issues community members have faced when being involved in research. Survey respondents included genomic and non-genomic researchers and health professionals, patient advocates and members of patient support and advocacy groups and peak bodies.

All recommendations (Figure 4) rated positively with over 80% of respondents indicating they were suitable. General feedback included suggesting that background content was made clearer and making the entire document more concise. Three of the 17 recommendations required more careful editing based on survey feedback. These were:

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

Following incorporation of public consultation feedback, it was decided that a separate community member review (n=4) be conducted to ensure the community voice remained at the forefront of the resource. Community members invited to take part in this review were external to the working group and were offered an honorarium for their time and efforts. Feedback included numbering recommendations and recommendation domains for easier referencing and conducting a plain language review of the document.

A report summarising feedback received and how the Guidelines were refined according to this feedback was developed and published on the Australian Genomics website to promote transparency and demonstrate the impact of consultations and the value stakeholders had on the project.

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.

Figure 4: Final Recommendations presented in the Involve Australia Community Involvement Guidelines

Post-development

Endorsements

Once the Guidelines were finalised, we requested endorsement from several patient support and advocacy groups, research institutes and alliances. Twenty-three different groups provided their endorsement (Table 3).

Table 3: Endorsements for the Involve Australia Guidelines
Patient support and advocacy groups
ausEE Inc.
Brainwave Australia
Breast Cancer Network Australia (BCNA)
Childhood Dementia Initiative
Genetic Alliance Australia
Genetic Support Network Victoria (GSNV)
Inherited Cancers Australia
Juvenile Diabetes Research Foundation (JDRF)
Mito Foundation
Multiple sclerosis (MS) Australia
Rare Cancers Australia (RCA)

Rare Voices Australia (RVA)
Rett Syndrome Association of Australia
Sanfilippo Children’s Foundation
Charities
Science For All
Research Organisations
Association of Australian Medical Research Institutes (AAMRI)
Australian Clinical Trials Alliance (ACTA)
Health Translation Queensland (HTQ)
Murdoch Children’s Research Institute (MCRI)
Research Australia
Victorian Comprehensive Cancer Centre (VCCC)
Walter and Eliza Health Institute of Medical Research (WEHI)
International organisations
Canadian Institute of Health Research – Institute of Genetics

Download statistics and web metrics

The Guidelines were published December 6, 2023. Before downloading the Guidelines, individuals were asked to complete a short survey so we could collect data on who is downloading the Guidelines and how they found out about them. The survey was taken off the website November 8, 2024.

During this period, the Guidelines were downloaded by 206 different users. Individuals most commonly heard about the Guidelines through Australian Genomics or Involve Australia, or their colleagues. The Guidelines were primarily downloaded by researchers (44%) and community members (20%). One-third of users who downloaded the Guidelines did not work in the genomics field.

Dissemination of the Guidelines and research findings

We held an in-person launch event for the Guidelines, where we invited working group members, all stakeholders involved in the project and Government representatives. We also posted on Australian Genomics social media to promote dissemination and were featured in the Australian Genomics newsletter. Working group members among others shared social media posts. Several endorsers also included the Guidelines on their websites or in monthly newsletters.

Findings from the Involve Australia research has been presented at several conferences and meetings. See Table 4 for further details.

Table 4: Conference presentations and posters
Presentations
Human Genetics Society of Australasia Conference (August 2024)
9th World Rett Syndrome Congress (October 2024)
National Human Research Ethics Committees conference (November 2024)
Posters
Human Genetics Society of Australasia Conference (November 2022)
National Human Research Ethics Committees conference (November 2022)
XXIII International Congress of Genetics (July 2023)
Human Genetics Society of Australasia Conference (August 2024)

Academic publications

A publication on the public-facing survey was published November 2024 in *Research Involvement and Engagement*. A manuscript has been drafted regarding findings from the scoping review, with drafting underway for the key informant interviews manuscript. A manuscript has been submitted for publication in the journal *Ethics and Human Research*, highlighting Involve Australia's work and its relevance in translation research internationally.

Development of the Recommendations to Research Institutes and Funders

Data collection and guideline development demonstrated that it is not just researchers and community members who are responsible for more effective community involvement, but also health and medical research institutes and funders. Informed by the data already collected and working group guidance and expertise, we developed recommendations to both institutes and funders on ways they can ensure community involvement occurs in a more effective way.

Recommendations were disseminated via Australian Genomics social media and directly emailed to relevant stakeholders in June 2024. Working group members among others shared social media posts. At the time of dissemination, the initial release post was Australian Genomics' most highly engaged with post on LinkedIn (81 reactions, 16 reposts, 2,938 impressions, 96 clicks on June 12th 2024).

Pilot of the Guidelines

Two projects consented to piloting the Guidelines. The purpose of this was to evaluate how they are being used in practice, if they can be implemented, and if there are any challenges or gaps when using the Guidelines. Community members involved, project coordinators and lead researchers were asked to complete initial surveys to guide focus group discussions on the use of the Guidelines. Focus groups were conducted via Zoom with community members, project coordinators and lead researchers.

One project used the Guidelines in their application for grant funding, stating that they would adhere to the principles. Both projects had a coordinator who relied heavily on the Guidelines in guiding their communication and practice involving community members. One researcher suggested the Guidelines could potentially be given to community members at the beginning of a project to hold researchers accountable to non-tokenistic community involvement practice. One community member suggested that the Guidelines were useful in encouraging researchers and project coordinators to go to community members with suggestions and options on how they can be involved, rather than community members having to lead these discussions by default.

Positive feedback received from focus groups included:

- The Guidelines were a useful resource for researchers experienced in community involvement as it validated their practices and could also be used as a reference point,
- The Guidelines were also useful for researchers without experience in community involvement as it “provided a good scaffold” to work within,
- The Guidelines were useful in initial relationship building between researchers and project coordinators and community members,
- Researchers felt the Guidelines were well-written and appreciated that they were written from the perspective of community members, with community member quotes throughout the document further emphasising the community voice, and
- Community members felt that the Guidelines “guided connection” between researchers and community members

Challenges in using the Guidelines suggested by focus group participants included:

- Evaluating community involvement within a project without it be coming an entirely separate research activity, and
- Deciding on impact measures to use when reporting on community involvement processes.

Several improvements were suggested by participants, including:

- A summary of the Guidelines for project coordinators, detailing specific ‘how to’ guidance
- A summary of the Guidelines for community members (e.g. “What should you expect from involvement when researchers are using these Guidelines?”)

- Provide researchers with the recommendations summary spread rather than the entirety of the Guidelines, as the likelihood of reading the whole document is low. Researchers can refer to relevant sections of the Guidelines when needed.
- An ‘Easy Read’ version of the Guidelines to increase accessibility
- Emphasising that researchers within a team should be aligned in their goals for community involvement
- Asking community members what language they use not only to describe themselves, but also the condition being studied and if there is any terminology that should be avoided
- Suggesting that projects decide who community members can contact if they believe there are issues with the project and would like a third party to discuss this with

Following the focus groups, it was noted that there were multiple researchers with lived experience. The Guidelines do not mention lived experience workforce, however this is becoming more common practice particularly in mental health research.

Recommendations

Future recommendations for improvement of the Guidelines include:

- Updating and refining the Guidelines to incorporate feedback received during focus groups
- Developing additional summary resources for different stakeholders to accompany the Guidelines (e.g. 'what can you expect as a consumer being involved in a project using these guidelines?', an Easy Read version of the Guidelines)

Future recommendations for the project include:

- Extend Involve Australia's scope to health and medical research more broadly as the Guidelines are relevant beyond genomic research, or
- Embedding the Guidelines further in genomic research through partnerships with funding bodies, research organisation and patient support and advocacy groups.

Conclusion

The Involve Australia project has found evidence for continued and increased support for community involvement endeavours in genomics *and* broader health and medical research. The project has created a set of guidelines to enable researchers and project coordinators to involve community in an effective and meaningful way.

The evidenced-based Guidelines and additional resources developed through the project are being used by Australin Genomics supported projects and others to improve community involvement processes as demonstrated through our pilot focus groups. The endorsement of the Guidelines by both national and international organisations underscores the significance of community engagement and the field's commitment to incorporating community feedback into research practices to improve research outcomes and consequently public health.

In future, Involve Australia's Guidelines should be revised and improved based on feedback from those implementing them. The Guidelines as well as the Recommendations to Institutes and Funders can continue to be used to form the basis of advocacy efforts to advance and overcome systemic barriers to community involvement in research.

Resources, publications and submissions

Table 5: Resources, publications and submissions	
Resources generated and where stored	The following resources are available on the Involve Australia webpage: • Involve Australia Guidelines for Community Involvement in Genomic Research • Guiding Questions for Researchers – supporting document for the Guidelines • Guidelines Consultation Feedback Report • Recommendations for health and medical research funders to support community involvement in research • Recommendations for health and medical research institutes to support community involvement in research • Australian Genomics consumer honoraria and reimbursement policy (downloadable PDF on Involve Australia project webpage)
Publications	**“I just don’t know enough”: Australian perspectives on community involvement in health and medical research** Manuscript published in November 2024 in the journal *Research Involvement and Engagement*, detailing findings from a survey of the general public conducted in 2022. An accompanying visual abstract for this manuscript was also published on GenomicsInfo, Australian Genomics’ public-facing website, here.
Consultation submissions	**Response to NHMRC Consumer Statement Review Public Consultation (2024)** • Also available on the NHMRC Consultation webpage **Co-design of an Enhanced Consumer Engagement Process for Health Technology Assessment (2024)**
STARDIT report	**Involve Australia Guidelines for Community Involvement in Genomic Research development and pilot** (STARDIT ID: 0202312040033) • Reports on how the project was conducted and how community was involved