

Melbourne Genomics Health Alliance

Global knowledge. Individual care.

Community Engagement Framework

December 2022



Alliance members



Supported by



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Introduction

Genomics is an area of science that examines a person's complete set of genetic information (their *genome*).

Genomic medicine involves using genomic testing to diagnose different health conditions, and determine the right treatment and therapies for each patient at the right time. This is sometimes referred to as *precision medicine* or *personalised medicine*.

The Melbourne Genomics Health Alliance is a group of hospitals, research and academic institutions, working together with the Victorian Government. Our purpose is to embed genomics within the Victorian health system.

Our studies have shown that genomic medicine may help people with genetic conditions and other concerns such as cancer, heart and kidney disease¹. Now we are working with healthcare providers on projects to introduce or expand the use of genomic medicine. This involves making changes to clinical practice, processes and systems.

Goals for community engagement

1. Enable equitable use of genomic testing

Everyone who needs a genomic test should be able to get one. Community engagement helps identify barriers and enablers to access, across the diversity of Victoria's population.

2. Enhance patient experience and safety

We need to ensure each intervention works for patients. Community engagement helps ensure that patients' needs, concerns and safety are at the heart of everything we do.

3. Learn what contributes to effective change

By sharing what we learn about community engagement in genomics, we make it easier for other healthcare providers to implement genomics.

Community Advisory Group

This framework was co-designed with the Melbourne Genomics Community Advisory Group.

The members of the Community Advisory Group (CAG) are champions of consumer rights in healthcare. They contribute to multiple boards, advisory bodies and support groups for people living with genetic conditions.

The CAG advises on community engagement for each of our projects: when it is needed, how to approach it, and whose voices must be heard. See p9 for tips on how to seek advice from the CAG.

¹ Visit melbournegenomics.org.au for our studies and an overview of our current program.

Purpose of this framework

This framework is a guide for Melbourne Genomics program staff.

It sets out:

- Goals for community engagement
- Guiding questions to plan and evaluate community engagement
- Principles that underpin community engagement

The framework can be shared with community stakeholders on request, including healthcare consumers, support groups and community organisations.

Definitions

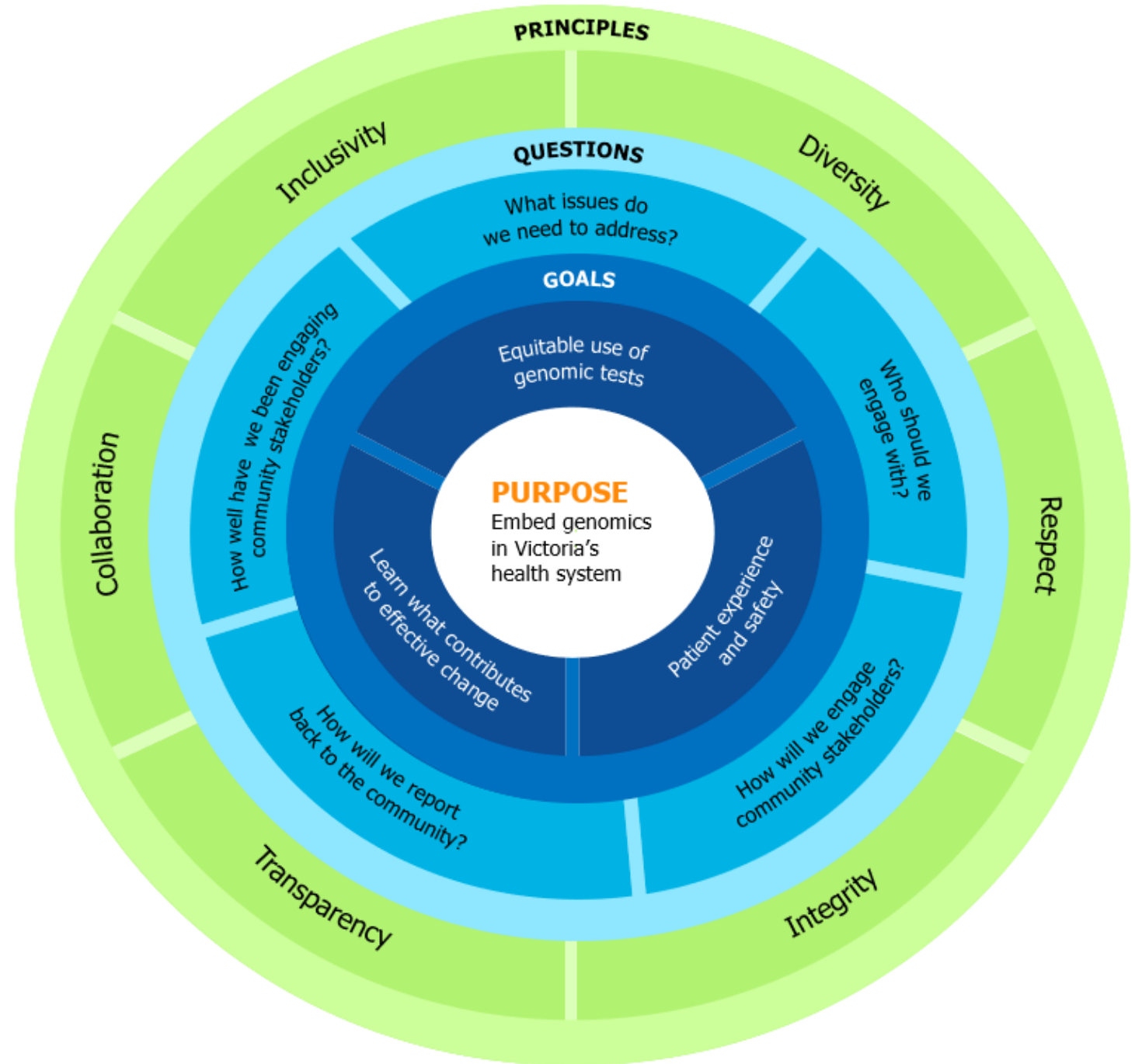
Term	How it's used in this framework
Health consumer	A person who uses or plans to use health services. May be referred to as a patient when they are actively receiving healthcare.
Community	A group of people (individuals, organisations and/or support groups), who share a common interest or experience. Different groups of people may have different engagement needs.
Community engagement	Within this framework, engagement refers to a variety of ways in which healthcare consumers, community groups and community organisations are involved in shaping the Melbourne Genomics program.
Co-design	Community members collaborate in the process of identifying issues and developing services or interventions
Stakeholder	A person or community that has an interest in or may be impacted by an activity. Stakeholders should reflect the diversity of the populations who may be impacted.
Equity	"Health equity is defined as the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically" ²

² The World Health Organization, Social determinants of health, https://www.who.int/health-topics/social-determinants-of-health#tab=tab_3, accessed 26/11/2021

Fig 1

Community Engagement Framework

on a page



Principles

These principles influence how we plan, undertake and evaluate community engagement.

Inclusivity

Our program and engagement opportunities should be accessible to people of all abilities and backgrounds. We need to identify and remove barriers to participation, and ensure cultural safety.

Diversity

Many different community perspectives are needed to inform genomic healthcare. This includes First Nations peoples, regional Victorians, culturally and linguistically diverse communities, people living with disability, individual health consumers and consumer advocacy groups.

Respect

We will respect diverse backgrounds, views, experiences and values.

Integrity

We will take an equitable approach to all we do. We will be open and honest when working with people, and acknowledge all viewpoints.

Transparency

We will be clear and honest about why and how we engage with consumers and communities; what we do with people's advice and feedback; and how we communicate the outcomes of our work

Collaboration

We will work together with consumers and community stakeholders: recognising different strengths, establishing shared goals, and promoting mutual respect and accountability.

A note on these principles

These principles were developed by the Community Advisory Group. They align with Victorian Government frameworks and guiding principles.³

They can also be mapped to the principles used in Deane's et al. *Quality Criteria for Engagement*,⁴ a co-created framework to facilitate evaluation of patient engagement in healthcare. Our evaluation tools will draw on this framework.

³ See Appendix 1 for a full list of frameworks that have informed this document.

⁴ Deane K, Delbecq L, Gorbenko O, Hamoir AM, Hoos A, Nafria B, Pakarinen C, Sargeant I, Richards DP, Skovlund SE, Brooke N. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. *BMJ Innov.* 2019 Jan;5(1):43-55. doi: 10.1136/bmjinnov-2018-000317. Epub 2019 Mar 2. PMID: 31645992; PMCID: PMC6792320.

Planning community engagement

These questions will guide the development of fit-for-purpose community engagement plans for projects.

The examples under each of these questions are not prescriptive. They provide guidance about the different types of activities that could be undertaken.

Fig 3 on p11 explains the planning process. The **tools** on p12 can guide the planning that you do with your stakeholders.

WHAT issues do we need to address?

Melbourne Genomics projects seek to embed genomics in the health system: whether by testing models of care, developing frameworks and tools, improving education, or managing genomic data.

Engaging consumers and community groups in the early stages of planning can (a) identify specific issues and barriers to address, and (b) ensure interventions work for patients.

Example: A project on genomic testing for children holds focus groups with parents of children with genetic conditions, to understand the issues they face and inform appropriate interventions.

WHO should we engage with?

It will be important to map all community groups that may be impacted: consumers, carers and families, support groups, local community organisations and special interest groups.

Carefully consider:

- groups that already experience barriers to healthcare (e.g. language, disability)
- people who may not be connected to existing advocacy groups. Please consider First Nations communities, multicultural community networks and faith groups.
- the level of engagement that is needed and that best suits consumers. The IAP2 Spectrum of Public Participation (Fig 2, p10) is a valuable guide.

Example: Family members of patients may need to be **consulted**. A hospital's consumer advisory committee may need to be **informed**. A rare disease support group can **collaborate** on an intervention.

HOW will we engage community stakeholders?

Engagement methods can be ongoing (e.g. a project reference group or consumer panel) or one-off (e.g. a focus group or information session). Use feasible methods that best suit the project's community stakeholders and the level of engagement appropriate for the project.

Carefully consider:

- how to make engagement culturally safe and trauma informed
- using inclusive methods for engagement when needed, such as interpreters (including Auslan), translated materials or bicultural workers

The Community Engagement Coordinator can advise on methods that may be suitable.

Example: The project team holds an information session for patients and a co-design workshop with members of patient support groups.

HOW WELL have we been engaging community stakeholders?

We will evaluate community engagement across our program, focussing on the **experience** of community stakeholders (and potential differences between communities) and the **extent** to which engagement was effective in creating change.

Data will be collected at regular cycles and analysed to understand the different experiences of people engaged across our projects.

This is to enable continuous improvement throughout the program, and to capture lessons learnt for future implementation of genomics.

Example: Project reference group members participate in a six-monthly survey to gauge their experience and identify areas for improvement over the project lifecycle.

HOW will we report back to community?

We will report back to community stakeholders about what the project accomplished, and how their advice and input was used.

Reporting methods should be accessible and appropriate. Consider language, format and channel.

Example: The project team invites community participants to a meeting to discuss the project's key findings.

Engaging with the Community Advisory Group

The Melbourne Genomics Community Advisory Group (CAG) meets quarterly.

These meetings provide a valuable opportunity for program staff to seek advice and think about engaging community early.

Contact the Community Engagement Coordinator to:

- arrange a time to present to the CAG
- craft your presentation and questions for advice
- update the CAG on projects they have previously advised on.

The IAP2 Spectrum of Public Participation

This spectrum guides public participation plans around the world.⁵ As you determine who needs to be engaged in your project, use the spectrum to understand how they should be engaged and choose the right methods for engagement.

A group's level of engagement may change as the project proceeds. For example, they may be consulted about a project idea but collaborate on the design of a specific intervention.

Fig 2

SPECTRUM OF STAKEHOLDER ENGAGEMENT	Inform	Consult	Involve	Collaborate	Empower
	<i>Information giving</i>	<i>Information seeking</i>	<i>Information sharing and joint planning</i>	<i>Participatory decision making</i>	<i>Stakeholder leadership</i>
Purpose of Engaging Stakeholders	To provide information to consumers and stakeholders to assist them in understanding issues, alternatives and/or solutions.	To gather information from consumers, communities and stakeholders, including to capture lived experiences.	To involve communities and stakeholders in research, planning, policy development, delivery and evaluation of services.	To work in partnership with communities and stakeholders.	To place final decision-making in the hands of stakeholders.
When to Use	One-way exchange of information, e.g. to assist in access to and management of health issues.	Two-way exchange of information; share views, needs and interests.	To ensure community and stakeholder views are considered and reflected in decisions and outcomes.	To jointly develop solutions and initiatives.	To enable communities and stakeholders to decide and implement solutions/ outcomes (often with specified guidelines).
Commitment to Stakeholders	We will keep you informed.	We will keep you informed, listen to you, acknowledge your views and provide feedback.	We will work with you, consider your views and provide feedback on how your input influenced the outcomes.	We will look to you for advice and innovation in the formulation of solutions and incorporate your advice to the maximum extent.	We will implement your decisions and support and complement your actions.
Methods of Engagement	Including: <ul style="list-style-type: none"> Public notices Announcements Websites Fact sheets Newsletters Education programs. 	Including: <ul style="list-style-type: none"> Public meetings Public hearings Focus groups (e.g. CALD and communities in need) Surveys. 	Including: <ul style="list-style-type: none"> Workshops Forums Deliberative polling Panels Task forces Working parties. 	Including: <ul style="list-style-type: none"> Reference groups Facilitated consensus building forums Advisory committees Policy round tables Clinical networks. 	Including: <ul style="list-style-type: none"> Steering committees Quality committees Boards Participatory governance Standing strategic committees.
Level of Stakeholder Influence	Minimal influence	Low influence	Moderate influence	High involvement and influence	Community/Stakeholder control

⁵ International Association for Public Participation (IAP2) framework adapted by Ken Knight, Impact by Design training program, Murdoch Children's Research Institute. 2014

Fig 3

Process for community engagement

01 What issues do we need to address?

 **TOOL:** Project plan

02 Who do we need to engage with?

 **TOOL:** Community engagement plan

03 How will we engage them?

 **TOOL:** IAP2 Spectrum of Public Participation

04 How well are we engaging them?

 **TOOL:** MEL framework, evaluation surveys

05 How will we report back to them?

 **TOOL:** Community engagement plan



Evaluation

Melbourne Genomics has a Measurement, Evaluation and Learning (MEL) framework to understand how effective our program has been and support strategic learning about achieving change.

Figure 4 contains key evaluation questions for community engagement, in particular, sub-question 1b. The [community engagement plan](#) (Resources, p12) includes a section to guide the evaluation of community engagement activities. Project managers need to collect information as outlined in the plan.

Fig 4
Community engagement in the MEL framework

Key evaluation question	Sub-questions	Indicators
1 How well are we implementing for change?	a. How well are we doing engagement and co-design? b. How well have we been engaging community stakeholders? c. To what extent have co-design and collaboration been effective in creating change?	Number of stakeholders engaged Breadth of stakeholders engaged Stakeholder satisfaction Case studies

Evaluation tools (surveys in Resources, p12) are available to help program staff capture data and reflections from community stakeholders. These tools have been informed by the Deane Quality Criteria (see p7) and the Community Advisory Group.

Support and tools

Community Engagement Coordinator

The Community Engagement Coordinator can assist program teams to develop community engagement plans, connect with community stakeholders, collect data, and evaluate community engagement.

Community Advisory Group (CAG)

The CAG meets quarterly and can advise on specific aspects of community engagement.

Resources

- Melbourne Genomics [Program Logic 2021-25](#)
- Melbourne Genomics [MEL Framework Key Evaluation questions](#)
- Melbourne Genomics [Community Engagement Plan template](#)
- Melbourne Genomics [Evaluation survey, one-off activity](#)
- Melbourne Genomics [Evaluation survey, on-going involvement](#)
- Queensland Health [Techniques for community engagement](#)
- Tamarack Institute [Index of community engagement techniques](#)

Appendix

Community Engagement Frameworks that have informed this framework

Partnering in Healthcare Framework. Safer Care Victoria, 2019,
<https://www.bettersafercare.vic.gov.au/publications/partnering-in-healthcare>

Public Participation and Stakeholder Engagement Framework, Department of Health and Human Services, 2019
<https://www.dhhs.vic.gov.au/sites/default/files/documents/201909/Public%20participation%20and%20stakeholder%20engagement%20framework-20190917.docx>

Community engagement, A guide to community engagement in rural and regional Victoria. Rural Councils of Victoria, 2020
<https://media.ruralcouncilsvictoria.org.au/wp-content/uploads/2020/08/06144245/Community-Engagement-Toolkit.pdf>

The Royal Children's Hospital Consumer engagement framework, 2019

The Department of Health, Stakeholder Engagement Framework, 2017
https://www.health.gov.au/sites/default/files/stakeholder-engagement-framework_0.pdf

Stakeholder Engagement Framework, North Western Melbourne PHN, 2019

Global Alliance for Genomics and Health: Framework for involving and engaging participants, patients and publics in research and health implementation, pre-approved draft April 2021

Western NSW Primary Health Network Consumer & Community Engagement Framework, 2020

Domestic Violence Victoria, The family violence experts by experience framework 2020

International Association for Public Participation (IAP2)
<https://www.iap2.org.au/resources/spectrum/>

Murdoch Children's Research Institute, Impact by Design Training

Deane K, Delbecque L, Gorbenko O, Hamoir AM, Hoos A, Nafria B, Pakarinen C, Sargeant I, Richards DP, Skovlund SE, Brooke N. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. *BMJ Innov.* 2019 Jan;5(1):43-55. doi: 10.1136/bmjinnov-2018-000317. Epub 2019 Mar 2. PMID: 31645992; PMCID: PMC6792320