



Tool: Recommendations to support hospitals involve consumers in genomic medicine

**Genomics and
Your Hospital**

A toolkit to support high-quality
genomic care



This document is part of the [Genomics and Your Hospital toolkit](#), a resource developed to support a 'whole of hospital' approach to genomic care. The complete toolkit is available at [GenomicsToolkit.org.au](#).

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Introduction

Consumer involvement can lead to safer and higher-quality healthcare. Genomics has unique and uncommon features that make consumer involvement both necessary and challenging.

This document was developed to help support health services involve consumers in genomic medicine planning. It contains a set of **recommendations for hospitals to consider**.

These recommendations are not meant to be prescriptive. Please consider and adapt them to suit your local context.

The recommendations are split into three sections:

1. Before you begin
2. After you've begun
3. Strengthening diversity, equity and inclusion

These recommendations are taken from the guide *Making a difference: The value of consumer involvement in genomic medicine*. The guide was developed by consumers and community advisors involved in Melbourne Genomics clinical projects and can help provide the foundations for respectful, meaningful consumer involvement in genomic medicine. It can be accessed on [Involve consumers in genomic medicine practice website page](#).





Before you begin: Planning for and embedding consumer involvement

Shift mindsets

More than anything, consumers want health services to recognise the value of their involvement in genomic medicine by actively involving consumers across all aspects of health services. (e.g., embedding consumer involvement into systems such as health service advisory panels or committees, individual projects, and clinical service design).

1. Actively promote awareness of the value and importance of consumer involvement in genomic medicine.

Take a systems approach

Reflecting on the current approach to involving consumers in genomic medicine, consumers advocate embedding consumer involvement in health service systems and leveraging existing consumer involvement mechanisms.

2. Take a systems approach by embedding genomics into existing consumer involvement mechanisms and improving or changing processes where required.
3. Build relationships with local Aboriginal Community Controlled Health Organisations and key groups, such as the Australian Alliance for Indigenous Genomics (ALIGN) and the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics, to:
 - a. Understand the priorities of Aboriginal and Torres Strait Islander peoples for genomic healthcare.
 - b. Embed these priorities in the services you provide.

- c. Learn from the Indigenous Governance models used by these groups and reflect on the diversity and representation of the Governance structures you practice within.
- d. Ensure there is representation and a voice for Aboriginal and Torres Strait Islander peoples within the Governance and Leadership groups.

4. Establish a Genomics Consumer Involvement Champion for each hospital and health service. This role could be shared across services recognising that some health services are earlier in their journey to establish and embed genomic medicine. The role should be to champion consumer involvement in genomic medicine within the organisation including educating clinicians on the value of consumer involvement.
5. Establish funded roles dedicated to support genomic consumer involvement to provide a central connection and coordination point for consumers and clinicians such as the Community Engagement Coordinator role at Melbourne Genomics. Note that the role requires attributes and skills of empathy, interpersonal skills, relationship building and communication.
6. Provide opportunity for cross-collaboration, sharing knowledge and learning between genomic consumer groups, and existing hospital and network consumer groups. This could be through regular meetings of all the consumer groups, or sharing information via email or a website. For example, the Health Issues Centre (ceased operations in 2024 and passed its legacy to Deakin University) used to run forums to bring consumers from different consumer advisory groups together across Victoria.



After you've begun: Enabling effective consumer involvement

Build relationships

Consumers note the critical importance of building relationships to enable a safe and respectful environment for consumers to provide their lived experience expertise. Building safe, respectful relationships between consumers and between consumers and health service staff enables consumers to stay involved, gain value and enjoyment from their involvement and provide effective expertise.

7. When involving genomic consumers to provide lived experience expertise, hold the first consumer meeting in person and provide adequate time for informal networking and building of personal relationships between consumers, clinicians and project staff. For genomic consumers that become involved later after the first meeting, provide them adequate opportunity to meet in person with other consumers, clinicians and project staff.

Start with outcomes, objectives and context

Sharing information from the outset about the context and intended outcomes and objectives of the project will build a shared understanding with consumers and enable them to position their advice more effectively.

8. When involving genomic consumers to provide lived experience expertise, provide information on the context and desired outcomes on the issue you are seeking advice on, from the outset. Be clear in the ask from consumers and build a shared understanding of what you are trying to achieve together in genomic medicine.

Be aware of power dynamics and value lived expertise

Consumers lead busy lives, managing their own health conditions or the health conditions of their family, working and/or studying. They may be different social inequities experienced by consumers or language barriers. Genomic medicine can often be quite technical and use medical jargon. Consumers will inherently have less information about the context and details of project or service than the health service, while having valuable knowledge and expertise to offer the health service.

When involving genomic consumers to provide lived experience expertise:

9. Be aware that there is information asymmetry and/or situational power imbalance between consumers and clinicians seeking advice from consumers and without appropriate preparation and sharing of information, consumers can feel that they are not contributing.
10. Provide opportunity for all consumers involved to share their expertise. There may be some consumers that are quieter and less confident than others, but they have significant lived experience expertise to provide.



Give and take feedback

Consumers asked for better two-way feedback between consumers, clinicians and other relevant staff so they can all improve understanding of each other's perspectives and increase the value of consumer involvement.

When involving genomic consumers to provide lived experience expertise:

- 11.** At the establishment stage ask consumers where they feel they can add the most value and what they would most like to contribute.
- 12.** Establish ways of working with consumers from the outset. For example, this could be through collaborating on development of a Terms of Reference for the consumer involvement group. This process would take into account consumer's individual needs and preferences for ways of working and decision making. Provide options for how you could work together.
- 13.** Consider introducing a process at the end of each meeting for consumers and clinicians to self-reflect on the value of the discussion from their perspective and what could be improved. Clinicians and health services should seek to cultivate psychological safety (i.e., agreeing ground rules for a non-judgemental and respectful space), to make this opportunity as safe as possible for consumers to share constructive feedback.

Remunerate consumers appropriately

Many of the consumers spoke of the material cost of participating and providing advice in genomic medicine which may not always be anticipated after offering an honorarium and/or travel expenses.

When involving genomic consumers to provide lived experience expertise:

- 14.** Be aware that there is often a financial cost for consumers beyond an offered honorarium, to provide their expertise and advice, particularly for those travelling from regional and rural locations. There are additional costs involved for time off work, childcare, travel, accommodation if needed.
- 15.** In consultation with consumers, appropriately remunerate them for their time and lived experience expertise. Consider consumer remuneration and reimbursement guidelines.



Use respectful language and adopt a social model approach

Consumers involved in genomic medicine have provided a lot of informal education of clinicians and researchers about their language and the challenges of the medical model. A social model of disability views disability as something someone experiences, not as a result of their impairment, but because of society's lack of adaptation to include people with a disability. The physical or psychosocial disability is not the problem to be solved. Instead, the problem is the barriers that society has made that impacts a person's ability to effectively participate in society and/or the economy.

When involving genomic consumers to provide lived experience expertise:

- 16.** Adopt a social model approach which does not view a genetic condition as a 'problem to be fixed' and 'deviation from the norm' but places the focus on the barriers which impact a person's ability to participate in society and the economy.
- 17.** Ask genomic consumers about their preferred use of language. For example, use strengths-based language rather than deficit language.

Take a trauma-informed approach

A trauma-informed approach is a term used in social work that seeks to understand the impact of trauma and promotes an environment and approach that promotes healing and avoids re-traumatisation. There are six principles of a trauma-informed approach: Safety, Trustworthiness and transparency, Peer support, Collaboration and mutuality, Empowerment, voice and choice, and Cultural, historical and gender issues.

- 18.** Take a trauma-informed approach to involving consumers in genomic medicine, applying the six principles.



Throughout consumer involvement: Strengthening diversity, equity and inclusion

Improve diversity, equity and inclusion

Consumers continue to highlight the value of involving people from diverse backgrounds. They note that the consumers directly involved in providing advice to health services and clinicians should reflect the community. Diversity in all its forms such as age, gender, ability, cultural and linguistic background, Aboriginal and Torres Strait Islander people, socio-economic background and metro/regional or rural location is important.

When involving genomic consumers to provide lived experience expertise:

19. Make a concerted and intentional effort to ensure the consumers represent the diversity of the communities served. Be flexible and make adjustments and accommodations to your involvement methods to attract and support greater diversity, equity and inclusion of diverse communities. For example, hold a meeting in a regional location, changing time and format of meetings.

20. Consider different ways of seeking involvement of diverse consumers that are community-led. For example, building relationships with ethnic community groups, tapping into existing networks such as Ethnic Communities Council of Victoria, and/or funding people or groups to engage with their own communities. Explore existing interpreting and translation resources when considering genomic consumer representation, recruitment and engagement from multicultural communities.

21. For First Nations communities, seek advice from Indigenous-led organisations on appropriate ways to engage consumers from Aboriginal and Torres Strait Islander communities. It may be best to tap into existing networks.

How was this tool developed?

These recommendations are taken from the guide *Making a difference: The value of consumer involvement in genomic medicine*. The guide was developed by a group of 25 consumers. These included members of the Melbourne Genomics **Community Advisory Group** and five consumer panels set up to guide projects in nephrology, dementia care, organ transplants, cancer and paediatrics.

Consumers attended either an in-person or an online workshop, where they were invited to identify where they had contributed most effectively, what could have been improved, and what lessons might be learnt for future consumer involvement in genomic medicine.

The guide – and its recommendations – were validated with the consumers prior to publication of the report.



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