

# Making a difference: The value of consumer involvement in genomic medicine



Alliance members



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## Acknowledgement of Country

Melbourne Genomics Health Alliance and the consumers involved acknowledge the Wurundjeri people of the Kulin Nation, on whose lands we work, and all First Nations peoples across Victoria. We pay respect to Elders past and present. We also acknowledge the First Nations health professionals, researchers and leaders who are shaping the future of genomic medicine.

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# Foreword

Having worked in varying roles over the years in disability, research, and genomics, consumer involvement in genomic medicine just makes sense to me. Engaging and listening to the voices of people impacted by genetic conditions can help ensure genomics is incorporated into care in a way that is meaningful and meets patient needs.

Since 2021, I have considered myself lucky to work with the Melbourne Genomics Community Advisory Group. In addition, we've also set up consumer involvement for five projects road testing models of care in genomics in different specialties. Actively involving and listening to consumers and lived experience experts has really shaped these projects. From influencing changes in the model of care to be more aligned with the patient journey, to producing patient friendly result letters and information sheets. I've witnessed clinicians who didn't really know how to engage with consumers realise the value of their involvement.

This resource has brought together the voices of community and consumer representatives. We hope that this will help encourage and support clinicians, health services and policymakers to continue involving consumers in genomic medicine.



**Chriselle Hickerton**  
Community Engagement Coordinator

A commitment to capture the voice of consumers and to listen to their distinct and relevant points of view that can be incorporated into actions that shape research, healthcare and services has been an integral part of the Melbourne Genomics Health Alliance since it began over 10 years ago. Initially through the establishment of the Community Advisory Group and later, the project consumer panels. It was this recognition of the significant value consumers can make to genomic medicine at the highest levels of the Alliance, that inspired me to accept the role of Chair of the Community Advisory Group in 2022.

During this time, I have listened, learned and seen firsthand, how consumers with lived experience have made significant contributions to all aspects of genomic medicine – from providing feedback on patient information and communication methods, to championing changes to clinician education and advocating for consumer involvement in genomics to be strengthened and embedded into policy and health services, being just some of the examples of how consumers have made a difference.

This resource is a culmination of the collective learnings and experiences of consumers who have worked tirelessly to ensure consumer engagement is meaningfully and respectfully sustained beyond the end of the Melbourne Genomics Health Alliance.



**Kellie-Ann Jolly**  
Chair, Community Advisory Group

# Executive summary

Consumer involvement can lead to safer and higher-quality healthcare. Genomics in particular has a number of [unique and uncommon features](#) that make consumer involvement both necessary and challenging.

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

The recommendations are split into three sections:

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

The guide was developed by consumers involved in Melbourne Genomics Health Alliance clinical projects and can help provide the foundations for respectful, meaningful consumer involvement in genomic medicine.

The recommendations are summarised below.



## 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 and actively promote involving consumers across all aspects of health services, from embedding it into systems such as health service advisory panels or committees, to individual projects and individual service advice.

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. There 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 (see section: *Further reading*).



### **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 (see *Case study: Using appropriate language in genomics*).

### **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.



# 1. Introduction

## 1.1 Purpose of this resource

This resource offers practical advice for health services when involving consumers in the development of genomic medicine services. It includes real examples of where consumers have added value to genomic medicine, with recommendations from consumers on how to improve their involvement.

## 1.2 Vision

Our vision is that all clinicians and health service providers involved in genomic medicine place the person at the centre of care and embed respectful and meaningful consumer involvement into all aspects of their work.

## 1.3 Who is this resource for?

This resource is primarily intended for clinicians and health service providers to:

- learn about the value of consumer engagement in genomic medicine from consumers themselves,
- inspire them to take action to engage consumers respectfully and meaningfully, and
- apply some of the lessons in this resource to their own clinical and research work.

A secondary purpose is for the resource to be used by consumers to:

- promote the value of consumer engagement in genomic medicine and in healthcare more broadly, and
- advocate for greater consumer engagement.

## 1.4 Background and context

**Genomic medicine is healthcare informed by knowledge of our DNA.** Genomics can be used to predict, prevent, diagnose or treat a wide range of health conditions. The **Melbourne Genomics Health Alliance** was established in late 2013 to help bring genomics into everyday healthcare, so Victorian patients could benefit. Consumer engagement has been central to the Alliance since its earliest days. A **Community Advisory Group (CAG)** was established in early 2014 to ensure that the needs of patients, families and communities were always championed.

The Alliance's final program (2021-2025) explored ways to increase the use of genomic testing across a range of health conditions. At this point, the CAG advised that more consumer voices would be needed, specifically from people with lived experience in each condition.

A total of 25 consumers were invited variously to:

- inform the wider use of genomic testing in **paediatrics**
- advise on how genomic testing is discussed with people with **cancer**
- explore ways to talk to families about genetic causes of **dementia**
- develop patient-friendly information on genetic causes of **kidney disease**
- develop patient-friendly information on genomic testing in **organ transplant** care

Clinicians and community engagement specialists worked together to recruit consumer representatives and support their involvement in relevant projects. This included regular meetings between project teams and consumer representatives, dedicated workshops, and out-of-session feedback on information materials.

It soon became evident that consumer involvement was adding value to each project. It was equally clear that clinicians wanted more support in this space: including how to engage consumers in topics as complex as genomics, and how to ensure the experience was inclusive and meaningful for the consumers who contributed.

## 1.5 Methodology

With the impending wind up of the Melbourne Genomics Health Alliance in 2025 and the CAG at the end of 2024, the CAG decided that a resource providing practical, tangible examples of where consumer involvement has improved outcomes or processes in genomics would be most useful and achievable in the timeframe. A face-to-face workshop was held in early June 2024 with 14 participants from the CAG and consumer panels. A follow-up online workshop was held in late June 2024, with 8 participants from the CAG and consumer panels who were unable to attend the face-to-face workshop. A further three provided input who were not able to attend either workshop.

## 1.6 What makes genomics different?

It is now widely accepted that consumer involvement leads to safer and higher quality healthcare. Genomic medicine, however, is an emerging field: one with unique features that make consumer involvement both necessary and challenging. For example:

**Patients are not always referred to specialist genetics services**, especially as doctors become more proficient at using genomics. While this enables patients to get their test results faster, it also means genetic counsellors may not be on hand to explain those results and their implications. Thus, involving consumers in developing patient information and communication materials is essential.

- Genomics is a **complex** topic, even for clinicians. Consumer advisors need time and dedicated support to understand the subject matter they need to advise on.
- Patients and their families may have been through many tests and investigations to find the source of their health problems, prior to getting a genomic test. They may feel considerable **apprehension around genomic testing**, possibly fearing the results of the test and/or not understanding the implications for them and their families. Understanding this 'diagnostic odyssey' and its impact on families is important.
- A person's genome holds **highly personal and sensitive information**, including clues to future health conditions and information that may be relevant to their blood relatives. Consumer involvement is crucial in developing appropriate consent, privacy and data management processes.
- Perhaps more so than other health issues, due to the inherited nature of genetic conditions they can present **complex and difficult choices for entire families**. Difficult choices require sensitivity, as they will be unique to each family's context, values and desires (see section on recommendations: *Systems approach and systems changes*).



Source: VCCC Alliance Model of Consumer Engagement

## 1.7 What is consumer involvement?

There is a spectrum of consumer engagement in healthcare. For example, the VCCC Alliance outlines the spectrum of engagement from informing consumers, to consulting, involving consumers (the focus of this resource), partnering and being led by consumers.

The Guidelines for Community Involvement in Genomic Research, while focused on research, defines community involvement as “consumers and community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy, and practice.”<sup>1</sup>

Involvement requires more active participation from consumers in both shaping and responding to issues. The range of issues that consumers provide advice and share expertise on in a diverse range of ways, and a wide range of areas. In Melbourne Genomics, consumers have been actively involved in a range of work that have shaped strategic decisions on consumer involvement in general as well as more specific involvement on areas such as models of care and patient facing materials.

## 1.8 How to use this resource

This resource is structured in three parts:

- **Introduction** section includes important context, definitions, and methodology in the development of this resource.
- **Consumers making a difference** section contains case studies of where consumers have added value and influenced knowledge, processes, outputs and outcomes in genomic medicine. Clinicians and health services that are looking for examples and inspiration about how consumers could be involved should read this section.
- **Recommendations** section outlines the recommendations from consumers about how to improve the value and contributions of consumers involved in genomic medicine. Clinicians and health services who are considering engaging or involving consumers should read this section.



# HOW CONSUMERS CONTRIBUTED TO MELBOURNE GENOMICS

This infographic outlines some of the ways that consumers have strengthened planning and delivery of genomic medicine in Victoria over the last decade.



## 01 Designing and planning

- Co-designing a community engagement framework
- Advising on strategy and processes to support consumer involvement within projects
- Helping to plan, design and evaluate video storytelling for clinician awareness
- Helping to evaluate consumer engagement/ involvement by informing data collection methods and helping to assess



## 02 Informing service provision

- Advising on patient journeys, referral pathways and proposed models of care





## 05 Advising on wider health system issues

- Providing perspectives on systemic challenges such as diversity of general practitioners and availability of genetic counsellors
- Advising on improving equity for consumers living in regional and rural areas



## 04 Helping clinicians understand the consumer's experience

- Contributing to education sessions for clinicians; advising on consumer views and potential concerns about genomic testing
- Providing lived experience perspectives on diagnosis and follow-up care



## 03 Strengthening patient communication

- Informing the content and design of patient information materials and webpages
- Reviewing letters that returned genomic results to patients and their doctors

## 2. Consumers making a difference to genomics patients and clinicians

The following are a series of case studies and success stories where consumer involvement has made a difference to patients and clinicians in the domains of:

- Patient information and communication
- Models of care
- Project design
- Clinician education
- Other consumer contributions

These domains are not mutually exclusive. In many cases, consumer involvement has started by providing advice in one domain, but the issues intersect so that the advice has implications for all the other domains. For example, consumer advice on how to communicate cancer test results to patients prompted an entire rethink about the model of care (see *Case study: Letters to cancer patients* and *Case study: Self-referral for genetic testing*). Consumer involvement can broaden the field of view of clinicians and health services and provide value beyond the immediate issue.

### 2.1 Patient information and communication

#### Case study: Letters to cancer patients

Consumers reviewed draft letters to patients from an oncologist informing them of their genetic condition. Consumers suggested a range of changes to make the letters more accessible and sensitive to the impact the news is likely to have had. For example, consumers suggested moving the results and findings to the top of the letter. This is what consumers want to know first. They suggested keeping language simple, gentle and avoid double negatives, acronyms or any ambiguous terms and to consider family members who may also read the letter.

Using the above feedback, the oncologist adapted the earlier versions of the letter into an editable word doc as an 'annotated patient letter'. This was so time poor clinicians could copy suggested phrasing and adapt to be specific to their patients results.

Here is the oncologist's response to suggestions made by the consumers:

*"The consumer [reps] have given some really great feedback on this, so helpful! I am really thrilled they were able to go through it. It has helped me look at my phrasing and consider better ways to phrase things. It is very challenging to do all of it: hit the right reading level, not overcall the importance of a finding, relay ambiguity and still be clear on the outcome... If the consumer [reps] are happy to have another look that would be great. I think this could be a great resource."*

- Medical Oncologist

#### Case study: Supporting families to tell their stories

Diagnosis Day is a micro-series filmed for YouTube and LinkedIn. It follows Victorian families with rare genetic conditions as they searched for answers, processed sometimes heartbreaking news, and came to terms with their diagnoses.

The Melbourne Genomics Community Advisory Group informed all stages of production: from topics to interview questions to how to ensure that families felt safe and supported. An evaluation of the series found that all participants felt respected and valued throughout the project, and almost all felt they had control over how their stories were told.

The series and evaluation report can be found at [DiagnosisDay.org.au](http://DiagnosisDay.org.au).



## 2.2 Models of care

### Case study: Self-referral for genetic testing

Consumers advising on a dementia care project were able to identify critical gaps in clinicians' understanding of a patient journey. Clinicians assumed that doctors refer patients for genetic testing and that is the only pathway for genetic testing. There were no pathways for patients to self-refer. Consumers shared that one person in a family getting genetic testing can prompt all family members to seek genetic testing. Further, families often live in other states and overseas and families can't be referred for genetic testing within one state. Consumers pointed to the large information gap for consumers outside of Victoria in knowing who to contact, and how to self-refer for testing. They advocated that health services should expand the information they provide beyond just listing relevant Victoria genetic testing services.

Consumers also identified the lack of awareness that specialist clinicians have about the option of genetic testing. There is still much more work needed to raise the awareness of clinicians about genomic medicine.

*"It wasn't until someone at the end of my father's life mentioned genetic testing. At each level of my father's health journey, not one clinician mentioned genomics until the final six months of palliative care even though there was a clear family history they were aware of."*

- Dementia Consumer Panel member

## 2.3 Project design

### Case study: Indigenous Governance Committee

The governance structures used by Indigenous health alliances enable meaningful, effective community involvement and leadership. The Australian Alliance for Indigenous Genomics (ALIGN) is a national consortium that aims to deliver sovereignty, equity, and benefit to Indigenous Australians through genomics. Indigenous governance both underpins and leads ALIGN's work. Jurisdictional Indigenous Governance Committees are vital in highlighting the voices, values, and priorities of Aboriginal and Torres Strait Islander peoples locally. The Victorian Committee generously shares a range of skills, knowledge, and experiences including leadership, policy, governance, clinical genomics, academia, and health. This diversity allows for insights which pioneer meaningful benefit for Aboriginal and Torres Strait Islander peoples and speaks to a self-determining model of care.

The Committee have contributed important insights into the design and conduct of two Melbourne Genomics funded projects:

**The Indigenous Genomics Health Equity project**, led by the Victorian Aboriginal Community Controlled Health Organisation ([VACCHO](#)). This project explores barriers and access (gaps) to genomic medicine and genetic service referrals for Aboriginal and Torres Strait Islander people in Victoria.

**The Achieving Equity in Genomic Health for Indigenous Australians project**, led by the University of Melbourne, exploring gaps for Aboriginal and Torres Strait Islander patients by looking at data on access to genetic services in Victoria.

*“The Committee always brings it back to the priorities of mob in Victoria. They are pivotal to ensuring the work we do will leave a lasting, positive impact for individuals, families, and Communities.”*

- Program Coordinator for ALIGN Victoria

## 2.4 Clinician education

### Case study: Using appropriate language in genomics

Consumers said they often needed to explain to clinicians and project staff that some descriptions of genetic conditions could be seen as inappropriate and hurtful to patients. Language that implies that patients with genetic conditions are deviating from the ‘norm’ and must be brought back to the ‘norm’ can be hurtful and derogatory, with subtle implications that somehow the patient is responsible for their genetics. Consumers shared common examples of value-laden language that clinicians have used such as, ‘genetic mutation’, ‘genetic anomaly’, and ‘genetic disease’.



Consumers requested clinicians use the term ‘genetic condition’ instead, and provided advice on using respectful language in Melbourne Genomics [resources](#) and education modules. Further exploration of the medical model and language is in the recommendations section: *Human rights and respectful language*.

*“For me it’s not about ending ableism in health. It is an aspect of healthcare discrimination when I am told that I am a mutant, or that I have an issue, or that I should only conceive using assisted reproductive technologies, or that fetuses with similar sequencing to me should be terminated. I am not someone to feel sorry for. I live a proud, full and rich life. Disability should be celebrated not eradicated. In these genomic health projects, echoes of similar ableist bias came through in communications, some covert and others overt. It is all stemming from systemic ableism. Working with consumers in genomic health requires anti-discrimination practice. That’s about being more than just sensitive or respectful, that’s about employing disabled people to work in health, to centre us in your work not only as consumers but as colleagues and leaders, valued equally and in our own right.”*

- Cancer Consumer Panel member

## Case study: Co-designing interventions with parents, paediatricians and genetic experts

Consumers participated in a co-design workshop with paediatricians and genetic experts to improve equitable access to genetic testing. The workshop helped build an understanding of different points of view. Consumers had a view that paediatricians were too busy to order genetic testing and felt “like they didn’t want to bother them”, so they went to a geneticist instead. The co-design workshop process was able to surface the misperception between consumers and paediatricians and bridge the disconnect between doctors and patients.

## 2.5 Other consumer contributions

Consumers are passionate about the importance of consumer voice in health systems, health research, health services and projects and they continue this work outside of direct participation in formal meetings. For example:

- **Education.** Consumers involved in Melbourne Genomics have spoken at a workshop as part of the International Congress of Genetics and Genomics. They have spoken at education sessions for Paediatricians.
- **Networks.** Consumers play a vital role in continuing to refer their networks for other consumer panels to make sure the ‘right people are at the table’ and that consumer voices continue to be heard.
- **Advocacy.** Consumers also shared that they are not as constrained as health services in advocating publicly for funding. They actively use their consumer networks to share real stories with the media and advocate for change.

More than providing specific advice on projects, consumers bring a lens and a perspective of the practical lived experience of seeking and receiving information and health services in genomic medicine. They can point to gaps in the patient journey, knowledge and communication and challenge assumptions that clinicians may hold.

*“People come with projects with the view to translate existing material. That is fine, however, good to start with a plain language version otherwise the translation may not work as well. People also start with the assumption that there is a certain amount of literacy, not everyone is literate. There are other ways to communicate health information visually... The way this is disseminated is also critical.”*

- Community Advisory Group member

*“Many families want to know their dementia risk. Sometimes GPs assume that families have children that are young and therefore are not thinking about dementia yet, but that’s not always the case. We want to be given the option.”*

- Dementia Consumer Panel member

*“Consumer feedback was influential in how the team thinks about the process of discussing genetics with families affected by young onset dementia. Basically, [clinicians should] follow up more, [and think about] how stigma can limit families opportunities for discussions about testing, that there can be an urgency to these discussions.”*

- Clinician

### 3. Where to from here? The foundations for respectful, meaningful consumer involvement in genomic medicine



Consumers have developed a range of recommendations to improve consumer involvement in genomic medicine. Many of these are not new ideas or practices in the world of consumer involvement, and we have referenced the relevant resources where appropriate. The themes and recommendations are interdependent and not mutually exclusive. For example, a mindset shift towards valuing consumers and their contributions underpins all other themes and recommendations. Similarly, there is crossover between themes and recommendations around providing information on the outcomes the clinician is seeking so that consumers can contribute better, and providing feedback on that advice.

#### 3.1 Mindset shift

Consumer involvement in healthcare has had a long history in Australia, with the formation of organised consumer groups such as the Health Issues Centre in 1985 and the Consumers' Health Forum of Australia in 1987. These organisations provided a voice for consumers to influence health policy, program development and service delivery.

More recently, health services are coming to more deeply appreciate the value of consumer involvement and lived experience. In some health services, they have established roles for mental health peer workers. In the human services system, there are established 'lived experience' peer roles for people who have experienced family violence or homelessness.

However, there are still many people in the health system who do not see the value of consumer involvement. Some clinicians see consumer involvement as vital to their projects, and others see it as a formality or simply a requirement for funding. As with any systemic change to ways of working, it takes persistence from consumers and champions of consumer involvement to continually demonstrate its value and persuade others to come on the journey.

*“Clinicians need to collaborate with patients. The clinicians feel that patients have no knowledge.”*

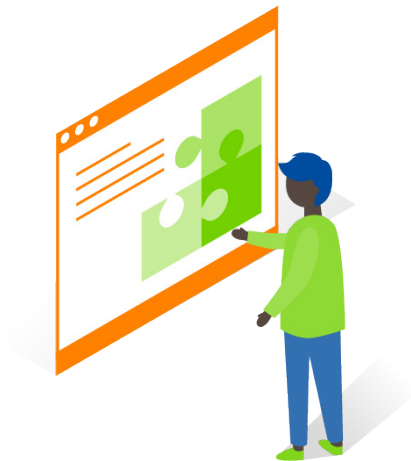
- Consumer Panel member

Consumers should be asked how much they wish to participate and what level they wish to engage, if any. All participants should be reminded that they can opt out at any stage.

### **Recommendations for health services:**

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

## **3.2 Systems approach and systems changes**



Many of the consumers remarked on the current fragmented and devolved approach to consumer involvement. Each genomic medicine project had to establish its own panel, recruiting and inducting consumers to provide advice. There is opportunity to take a systems approach to consumer involvement, which means looking not only at individual services but at the health system and institutions as a whole.

Taking a systems approach means that consumers will be able to provide more meaningful advice on organisational issues such as the strategic planning of the organisation, not just on direct service delivery.

One example of a systems rather than a piecemeal approach to consumer involvement in genomics is the Australian Alliance for Indigenous Genomics (ALIGN). ALIGN's purpose is 'to articulate and undertake a transformative approach to the development of responsible, culturally appropriate, nationally consistent and internationally relevant Indigenous genomics efforts.'<sup>2</sup>

This involves four core activities: 1) Indigenous Governance of genomics research and clinical care; 2) the development of best practice data systems and data sovereignty; 3) genomics policy; and 4) developing capacity.

Hospitals and health services have established processes for consumer involvement such as formal Consumer/Community Advisory Groups that provide advice to Boards, as well as specific panels and committees. Some health services have established consumer committees that review all patient-facing material. Genomic medicine information, if relevant, will need to be incorporated into some of this patient-facing material. It is incredibly important for consumers with experience of genomic medicine to be involved in these broader processes, as genomic medicine does not sit alone but is always part of a patient's broader health journey.

Consumers suggested a model where there is a broader group of consumers with genetic conditions that health services could call upon when needed. This model would reduce the impact on the same consumers, as well as giving consumers choice in the type of work and the process they want to be involved in.

**“There are several levels of consumer engagement. There's telling your story, and then there's knowing where and how you want to engage.”**

- Consumer Panel member

Consumers remarked on the benefits of a coordination role and the importance of empathy and communication skills in that role. It is important that this role recruits someone who has a consumer centric mindset that can check in, support and advocate for consumers on their involvement journey.

*“A dedicated community engagement coordinator role is essential for a one point of contact for all consumers. This role should be employed by someone who has a unique skillset that includes highly empathetic and is a plain language communicator. The McGrath Foundation nurses are good examples of this and so is Chriselle [Community Engagement Coordinator].”*

- Cancer Consumer Panel member

Consumers noted sensitivity may arise in involving consumers in genomic medicine. More than other health issues, understanding genetic conditions and risks necessitates complex decision making that only each individual and family can decide for themselves. Having a dedicated consumer coordination role provided them with someone they could debrief with and help them navigate through providing advice and feedback on their own circumstances without it casting judgement on other experiences.

*“I've learned a lot about myself and my family. Sometimes I worry that in making a comment, it could be taken as a personal slight against someone else. I.e., Whether you decide to have a child or not after finding out this information or whether you want to know this information at all. Everybody has their own way of processing the news and their way of dealing with the information. Chriselle [Community Engagement Coordinator] always checked in with me so that I could have these conversations.”*

- Dementia Consumer Panel member



## Recommendation for hospitals and health services:

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.

### 3.3 Building relationships

Consumers stressed the importance of building personal relationships with all of the people involved in the project or service. Building personal relationships are the foundation of effective communication between consumers, clinicians and project staff and improves consumer's ability to provide valuable advice. Building relationships, unsurprisingly, is one of the recommendations of the Guidelines for Community Involvement in Genomic Research.<sup>3</sup> Meeting in person helps to build rapport and establish ways of working and define outcomes.

*"We are only just getting to know each other and understand each other's stories and background now, but it would have been so much better to meet in person at the start."*

- Cancer Consumer Panel Member

### **Recommendation for clinicians, health services involving consumers:**

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.

### **3.4 Outcomes, objectives and context first**

Consumers spoke about the lack of understanding on both sides of consumer engagement, of clinicians not knowing how best to engage with consumer advisors, and consumers not knowing if the advice they were providing is valuable. If consumers and clinicians had a broader discussion about what patient or clinician outcomes and objectives they are trying to achieve from the outset, consumers would be able to position their advice more effectively. Unclear goals make it difficult for consumers to know what and how they should be giving input on and how it will be used in the project. This can risk being a 'tick box' exercise, if clinicians are not thoughtful about how and why they are seeking consumer involvement.

*"We don't know if the clinicians got what they wanted. What were the outcomes that we were trying to achieve through the advice? Otherwise, we're just telling our story over and over."*

- Dementia Consumer Panel Member

Similarly, clinicians and project staff should thoughtfully consider the purpose of engaging consumers in a particular process to ensure that it is meaningful. In some cases, this may mean appropriately briefing participants in the process to make sure they understand the purpose and value of consumer engagement. In some instances of consumer involvement, consumers felt their contribution was unnecessary and unwelcome.

*"I feel there were some very strong personalities in our group who were qualified in technical writing [and also had lived experience as consumers]. It was very hard to express thoughts on how the information should be structured."*

- Transplant Consumer Panel member

*"I just felt outgunned by others who had greater knowledge and expertise on the subject."*

- Transplant Consumer Panel member

### **Recommendation for clinicians and health services involving consumers:**

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.

### 3.5 Power dynamics and the value of lived expertise

With any area of consumer involvement in healthcare there is a risk that consumers feel that they are not contributing. Healthcare and genomic medicine is complex. Inherent to any consumer involvement is *information asymmetry* where clinicians and teams have more information about the service they are seeking advice on and more technical knowledge of genomic medicine. Consumers have a personal and emotional context that they are coming from in providing advice. They may be dealing with trauma from their experiences of their health journey and its impact on their family. They may be coming from different understanding of the English language and different socio-economic circumstances. For all of these reasons, clinicians and project staff are in a position of greater power than consumers. It is easy under the circumstances for consumers to feel intimidated, not confident in their knowledge and that they are not contributing meaningfully.

*"I am not totally sure where my involvement has contributed to the project's outcomes as I haven't received any personal feedback. In all the meetings I attended I expressed my personal experiences and how I believed that genomics testing I have received to date has helped me, and possibly my family/future family over the coming years. I do hope what I had to share was of value."*

- Consumer Panel member

Consumers may also have different levels of health knowledge and literacy and it is important for clinicians and researchers to not make assumptions.

There is a distinction between lived experience and lived expertise. Lived experience can be defined as "the experience(s) of people on who a social justice issue, or combination of issues, has had a direct impact." Whereas lived expertise can be defined as "the knowledge, insights, understanding and wisdom gathered through lived experience."<sup>4</sup> In practical terms, this can mean providing training and/or sufficient information for consumers to use their lived experience to provide lived expertise.

#### Recommendation for clinicians and health services involving consumers:

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.

### 3.6 Feedback loops



Feedback loops are not a linear process of seeking advice, action, then communicating the outcome and ‘closing’ the loop. Often, the assumption is that feedback will occur from clinicians to consumers about the impact of their advice, however, effective feedback loops are two-way, continual communication between consumers and clinicians that support an iterative learning process. Consumers asked for better two-way feedback between consumers, clinicians and project staff so they can all improve understanding of each other’s perspectives and increase the value of consumer involvement.

Consumers should consider the following questions and provide the relevant feedback to clinicians and project staff:

- How was the information provided to us? What guidance were they seeking? Did we have enough information and context to provide valuable guidance? How could clinicians improve in the way they present and communicate information to us?

Clinicians and health services should consider the following questions and provide feedback to consumers:

- How do we want to work together? What are our ways of working including ways of communicating, operating rhythm (frequency and rhythm of involvement), sharing of information and conduct of meetings. How do we work with consumers to co-create ways of working that work for everyone?
- What parts of the advice were helpful and what was not? What would make it more helpful in the future? How can consumers improve the value of their advice? How can I keep consumers involved in this issue going forward to build on the advice and keep continuity of knowledge?

#### **Recommendation for clinicians and health services involving consumers:**

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.

### 3.7 Remuneration

Many of the consumers spoke of the material cost of participating and providing advice in genomic medicine, which may not always be anticipated after offers of an honorarium and/or travel expenses. They noted that there is a disparity in remuneration of consumers providing formal advice in health care. There are a wide range of rates for consumer involvement, with no clear standard rates for involving consumers. Paying consumers for their expertise, demonstrates the mindset shift valuing consumers (see sections above). Payment recognises that unlike consumer product testing - where general members of the public provide consumer feedback on their preferences and tastes - in the field of healthcare, consumers are providing lived *expertise* based on their experiences.

*"I had to pay for a carer for my husband to be here today."*

- Dementia Consumer panel member

*"I will have to work late tonight to make up for the half-day that I'm here today."*

- Cancer Consumer panel member

#### **Recommendation for clinicians, health services and researchers involving consumers:**

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 (see section: *Further reading*).

### 3.8 Respectful engagement and language

Consumers spoke of having to provide a lot of informal education of clinicians and researchers about their language and the challenges of the medical model as part of their involvement. The term 'medical model' was coined in the 1950s to criticise how physicians only viewed physical symptoms and overlooked psychosocial aspects of health. The term 'medical model' has often been used in the context of identifying underlying beliefs and worldviews about disability and mental health.<sup>5</sup>

In a medical model, diseases are seen as a deviation from what is 'normal' and the condition must be fixed so they can become 'normal' again. The language of genomics has many examples that reveal a medical model as an underlying worldview. Terms such as 'mutation' and 'anomaly' imply deviation from the 'norm'. They view the condition as a problem to be solved. In a medical model, the focus is on the individual's deficit and what they cannot do as a result of their condition. Any deviation in a person's experience of life is due to their condition, disability or mental health issue.

In contrast, 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.

Applying a social model to genetic conditions, medical treatment or interventions are a means, not to return to the 'norm', but to undertake the activities that they determine they want. The genetic condition should not be viewed or discussed by clinicians as a problem to solve. The focus in a social model is on how clinicians and other services can support an individual and their family to participate in society and the economy in the way they wish to.

Consumers advocated for clinicians and researchers to ask consumers and patients about their preferred language and terminology. This recognises that language continues to evolve, and each hospital, service and department uses different language. For example, consumers may prefer use of the term genetic condition rather than genetic 'disease'. There are guidance documents available from the Victorian Department of Health and People with Disability Australia (see section: *Further reading*) on inclusive language. Consumers advocated for clinicians and researchers to use respectful strengths-based and person-first rather than identity-first language (e.g. person with a disability rather than disabled person).

*"(Sometimes I was) spoken to loudly or slowly because I have a rare disease."*

- Cancer Consumer Panel member

*"See the person, not the condition. The condition should not define the individual."*

- Consumer Panel member

### **Recommendation for anyone involving consumers in genomic medicine:**

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 (see *Case study: Using appropriate language in genomics*).

### **3.9 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. The six principles of a trauma-informed approach to care are:

- Safety
- Trustworthiness and transparency
- Peer support
- Collaboration and mutuality
- Empowerment, voice and choice
- Cultural, historical and gender issues<sup>6</sup>

Consumers noted that a trauma-informed approach would be valuable in genomic medicine. Genomic medicine and the impact of being diagnosed with a rare disease or genetic condition can be traumatic for individuals and families. An approach that understands this, and prioritises engaging with patients to build trust, provides choice and agency, and empowers individuals and families to make informed decisions would be hugely beneficial for people with genetic conditions. Similarly, it would be valuable if clinicians brought an understanding of cultural, historical and gender issues to their engagement with patients and consumers, particularly First Nations peoples and people from culturally diverse backgrounds.

**“Sometimes clinicians act like patients don’t know their own bodies.”**

- Consumer Panel member

### **Recommendation for anyone involving with consumers in genomic medicine:**

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

## **3.10 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, ability, cultural and linguistic background, Aboriginal and Torres Strait Islander people, socio-economic background and metro/regional or rural location is important. There are a range of intersecting barriers for consumers from diverse backgrounds to be formally involved in providing genomic lived experience expertise such as:

- Language, literacy and cultural barriers to participate including that all of the papers for consideration are in English
- Socio-economic barriers to bear the cost of participating and the flexibility to take time off from work if they are employed

- Caring responsibilities and finding alternative care arrangements for children or other dependents so they can participate
- Location of meetings and events in metropolitan areas rather than regional and rural locations, with increased time and cost to travel
- Technology barriers such as use of a device and access to internet connection/data

These barriers can intersect and compound, leading to consistent processes and cycles where certain voices and experiences are excluded. For example, consumers are often recruited by clinicians, who look to their own patients. But in many cases, their patients are the ones who have access to specialist services and therefore, more likely to be from a White, middle-class, English-speaking background. This extends to support groups, which are established by patients, often from a white, middle-class, English-speaking background.

The Victorian Government supports funded services to identify when language services should be offered to consumers and carers based on legislative requirements and good practice service delivery. The Victorian Department of Health offers access to language services credit lines for select funded agencies.

In the experience of Melbourne Genomics involving Aboriginal and Torres Strait Islander consumers, it has been more effective to support and partner with ALIGN and VACCHO to lead the process. These Aboriginal-led organisations can engage communities in a more coordinated, meaningful and appropriate way than mainstream services.

**“The focus of projects was on ‘mainstream’ populations. They didn’t have the lens of different languages and cultures and how they would be reached.”**

- Community Advisory Group member



### Recommendations:

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.



## Further reading

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NSW Health, All of Us: A guide to engaging consumers, carers and communities across NSW Health website including tools on Six Ways of Working available at <https://www.health.nsw.gov.au/patients/experience/all-of-us/Pages/six-ways-of-working.aspx> and Essentials Checklist available at <https://www.health.nsw.gov.au/patients/experience/all-of-us/Documents/essentials-checklist.pdf>

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VCCC Alliance, Model of Consumer Engagement available at <https://vcccallyance.org.au/consumer-engagement/model/>

Victorian Government, Language Services Policy available at <https://www.health.vic.gov.au/publications/language-services-policy>

# Endnotes

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