

HCQ

**HEALTH
CONSUMERS**
QUEENSLAND

Consumer and Community Engagement Framework

For Health Organisations and Consumers



Acknowledgement of Traditional Owners

Health Consumers Queensland acknowledges the First Nations peoples who are the traditional custodians of the land on which we live, work, and play. We pay our respects to Elders past and present of the Aboriginal and Torres Strait Islander peoples as cultural authorities of the world's two oldest living cultures.

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1. Introduction

Purpose of the Framework

The Consumer and Community Engagement Framework (the Framework) is designed to orient health organisations to what underpins successful consumer and community engagement. The goal of this Framework is to encourage health organisations to embed consumer and community engagement in their work. This requires staff thinking beyond accreditation against the National Safety and Quality Health Service Standards. Meaningful engagement connects staff to the people they support, the purpose of their work and enables them to deliver care that leads to better outcomes.

Ten years after the first update of this Framework, Health Consumers Queensland has begun to use the term 'partnership' as it describes the relationship more clearly. Partnerships need to be two way, equal, respectful and cooperative. Throughout this document, the terms are used interchangeably.

The Framework can be used across the health system from public and private health services, primary health organisations, government departments to universities and research centres. It will support health providers to develop strong consumer and community partnerships that drive changes, deliver better outcomes and provide healthcare the community wants and needs.

Though written primarily for health organisations, it is hoped that the Framework will also assist consumers to understand what they can expect from health organisations they engage with and support them to develop effective partnerships and a common understanding of their possible roles.

This Framework is not a 'how-to' guide. The Framework provides health organisations with an understanding of *what* engagement is, *when* and *where* it can take place and *why* they are doing it. When these solid foundations are present, typically, effective and meaningful engagement processes occur.

Two additional Health Consumers Queensland documents support the *how* of engagement:

- *A Guide for Health Staff – Partnering with Consumers*
- *A Guide for Consumers – Partnering with Health Organisations*

History of the Framework

The Framework was first published in 2012 as the National Safety and Quality Health Service Standards² (the National Standards) came into effect and the *Hospital and Health Boards Act 2011* (Qld)³ was passed into legislation in Queensland.

Both these reforms acted as levers for health organisations to begin to embed consumer and community engagement into their services and continue to do so. The Standards require hospitals to meet Standard 2: Partnering with Consumers and the *Hospital and Health Boards Act* requires all publicly funded services to have a consumer and community engagement strategy in place.

The Framework was developed via widespread consultation with consumers, carers and health services with the aim of supporting health organisations to do this work.



DEFINITION

Consumers

Consumers are people who use, or are potential users of, health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.¹

Current context

Since the introduction of the Framework in 2012, health organisations have deepened their knowledge and experience in consumer and community engagement. Health Consumers Queensland undertook a first review of the Framework in 2016/2017 to ensure it remained relevant and useful for this changing environment.

The current review commenced in 2025 at the same time as the Australian Commission on Safety and Quality in Health Care began its most recent review of the National Standards. Our review ensures that the Framework will continue to act as a guide against the National Standards.

In primary health, Primary Health Networks are mandated to have a community advisory committee as a way of engaging with their communities.⁴

Concurrently, the community sector is continuing to witness a significant shift to consumer directed care.

The National Disability Insurance Scheme and aged care sectors are

now increasingly driven by the needs and preferences of the consumers of services. This shift in choice and control will likely increase the demand for, and hasten the necessity of, consumer-centred care in the health system.

Consumers have greater expectations of the level of involvement they should have when making informed choices about the services they receive individually and collectively expect greater involvement of consumers in the planning, service delivery and evaluation of healthcare services.

The move towards consumer rights is not new. In fact it has grown out of the consumer, civil and human rights movements which had their births in the 1960s.⁵ Health organisations have embraced these movements at varying rates as in order to do so requires enormous cultural shifts in the mindsets of all leaders, clinicians, policymakers and the community. It also requires supporting consumers and community to be actively involved through the sharing of control and decision-making.

About Health Consumers Queensland

Health Consumers Queensland (HCQ) is the peak body representing consumers of the health system, their loved ones and carers in Queensland. By elevating and amplifying the diverse voices and lived experiences of consumers, and by advocating on their behalf, we are building more responsive public and private health services and systems for all Queenslanders.

We are committed to building and supporting a network of consumer representatives that reflects our community's richness – including rural, regional, and remote areas; varied faith, language, educational, and socio-economic groups; and all ages. In particular, we uphold strong, respectful, and genuine partnerships with Aboriginal and Torres Strait Islander communities, ensuring that First Nations voices remain at the forefront of decisions affecting their healthcare.

SECTION SUMMARY

- Health Consumers Queensland is a not-for-profit peak organisation representing the interests of health consumers and carers in the state.
- Our first Framework was published in 2012 to support the new National Standards and the Queensland Health and Hospital Board Act's requirement for all Hospital and Health Services to have a consumer and community engagement strategy.
- Consumer and community engagement has evolved significantly since 2012. The Framework has been reviewed to ensure it remains relevant and continues to assist health organisations work in this area.
- The revised Framework is designed to help health organisations achieve meaningful consumer and community engagement and to assist consumers to understand what they can expect when engaging with health services.

2. What is consumer and community engagement?

Consumer and community engagement refers to the activities and processes through which consumers and their communities partner with health organisations in the design, delivery, evaluation and monitoring of their services.



DEFINITIONS

Consumer engagement

Processes through which consumers and carers actively engage with health organisations in their own healthcare and in health policy, planning, service delivery and evaluation at all levels of the health system.¹ The goal is for this engagement to become truly collaborative with sharing of power and decision-making. This can then be referred to as consumer partnerships.

Community engagement

Community engagement refers to activities and processes where the opinions, concerns, needs and aspirations of community members are sought by government or non-government services and are incorporated into the planning, design and delivery of health organisations. Community engagement is based on relationship building, partnership and the principle that community has resources and expertise.⁷

Health services

Health services refers to public and private health and community services delivering services which include health promotion, disease prevention, diagnostic, treatment, primary, acute, sub-acute and support services. It also includes the policies and activities of departments and Ministries, related non-government organisations, consumer and community groups and professional associations.⁸

Put simply, meaningful engagement and co-design between health services and consumers, where lived experience is the primary contributor, is the most effective way for health organisations to understand what and how their community wants healthcare to be delivered.

Consumer and community engagement is not uniformly defined.⁶ There is no arbitrary line where consumer engagement finishes and community engagement begins. However, generally speaking, consumer engagement in health occurs in activities where consumers partnering with health organisations have a lived experience of the service and/or the health issue in focus or are a part of a group that share a particular collective experience of healthcare e.g. people of culturally, spiritually and linguistically diverse backgrounds or Aboriginal and Torres Strait Islander peoples.

Community engagement takes place with broader groups of consumers and community members who are able to speak about the types of healthcare they would like and contribute to addressing issues such as access, health literacy and strategic priorities. In community engagement, it may be likely that some participants do not identify as health consumers, but as community members.

Community engagement is more likely to occur to inform broader strategies and to ensure the health organisation is connecting with communities that face barriers to accessing healthcare (see 'Extending your reach', p22).

There are diverse ways in which engagement can occur. A health organisation that has embedded engagement as an essential way of doing business will be continuously partnering with consumers in multiple ways and phases of projects, across the organisation.

Person-centred care can be viewed as the individual level of consumer engagement and may contribute to the design, delivery, monitoring and evaluation of services if feedback is acted upon to inform patient experience and shared decision-making in clinical practice. The purpose

of consumer and community engagement is to achieve meaningful improvement in both the quality and safety of services being delivered and in order to achieve this consumer and community engagement must have a broader focus than individual clinical care.

Engagement can be done in collaboration with other health and community organisations and result in shared learning and more integrated services. Consumers' main concern is not with the source of funding for their services but with the accessibility and coordination of their individual healthcare journeys and how these relate to broader issues such as transportation, cost of living and education.

Partnering with consumers in the health system is only limited by willingness and imagination.

Consumer roles

A diversity of roles, expectations and terminology exist around the concept of a consumer in the health sector.

While all people can be considered consumers through their use or potential use of health services, in a consumer engagement setting, there are additional expectations.

Consumers participating in engagement activities in the health sector are recruited for specific experience and strengths. Consumers can have a lived experience of using health services and networks and also represent a group, network or consumer organisation and the ability to present perspectives other than their own (consumer representative).

Health services must be clear about the experience, strengths and networks they are seeking from consumers for engagement opportunities. In many cases it will be appropriate to have multiple consumers with a variety of abilities. The diversity of voices engaging with an organisation is important (for more information please see 'Extending your reach' on p22).

Consumers may have an in-depth knowledge of health conditions and evidence for treatment and models of care, but they should not be expected to have a technical or clinical background. They may have a legitimate and personal interest in a health subject and they are at the table to share their lived experience of receiving clinical care. It is the responsibility of the health service to ensure that consumers have clinical information explained to them where it is necessary in order to be able to partner effectively.

We acknowledge current staff of health services are also consumers of healthcare. It is strongly recommended

that staff should not take on the role of a consumer within engagement activities in their service as:

- staff knowledge of the service can create biases and make it difficult for them to see barriers and/or possible solutions (or think outside the box). This might still occur with past staff members or staff from other areas of the service
- staff in a consumer role may find it challenging to be impartial or advocate effectively when other staff are present.



DEFINITIONS

Consumer representative

A health consumer representative is a health consumer who has taken up a specific role to advocate on behalf of consumers, with the overall aim of improving healthcare.

A consumer representative is someone who voices consumer perspectives other than their own and takes part in decision-making on behalf of consumers. A health consumer representative may be nominated and supported by and accountable to, a consumer organisation.⁹

Carers

Carers are people who provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems. Australia has over 2.8 million carers, 12% of the population.¹⁰

Other consumer roles

Other consumers whose experience and strengths come from their lived experience of using health services can be referred to in a number of ways, for example, consumer advocate, consumer advisor, community advisor. Consumers engaging in mental health are often referred to as lived experience representatives.

There are two exceptions to this:

- staff who are participating in an activity coordinated by an area of the health service outside of their own role, who have specific representative experience and skills; and
- peer workers whose roles are primarily to support consumers.

Staff can always still participate in engagement activities as staff representatives rather than consumers.

The evidence for consumer engagement

There is a growing evidence base on the benefits of consumer engagement within health organisations. This evidence is however focused largely on consumer-centred care and building a body of evidence has been limited by the variety of language used to describe consumer and community engagement concepts. For example, patient-

centred care, patient experience, co-design, partnerships, shared decision-making, co-creation, consumer engagement, and so on.¹¹

The paradigm in which the health system operates values evidence that is academic, empirical and published in journals and places less weight on anecdotal and experiential knowledge. Consumer engagement is designed to improve services and generate new and innovative ideas. People working within health services who have led and participated in engagement with consumers and community have witnessed and can articulate how these partnerships have resulted in outcomes such as more appropriate, safer, higher quality, more efficient and cost-effective services. A challenge for the health sector is to turn this anecdotal knowledge gained through experience into knowledge that is evidence-based and empirical.¹²

CONSUMER ENGAGEMENT MYTHS



I'm a clinician, engagement has nothing to do with me

As a clinician you may already see gaps in your service, sometimes brought to your attention by the people you provide care for. Partnering with consumers to address these gaps helps to ensure solutions are found that are more broad (not just focusing on clinical aspects but also social and emotional wellbeing for consumer and staff), more sustainable and consumer-centred.

As a clinician, regardless of whether you are a graduate or in a leadership role, you can demonstrate to others the value of partnering with consumers in decision-making. This could be as simple as asking a question in your team meeting, "How can we ask consumers what matters most to them in relation to an issue?" or "What can we do to address the issues that matter most to consumers?"

If you are unsure how to partner with consumers or don't know where to begin, there will be colleagues in your organisation who can help you.



I only know of a few experienced consumers

Health services and organisations play a crucial role in developing and supporting consumers so they gain confidence and more experience in partnering with health services. Every consumer you consider experienced started with no experience. You can play a crucial role in recruiting and retaining a pool of consumers and help them to build up their own knowledge and expertise in the area. For example:

- Start small and grow your network of consumers over time
- Ensure you provide orientation, training, support and professional development to consumer advocates so they can be an effective voice for consumers more quickly
- Host a morning tea so consumers get a chance to come together and provide some peer support and ideas to help others in similar roles
- Engage two consumers on a steering committee or a working group so the new consumer can

This does not have to be the only approach to gathering evidence. Consumers, consumer organisations and health organisations need to work together to capture and document consumer and staff experiences and their impact on service delivery and engagement processes. Health services can recognise the intrinsic value of this knowledge as evidence and use it to inform the planning, delivery and evaluation of services. These stories can also be powerful tools for championing health service achievements.

Of the empirical evidence that is available, consumer and community engagement has been shown to:

- improve experiences of care which is known to be associated with improved health outcomes
- produce health information that is understandable and meets the needs of consumers¹¹
- ensure more accessible services (e.g. transport, appointment processes)¹²

- result in attitudes and cultures of health organisations being more open to involving consumers¹²
- increase quality of services¹²
- create more responsive services and better outcomes¹³
- lower risks of post-treatment complications and reduced hospital and medical visits.¹⁴



What can you do to increase the body of evidence that shows the positive impact consumer engagement has on health services? Can this research be led by consumers?

be mentored by an experienced consumer and both consumers can learn from and support each other

- See every interaction with a consumer as an opportunity to invite someone to partner with your service. Even if it is just “You have some really great ideas, would you be interested in helping us to improve the service?”



I'm too busy and the timelines are really tight

Consumer engagement does require some investment of time – building relationships, building skills and empowering individuals to view their lived experience as expertise. When consumers are engaged at the planning stage of your project it can make the project more focused and you realise effective outcomes sooner.

You will end up with a service that meets the needs of your community while at the same time building the capacity of consumers to better manage their own health. It's better for everyone to engage early than to face a community protest at your door or an adverse outcome that could have been prevented.



I'm engaging with consumers all the time, we see them every day

Providing consumer-centred care is an important level of

engagement, but how do you know that you (and your team) are providing care that feels safe and is appropriate for the person? Asking questions to people beyond their clinical needs helps you to know some things you would never have known unless you asked and this is one of the key tasks of consumer engagement. For example, the question “How easy is it for you to attend this clinic?” can provide valuable insight.

You may already feel that a clinician's ability to provide consumer-centred care is constrained by a number of elements (e.g. funding, time, confidentiality). Partnering with consumers to co-design a model of care, process or clinical guideline, can help you to provide each consumer with the best care possible because it's been designed with the needs of the consumer in mind.

The drivers of engagement

Most people choose to work in the health sector so they can contribute to the wellbeing of their community. Consumer partnerships reconnect health staff to their values and reasons for working in health, to the people they support, and enables them to deliver care that leads to better outcomes.

The drive to engage with consumers goes beyond simply satisfying the requirements of accreditation under the National Safety and Quality Health Service Standards.

Following are some quotes from health staff from Hospital and Health Services across the state which illustrate the value they gain engaging with consumers.



Telling their personal stories can be a powerful way for consumers to engage and influence healthcare. People remember stories because they have heart-felt reactions to them. Focusing on the personal can refocus health staff to keep consumers at the heart of the care they deliver.



“(Having a consumer group) adds a whole lot of merit. It opens conversations that otherwise wouldn’t happen. As clinicians we think about how it would feel or look for a patient, but at the end of the day we work here ... I would encourage anyone to have a consumer representative at their meetings.”

– Hospital Nursing Director, Women’s and Family Services, and Chair of a maternity consumer advisory group



“Partnering with consumers actually makes life easier for health staff. It adds additional expertise into the system that supports decision-making and enables staff to be more confident that we are actually delivering services how the community wants them to be delivered ... I have also found that consumers can be tremendous advocates for the health service as well. They start to understand how complex a health service can be, and that there are many factors that need to be considered in planning and design. I find they take this information back to the community and help the community to understand how healthcare works and the rationale behind the system. This creates shared understanding and, in my opinion, makes things better for everyone.”

– Person-centred Care Lead, public hospital



“As a healthcare provider it is vitally important to actively listen, to listen with intent, because only then can we fully appreciate and understand the patient experience of care. The patient experience of care is critical to driving and shaping effective 21st century health systems.”

– Executive Director, Mental Health Services

The legislative and policy context of engagement

There are a number of drivers of consumer engagement at state, national and international levels, the majority of which articulate the need for participation of consumers and community in their health systems. Health organisations should be aware of these not only for the purposes of accreditation and meeting legislative requirements, but because they outline the aspirations and expectations of consumers for health services that meet their needs.

National Safety and Quality Health Service Standards

The National Safety and Quality Health Service Standards (NSQHS) have been an important driver of the growing focus on consumer and community engagement in Australia. The Standards came into effect in 2012 and are designed to drive the implementation of safety and quality systems within both public and private hospitals. “They provide a nationally consistent statement of the level of care consumers can expect from health service organisations”.²

The 10 standards include **Standard 2: Partnering with Consumers** which articulates that engagement must take place at all levels of the health service. Each of the remaining standards also incorporate consumer engagement requirements, demonstrating its relevance in all areas of clinical governance.

The current standards are being reviewed (referred to as version 3) and will come into effect in 2028. Version 2 saw a shift in criteria for accreditation in relation to Standard 2.¹⁵ The criteria are:

- clinical governance and quality improvement systems to support partnering with consumers
- partnering with patients in their own care
- health literacy, and
- partnering with consumers in organisational design and governance.

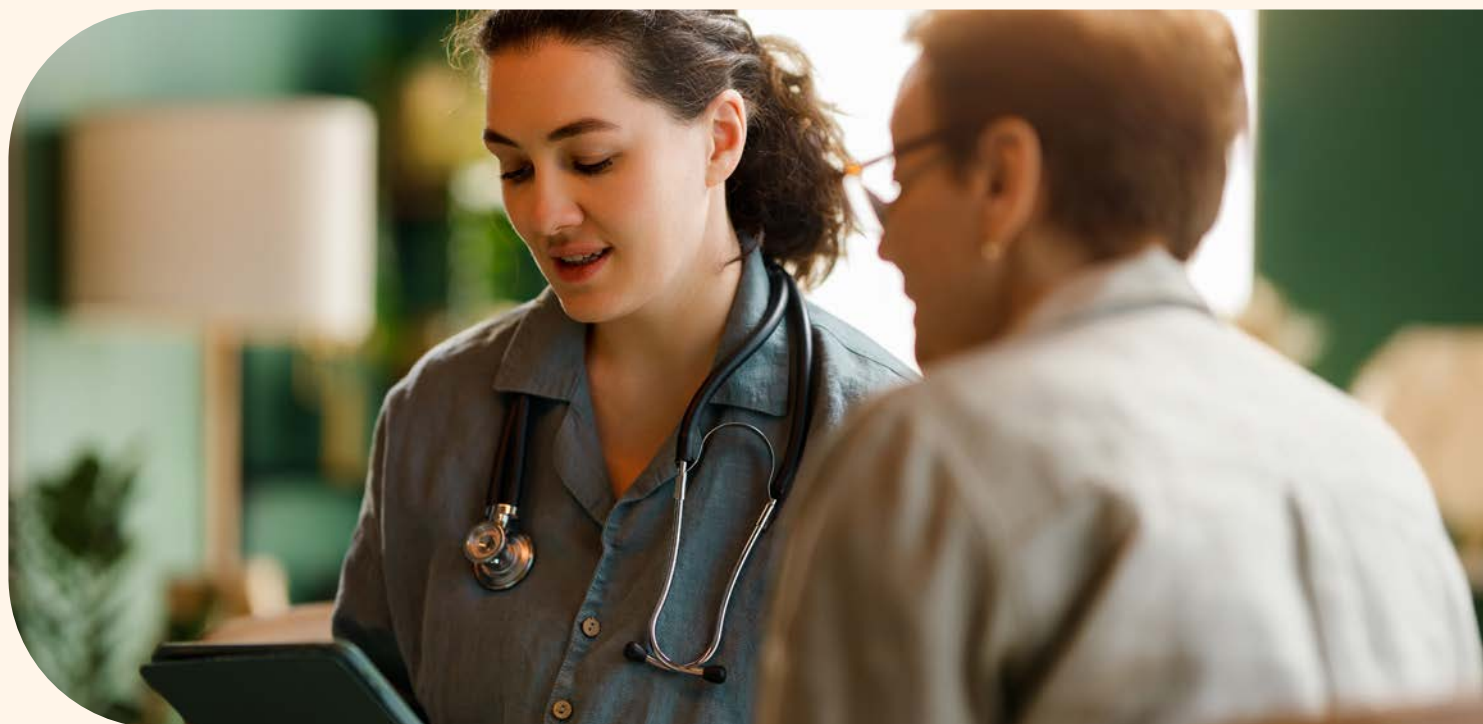
While the Standards have been effective drivers of engagement, accreditation against them should not be the benchmark to which health services are working as they are designed to ensure that minimum safety and quality standards are met.



DEFINITION

Health literacy

Health literacy is your skills and abilities, how well you can find, understand and act on health information, make health decisions and find and use health services.²



National Standards for Mental Health Services

Mental Health Services operating outside the health system in community are required to meet the National Safety and Quality Mental Health Standards for Community Managed Organisations.

The Standard: Partnering with Consumers, Families and Carers outlines clearly the centrality of consumer engagement for accreditation, including the provision of training and support to consumers and their reimbursement and remuneration for participation.¹⁶

Human Services Quality Framework

Organisations delivering health services in Queensland may also be contracted to provide programs through other departments. In this case they must meet the requirements of the Human Services Quality Framework which also requires that services demonstrate how they partner with consumers.¹⁷

Queensland Health NGO Performance Framework

Non-government organisations receiving Queensland Health funding are required to report on a six-monthly basis against the Queensland Health NGO Performance Framework. They must demonstrate that they promote accountable management practices and address a range of consumer involvement and quality improvement activities, including how service users can inform and participate in service planning, delivery and improvement, as well as describe their organisation's strategies to deliver culturally appropriate services and address service barriers.

Legislation

In Queensland, section 40 of the *Health and Hospital Boards Act 2011* mandated that Hospital and Health Services have a Consumer and Community Engagement Strategy in order to promote consultation with health consumers and members of the community.³

Contractual requirements

Primary Health Networks (PHNs) are required under their contractual arrangements to have a community advisory committee to provide a community perspective to PHN Boards and engage broadly across their region with other health organisations.¹⁸

National strategies and frameworks

There are strategies and frameworks that guide work in many areas of health. These national frameworks have a focus on engagement with consumers. For example:

- National Dementia Action Plan 2024-2034¹⁹
- National Consumer Engagement Strategy for Health and Wellbeing²⁰
- Framework for Mental Health in Multicultural Australia 2014²¹
- National Strategic Framework for Chronic Conditions 2017²²

Health staff should be aware of any frameworks and strategies that may support their work.

Broader context

The Australian Charter of Healthcare Rights articulates that consumers have the right to have our say and be heard not only about our own healthcare journey, but in shaping the health system.²³

International charters and treaties, such as the Alma Ata Declaration (1978),²⁴ Ottawa Charter for Health Promotion (1986)²⁵ and Jakarta Declaration on Leading Health Promotion into the 21st Century (1997),²⁶ while not enforceable in law, are relevant as they recognise the principles and actions on which governments and services should develop health policy and services. All these documents highlight the importance of the participation of consumers in their own healthcare and in health systems.



What facilitates engagement and what gets in the way?

Health Consumers Queensland has worked closely with both health organisations and consumers across Queensland since 2008. In that time, feedback has been sought regarding what enablers and barriers exist to embedding consumer engagement into health services.

This experience has also shown that the barriers and enablers identified by both health staff and consumers are very similar. This aligns with research published on the subject.⁶

Below are the common elements that can help and hinder services to excel at consumer and community engagement.

Barriers to consumer engagement

Time and budget

- Timelines too tight for effective engagement process.
- No budget allocated.

Resources

- Consumers not remunerated or reimbursed (e.g. for childcare, parking) and unable to participate due to specific assistance required but support is not available.
- Accessing consumers who are interested in participating.

- Lack of non-clinical time for senior clinicians to manage, develop and support engagement.

Understanding and attitudes

- Clinician/health staff and consumer professional divide.
- Fear of change and accountability.
- Lack of understanding of the benefits of engagement.
- What do they know anyway? What do I know?

Training and support

- Staff don't know how to engage.
- No policies and procedures in place.
- No orientation, training or professional development provided.
- Single consumer on clinical committees.

Lack of leadership

- Lack of board, executive and management leadership and support.
- Engagement not a priority and often tokenistic.
- Processes start but aren't ongoing/completed due to restructure and/or funding changes.
- Lack of clarity around who is responsible for engagement? Or the belief that it is the responsibility of only one person across an organisation.

WHAT CONSUMER AND COMMUNITY ENGAGEMENT IS NOT

ONE-WAY. The health service is only informing the community, not listening or learning from it and involving consumers in meaningful partnerships.

TOKENISTIC. It is not about seeking agreement to pre-determined decisions.

ONLY COMPLETED WITH PEOPLE WHO ARE EASY TO REACH. Health services must deliver services that are appropriate for their entire population. This cannot be done without engaging with the diversity of people in the organisation's community.

USING THE SAME FEW VOICES TO REPRESENT THE ENTIRE COMMUNITY. Queensland communities are diverse and organisations must work to engage with people from a variety of backgrounds with varied opinions and ideas through activities throughout their region.

A SINGLE PROCESS. Organising an annual online survey to hear from the community or involving a consumer or two on a high level patient safety and quality governance, strategic projects or capital works committee is not enough. Engagement needs to occur in multiple ways and places at multiple times.

Enablers of consumer engagement

Leadership

- Led from the top down, genuine buy-in from executive and board levels.
- It is a strategic priority with a budget and resources.

Commitment

- Genuine commitment to partnerships to achieve service improvement processes are not tokenistic and demonstrate shared influence over outcomes.



- Culture of the health service is that engagement is valuable and everyone's responsibility.

Values-based

- Activities are clearly based on values and principles (see p20 for principles).

Processes and support

- Standardised processes are established to support engagement (e.g. policy, remuneration and orientation manuals).
- Documentation, evaluation and networking opportunities are in place.
- Provide training for consumers and staff.
- Well-defined strategies in place to engage with culturally and linguistically diverse people and Aboriginal and Torres Strait Islander peoples.
- Provide and communicate the mechanisms for consumers and community to bring ideas to the service and processes in place to close the feedback loop on the impact of these ideas.

- Consumer and community engagement is the most effective way for health services to understand how to best meet the healthcare needs of their community.
- Consumer engagement utilises the lived experience of consumers of a service or health issue.
- Community engagement can inform issues such as access, health literacy and strategic priorities.
- Engagement can take place in a variety of ways across a health service and is only limited by willingness and imagination.
- Consumers are recruited for specific experience and strengths including their networks and lived experience.
- Evidence exists that shows consumer and community engagement in health services results in better access, increased quality and better outcomes. More work needs to be done to develop this evidence base further.
- There are legislative and policy drivers of consumer and community engagement, however for many health workers, they understand its importance and value beyond the formal requirements.
- There are common elements that help and hinder health services to excel at consumer and community engagement.

SECTION SUMMARY

3. A framework for consumer and community engagement

Where does engagement take place?

Consumer and community engagement can occur in all facets of health. From priority setting for strategic planning of a statewide service or an entire health region, to developing health literate information, and to making decisions about their own care, consumers should be involved. These activities fall into 4 areas: individual, service, network and system.²⁷

AREA OF ENGAGEMENT	WHERE THE ENGAGEMENT OCCURS	EXPLANATION
Individual	<ul style="list-style-type: none"> Individual healthcare delivery 	Engagement in individual care sees consumers as partners in their own (or loved ones') healthcare and treatment. It is referred to as person-centred care.
Service	<ul style="list-style-type: none"> Program and service delivery Facility/hospital 	Service level engagement is focused on partnerships that impact on the planning, delivery, evaluation and monitoring of programs and services at a facility level.
Network	<ul style="list-style-type: none"> Health and Hospital Services Primary Health Networks Non-government and other community stakeholders 	Regional engagement processes as health organisations seek input into broader plans across their service area.
System	<ul style="list-style-type: none"> Local government State government Commonwealth government 	Engagement on health policy, reform and legislation influence and change the health system across local, state and Commonwealth jurisdictions.

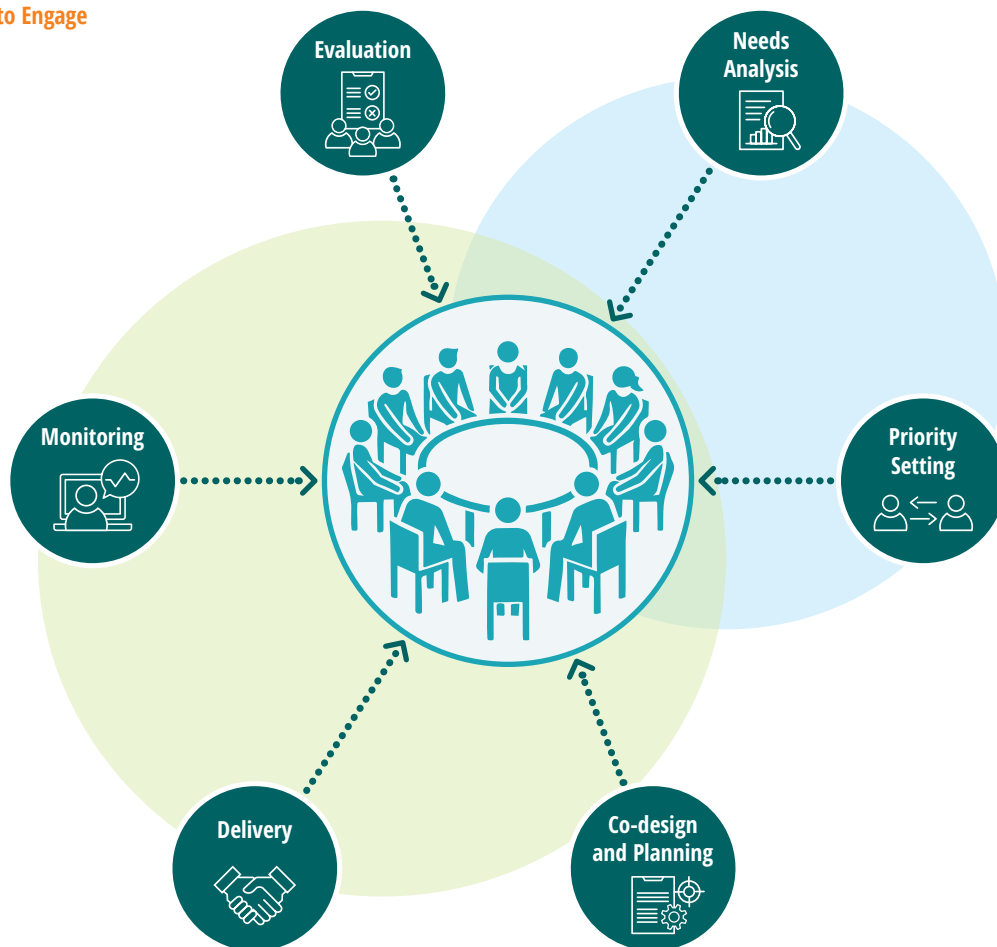
When does engagement take place?

Partnerships should take place across planning, implementation, monitoring, evaluation and review and are an integral part of continuous improvement processes. Good engagement occurs early; at the priority setting and planning phase and can (and should) continue through to evaluation and review. Refer to Diagram A.

A range of engagement processes can be utilised at different

phases of a project, ensuring that a broad range of consumers have been involved. For example, a forum may be held to involve a number of consumers to identify priorities. Out of this a steering committee, which includes consumer representative(s), may be set up to implement some key recommendations. Additional consumers may be engaged in focus groups to ensure inclusive models of care are developed.

Diagram A: When to Engage



Person-centred care is the individual level of consumer engagement. However, clinicians can only provide true consumer-centred care if the services being delivered have been developed with consumers.

For example, a clinician may involve a consumer in all decisions about their healthcare (which is one feature of person-centred care), but in order to see that clinician the consumer has to wait 2 months for an appointment, travel 3 hours and take time off work to get to the appointment as no after hours and local services are available.

By engaging and working with consumers at a service level, the clinician (and other stakeholders) may develop an alternative model of care where appointments can be completed via telehealth (video link) with the consumer visiting their local health service.

Through service level engagement with consumers individual person-centred care for best possible consumer outcomes becomes possible.



What role can consumers play?

Consumer and community engagement activities vary according to the level of influence that consumers have over the process and any outcomes. Currently this level of influence is defined by the health organisation.

The International Association of Public Participation (IAP2) spectrum, developed by the Engagement Institute, is useful to define the consumer role in engagement processes.²⁸ It is widely used in engagement activities internationally across industry, government and community.

Each level on the spectrum from 'inform' to 'consumer-led' indicates the greater involvement of consumers in defining the issue/area that needs to be addressed, decision-making and the outcome.*

**In this Framework, the final level of engagement in the IAP2 spectrum has been changed from 'empower' to 'consumer-led' to reflect the specific and active role of consumers.*

This can be understood in terms of Diagram B below.

Different levels of influence will be appropriate for specific activities, and a health organisation may have engagement activities taking place across all levels of the spectrum simultaneously.

It is important to recognise that one end of the spectrum is not bad nor the other fundamentally good. In fact, all

engagement activities rely on the effective use of the *inform* level. Information empowers people to make decisions. Consumers can work most effectively with health organisations when they are provided with information that supports them to partner to the fullest extent possible.

Consumers should be involved in processes from as early as possible regardless of the level of engagement. In order to partner at the *collaborate* and *consumer-led* levels consumers must be engaged at the planning and design phases as it is at these levels consumers play a role in defining the issue(s) to be addressed.

Generally, the way in which a health organisation engages (the 'method') is not an indicator of the level of engagement. For example, a consumer advisory group can be functioning at an *inform* level if their primary responsibility is to feedback information from the health organisation to the community. An advisory group can be working at a *collaborative* level if they are working with the health organisation to define and solve issues.

Health organisations should ensure that they are engaging with consumers at the *involve*, *collaborate* and *consumer-led* levels of the spectrum wherever possible. These levels indicate a genuine partnership with consumers and will result in services that deliver care that the community wants and that responds to community need.

Diagram B: The Engagement Spectrum

Engagement Spectrum

LEVEL OF INFLUENCE

PASSIVE

ACTIVE

IAP2 SPECTRUM

INFORM

CONSULT

INVOLVE

COLLABORATE

CONSUMER-LED



How can health organisations use the spectrum in practice?

When planning engagement activities, health staff can use the spectrum to establish the level of impact that the consumers they partner with will have over the proposed process and outcome.

Example 1 of the spectrum in practice

Health literacy information

INFORM

The health organisation provides consumers with information about their medical condition and treatment options.

CONSULT

An area of the health organisation has written a new pamphlet about a medical condition and before going to print, they send it out to consumers on their network for comment. These comments may not necessarily be incorporated in the final document.

INVOLVE

An area of the health organisation is updating its patient information pamphlets. Before they write it, they seek feedback from consumers of the service on what they like and don't like about the current pamphlet and ask for ideas for what should be included in the revised version. This input is reflected in the final product.

COLLABORATE

The health organisation has received feedback about some of its patient information pamphlets. The service invites the consumers who provided feedback and other users of the service to come together and partner to create new patient information, including co-designing the content and layout. This might include an alternate method for providing information.

CONSUMER-LED

Consumers approach the health organisation to identify a gap in accessible health information. The consumers lead the process, working with the health service to create a new fact sheet and deliver consumer-led health literacy that meets the need of the people using the service.

Health organisations must be clear with consumers about their level of influence in a project. Consumers who understand their roles and how their input will be used are able to approach their roles effectively and the health service has established trust which is essential for building productive partnerships.

Example 2 of the spectrum in practice

Developing a model of care

The health organisation produces a fact sheet and media release to let the community know of a new service being offered to renal patients.

INFORM

The renal unit has designed a new service to be delivered at the main hospital in the region. They draft a model of care and ask the hospital's consumer advisory committee for feedback (whose members have not used renal services). Some of the feedback is evident in the final model.

CONSULT

Recognising a need for a new renal service, staff put together a focus group of consumers who have used renal services to consider their concerns and preferences. The service incorporates this information in the development of the model and then engages with the same consumers and then more broadly, to ensure the model reflects community needs.

INVOLVE

The renal unit puts together a steering committee made up of clinicians and renal consumers to oversee the development of a new model of care. This steering committee is involved in all aspects of decision-making and engages with consumers more broadly throughout the process to ensure a wide range of views and needs are catered for.

COLLABORATE

Users of the renal service suggest changes to the existing model of care in feedback provided to the hospital. Staff follow up on this feedback and ask the consumers who provided it to lead a process to develop a consumer-centred model of care with the support of staff. This is done through a process of collaborative, consumer-led activities and decision-making.

CONSUMER-LED

What are the fundamentals of good engagement?

Consumer and community engagement work must be underpinned by principles. Engagement is relationship-based work. The principles below reflect the values that have been articulated as desirable by consumers and health services who have participated in the development of this Framework.

PRINCIPLES

Intentional

Partnering is not a one-off event but rather an ongoing process integrated into the everyday work of health organisations. Partnership activities are carefully considered, and all participants are working with a shared purpose and understanding about outcomes.

Respect and dignity

Engagement partners value each other's perspectives, knowledge and beliefs and develop relationships based on clear and open communication, transparent processes and shared goals. Partnerships focus on solutions and support the participation of consumers and community.

Inclusive

Engagement processes are accessible, flexible and designed to promote partnerships with populations that reflect the diversity of their communities and identified health needs. The health service engages through outreach and is respectful of existing community resources and expertise.

Improvement

All engagement activities are evaluated by health staff and consumers and findings implemented for continuous improvement. Ongoing training and development opportunities are provided to support the capability building of all engagement partners.

PRINCIPLES IN PRACTICE

How do we know we are working to our principles?

Guidelines, policies and procedures are in place to guide transparent, accountable and creative processes that support staff to create meaningful and equal partnerships within their health organisation and communities.

Consumers and community are engaged at the planning phase of projects to maximise their opportunity to contribute to and shape the outcome.

Consumers and staff are provided with clear information about the engagement activities they participate in, including the scope and responsibilities of their roles (e.g. in Terms of Reference) and the outcomes and progress of their partnerships.

All staff and consumers are provided with training on consumer and community engagement, how to partner effectively, and effective communication and facilitation.

Engagement partners have opportunities for professional development e.g. attending conferences, forums and external training.

Evaluation of engagement activities is built into all project plans and undertaken to assess the quality of the partnerships and encourage continuous improvement. Both health staff and consumer feedback on activities is sought.

Remuneration and reimbursement processes are in place to ensure consumers are not out of pocket and are remunerated for their time.

Engagement activities are held external to the health organisation in local communities and are scheduled at a variety of times and days to respect the needs of consumers with work and family responsibilities.

Health organisations partner with external agencies (e.g. multicultural, youth agencies) and, where appropriate, external staff lead culturally appropriate processes.

Creative engagement methods are explored to ensure that activities are appropriate for all parts of the community, e.g. people with low literacy, children and young people.

Principles are an important foundation to engagement processes but are only relevant if they are evident in the policies, processes and activities completed every day. The table below shows how principles are evident in engagement practice and what the key outcomes of principled, or value-based engagement are.

KEY OUTCOME AREAS	OUTCOME THEME
<i>What will we see happening?</i>	
Health organisation staff feel confident and supported to engage with consumers and community to achieve outcomes.	Staff capacity
The work you do, when done in partnership with the community, will reflect their needs, deliver appropriate care to all sections of the community and lead to better health outcomes for all.	
A growing number of consumers are partnering with health organisations with the confidence that they share goals, and they will be heard and have influence over outcomes within their health organisation.	Organisational capacity
The health organisation has a broad range of identified partners in the community, e.g. community organisations, primary health organisations, local clubs.	
The health organisation is an integral part of the community and participates in community events.	
A transparent continuous improvement cycle is in place for engagement and partners share their learnings and successes.	Consumer and community capacity
An ongoing allocation for consumer and community engagement is required in budgets in all areas and at all levels of a health organisation.	

Extending your reach

Queensland is a diverse state; geographically, culturally, economically and socially. Health organisations must consider the diversity of their service areas and population health needs when planning their services and developing strategic and operational plans.

Consumer engagement takes place most often within health organisation facilities and within existing activities (e.g. committees which are made up with a majority of health staff, such as quality and safety committees). Community engagement is more focused on connecting with the community through outreach.

Outreach is especially important for health organisations to complete in order to ensure that the diversity of their community is reflected in the voices and opinions being heard in both consumer and community engagement.

Health organisations must ensure that their reach extends to population groups** who face barriers to accessing healthcare and are less likely to volunteer to engage in activities through commonly used engagement methods (e.g. call for volunteers advertisements). The people more likely to respond to general calls for consumers to participate are those who are familiar with the health system, do not see it as intimidating and have enough confidence to believe they may be able to contribute.

These harder to reach groups may include:

- Socially and economically marginalised
- People living in remote communities
- People with a disability
- People who are homeless
- Culturally and linguistically diverse peoples and refugees
- Aboriginal and Torres Strait Islander peoples
- Lesbian, gay, bisexual, transgender, intersex and queer people (LGBTIQ)
- Young people.

These groups can be less likely to volunteer to engage for a range of reasons. For example, many people from culturally and linguistically diverse communities come from a culture that uses alternate treatment options other than a hospital service. They may not necessarily see the service as providing culturally informed and respectful services, do not like to be seen as “complaining”, and may have limited health literacy.



Think about the last time you advertised for a consumer.

- **How and where did you invite people to participate – in writing to your existing networks?**
- **Did they have to volunteer? Or were you able to remunerate and reimburse for their time and costs such as transport and parking?**
- **Did they have to complete a written Expression of Interest?**
- **Was the activity located in the local hospital, face to face?**

There are many associations and organisations within the community that health organisations can partner with to support this engagement work. These organisations have existing relationships with communities they serve and may be more appropriate to lead processes on behalf of the health organisation. This can also assist health staff to develop trust with new communities.

*** For the purposes of this document, 'groups' is used to describe people with similar characteristics. These groups are in no way homogeneous, nor do they necessarily identify as a group and individuals can belong to multiple groups.*



DEFINITION

Community

Community refers to groups of people with diverse characteristics who are connected through common location, attitudes, cultures or interests. Individuals can be considered to be members of multiple communities at once. In the health context, it can be used to describe the population of the area serviced by an organisation, a cultural group or a group of people who all experience a particular health condition.²⁷

ENGAGEMENT MYTHS – CULTURALLY AND LINGUISTICALLY DIVERSE AND REFUGEE POPULATIONS

“Engaging with culturally and linguistically diverse and refugee communities costs too much. Our service does not have the money or resources to do it.”

All health organisations have a responsibility to engage with their community in a way that ensures that diverse voices are captured and should allocate budget to be able to do so. There are also resources/people in the community that you can work with in order to engage with culturally and linguistically diverse and refugee consumers.

By partnering with other organisations and groups who already work with culturally and linguistically diverse consumers and other health organisations, you will find that there are existing programs and additional funding opportunities available to support you to collaborate and engage.

- Identify current resources available, e.g. local neighbourhood centre.
- Connect with community organisations that engage with these priority populations.
- Partner with organisations/existing programs.

“I’m not sure what I need to do to work with culturally and linguistically diverse and refugee consumers and communities and I have to do it all myself.”

You don’t have to do it all yourself. There are many community organisations and associations that have expertise that health organisations can work with.

- When working with culturally and linguistically diverse and refugee communities, developing relationships is central.
- It may be better to ask members of the community to lead the project. There are many people in your community who want to improve healthcare for culturally and linguistically diverse and refugee communities and by collaborating with them you will learn the skills to do it and develop partnerships for the future.
- Connect with community networks, e.g. Pasifika Women’s Alliance.

“We’ll begin to co-design with ‘mainstream’ consumers and then we’ll figure out how to do it with culturally and linguistically diverse consumers.”

By flipping this belief and designing health organisations and programs with culturally and linguistically diverse and refugee communities (or any other vulnerable or marginalised group of people) first you will increase your chances of developing a holistic, integrated, consumer-centred service that meets the needs of all health consumers and their families. For example, developing an oral health service with the culturally and linguistically diverse and refugee communities will ensure that access, affordability, appropriateness and availability is addressed, and will most likely result in a service that can adapt and respond to the individual needs/preferences of all health consumers and carers who might potentially use the service.

- It is important that health organisations develop consumer-centred services for all members of their community, not just for those who are easy to reach.





Aboriginal and Torres Strait Islander communities

“Indigenous Australians continue to have lower life expectancy, higher rates of chronic and preventable illnesses, poorer self-reported health, and a higher likelihood of being hospitalised than non-Indigenous Australians.”²⁹

While progress has been made in some health areas, many health services are still not as accessible and appropriate for Aboriginal and Torres Strait Islander populations as for non-indigenous people.³⁰

As some mainstream health organisations can be viewed as unsafe places, community engagement is an effective and essential way for health organisations to partner with Aboriginal and Torres Strait Islander people to ensure organisations are culturally respectful. Aboriginal and Torres Strait Islander community-controlled health sectors can be a valuable partner for health organisations in the community, and services are required to work with them under the *Making Tracks Together Framework* which is part of Queensland’s response to health targets identified through the National Indigenous Reform Agreement (Closing the Gap).³¹

The development of respectful and honest relationships is central to successful engagement with Aboriginal and Torres Strait Islander peoples and it is understandable that this will take time. Some key people within Aboriginal and Torres Strait Islander communities that health organisations should connect with prior to commencing and during any engagement are:

- local Elders
- regional councils/authorities
- community controlled organisations
- local churches.

Within Queensland, the *Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Framework 2010–2033* is designed to support health staff in public health services with regards to developing services that are responsive to the cultural needs of Aboriginal and Torres Strait Islander Queenslanders, and that can also be of value to other health organisations.³²

Nationally, the *Cultural Respect Framework 2016–2026 For Aboriginal and Torres Strait Islander Health* seeks to guide delivery of culturally safe, responsive, and quality healthcare to Aboriginal and Torres Strait Islander people and communities. Consumer participation and engagement, and stakeholder partnerships and collaboration are two focus areas identified in this Framework.³³

Aboriginal health workers within your organisation can also be a valuable resource for engagement processes as they have established relationships within the communities in which they work.

Health organisations must be willing to take the time to develop relationships with Aboriginal and Torres Strait Islander communities before beginning engagement activities and work with community partners to ensure that partnerships with consumers and communities result in more accessible and appropriate services.

Evaluation and measurement

There are two elements to evaluation and measurement that need to be considered by health organisations engaging with consumers and community. How to evaluate:

1. The quality of the engagement process undertaken

In order to measure that health organisations are improving their partnerships with consumers, evaluations of the process of engagement should be undertaken. This can include examining the experience of consumers. For example, did they think:

- the purpose of the activity was well defined
- their role was clear
- their ideas were listened to
- communication was respectful and they were kept up to date with progress and the impact of their engagement
- the issues that matter to the consumer are being addressed.

2. What outcomes were achieved for the health organisation and/or consumers

The purpose of engagement is to improve the health and wellbeing and care experience of consumers and the community through the development of services and policies. As outlined in the section 'The drivers of engagement' (p8), there is a need for the development of evidence on the efficacy of engagement.

All health organisations can play a role in developing this evidence base through building evaluation processes into their engagement projects and forming partnerships with universities and other research bodies to strengthen the authority of their findings. There may be established processes in place that can support the evaluation of engagement processes. For example, staff might consider how they can link in with their organisation's existing quality improvement initiatives or research agendas.

SECTION SUMMARY

- Consumer and community partnerships can take place on the individual, service, network and system levels.
- Engagement can be completed at any stage of a project cycle and it is best to get consumers involved in early planning stages.
- Different engagement processes can be used within and across projects.
- Consumers can have different levels of influence over projects and processes. This can be understood by using the International Association of Public Participation Spectrum.
- Consumer engagement must be underpinned by principles which must be built into all policies, processes and activities. These principles are intentional, respect and dignity, inclusive and improvement.
- Health organisations must engage with groups who experience barriers to accessing healthcare through community engagement to ensure they hear the voices and opinions of the diverse groups within their service area.
- Evaluation and measurement should be incorporated into all consumer and community engagement activities. This includes understanding the experience of the consumers involved in engagement and the impact engagement is having on outcomes.

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Consumer Experience Recognition Statement

Health Consumers Queensland is proud to acknowledge the value consumer representatives contribute to the improvement of health system accessibility, services and outcomes.

As a member of the national peak body representing the interests of health consumers, Consumers Health Forum Australia, we join them in sharing a Consumer Experience Recognition Statement, developed in consultation with consumers, that reflects our shared vision to advocate for consumer-centred healthcare for all communities without discrimination.

We acknowledge and deeply respect the lived and living experiences of health consumers, carers, families, and communities across Australia.

We recognise the right of every person to equitable access to healthcare, regardless of their background or circumstances.

We value the lived experience expertise and personal commitment of consumer health advocates working to influence change.

We seek to elevate the voices of those who have navigated the complexities of the health system and partner with them to drive meaningful and inclusive change.



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