



Health Issues Centre
Consumer voices for better healthcare



Consumer Model - Partnering with

Healthcare Organisations

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Acknowledgements

Diversity & Inclusion statement

We all have a responsibility to promote inclusive practice and diverse representation within the health system. This means ensuring that the needs of all people are represented – not just the consumers most able or willing to participate.

Groups most likely to be left out of consultation or decision-making processes are often the most marginalised and seldom heard groups. They include people from culturally diverse backgrounds where language may be a barrier, LGBTQIA+ communities, people with low literacy levels, Aboriginal and Torres Strait Islander people, refugees and asylum seekers, people with a disability or mental health challenges, young people, people experiencing homelessness and other socio-economic challenges, and isolated elderly people.

By partnering and supporting consumers with different backgrounds and experiences, we can influence improvements that reduce health inequities. Health organisations need to prioritise the removal of barriers to participation and create opportunities that support consumers to have a say in a way that is meaningful, inclusive and accessible.

Health Issues Centre would like to thank the following individuals and groups who contributed to the development of this resource

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Health Issues Centre acknowledges the Traditional Custodians of the unceded lands on which this resource was created. We honour and pay our respects to Elders past and present. We are committed to shaping a health system that supports self-determination.

Health Issues Centre also acknowledges lived and living experience of ill health, harm and recovery. We honour the courageous and important contribution of those who draw on their experiences to transform our health system.

Definitions

We understand language can be confusing, particularly to those new to this type of work. As such it's important to start by defining some key terms used widely in this resource. You will also find interactive links to the glossary throughout for terms that may be new or unfamiliar.

Healthcare organisation

Organisations and services that make up our health system including but not limited to public health services, private health services, aged care services, community health services, certain government agencies and research institutions.

Health service

The provision of prescribed health services must take place in a registered premises. These include medical, surgical and speciality services. The Department of Health (the department) is responsible for the regulation of health service establishments under the *Health Services Act 1988* and the *Health Services (Health Service Establishments) Regulations 2013*.

Health consumer

Health consumers are people who use health services, their carers and family members. This includes community members who have used a service in the past, are current service users, or who could potentially use the service in the future.

Consumer Advisor

Someone who is interested in using their knowledge and experience to influence change in the health system can choose to become a consumer advisor. Consumer advisors bring an outsider perspective to health organisations and are the voice for what really matters to health consumers and communities.*

*We recognise the importance of terminology and that there are different terms that resonate more strongly with some individuals and organisations. This includes terms such as 'Consumer Partner', 'Consumer Representative', and 'Lived Experience Advisor'. These terms can carry slightly different meanings to different people. For simplicity, the term 'Consumer Advisor' has been used as a generic term throughout this Model but aims to speak to all these roles.

Introduction

Background

Better health outcomes happen when healthcare organisations work in partnership with consumers. An effective, efficient, and safe health system needs input from consumers. Health services, researchers and government agencies are actively looking for consumers to participate in a variety of ways to contribute to improvements in the health system and health outcomes.

There are many helpful resources available to health services that outline ways to partner with consumers. Health services are currently advised on the ways they can successfully engage with consumers through two key frameworks:

1. The [National Safety and Quality Health Service Standards](#) which states:

“Leaders of health service organisations develop, implement and maintain systems to partner with consumers. These partnerships relate to the planning, design, delivery, measurement, and evaluation of care. The workforce uses these systems to partner with consumers.”

Standard 2, [Partnering with consumers](#)

2. Safer Care Victoria’s [Partnering in Healthcare – a framework for better care and outcomes](#), which advises health services how they can meet and go beyond the National Standards in their ability to partner with consumers to drive positive health outcomes.

Health Issues Centre (HIC) and Safer Care Victoria identified a gap - we needed to create a resource that looks at this partnership journey from the perspective of the consumer, and so **the Consumer Model – Partnering with healthcare organisations** was developed.

Purpose

The Consumer Model – Partnering with Healthcare Organisations (Consumer Model) highlights the opportunities that exist for consumers to contribute to transformational change of the health system, no matter their level of experience. It outlines how consumers and health organisations can work in effective partnership that is mutually beneficial.

Audience

The Consumer Model is for staff involved in leading or managing consumer engagement as well as for consumers.

How to use this resource

Watch [‘Activating the potential of consumers partnering with health services’](#), a short video that introduces the Consumer Model and provides ideas for application.

The Consumer Model is intended as a high-level document used to inform or influence how an organisation works in partnership with consumers. There is a flexible approach to how each health organisation might use the Consumer Model in practice.

For example, it could be used to:

- Review and update consumer engagement policies or strategic plans.
- Inform ways of working with consumers on their capability development goals.
- Influence the uptake of consumer engagement across different work areas.
- Support in the recruitment of consumers to engagement opportunities.
- Generate conversation and planning with current consumer representatives and advisors about quality and improvement opportunities in the health service’s consumer engagement.
- Inform consumer onboarding or training programs.
- Facilitate understanding about consumer engagement within the broader team.

There is an interactive glossary to help readers understand new or unfamiliar terms.

Additional resources

This resource is part of a suite of resources developed by Health Issues Centre with funding from Safer Care Victoria to support consumers and health organisations to work more meaningfully together in partnership. These have been developed in collaboration with consumers and staff whose insights and experiences have significantly shaped the final products.

The resource pack includes:

- Guide for Consumers to self-assess the quality of their engagement in health organisations.
- Onboarding resources:
 - Six steps to becoming a consumer advisor
 - Six steps to successfully onboarding consumer advisors
 - Consumer advisor skills checklist

Access all the resources at [Health Issues Centre website](#)

Consumer Advisors – an overview

Someone who is interested in using their knowledge and experience to influence change in the health system can choose to become a consumer advisor. Consumer advisors bring an outsider perspective to health organisations and are the voice for what really matters to health consumers and communities.

Health organisations use different terms such as Consumer Partner, Consumer Representative or Lived Experience Advisor and terminology is regularly evolving.

The role of a Consumer Advisor

Consumers play a critical role in transforming our health system. Consumer advisors give their time to health services, researchers, or government agencies and become important partners in improving outcomes for consumers.

Consumer advisors can take on many different roles within the health system depending on their interests, skills, and level of experience. They may draw on their lived experience of being a health consumer. They may also contribute other relevant personal and professional experience that helps them to effect change.

More experienced consumers can use their position to advocate or represent broadly for the needs of health consumers. However, it is important to mention they are not ['patient advocates'](#).

The specific responsibilities of a consumer advisor will change based on the way a health organisation plans to involve them in the organisation.

Recognising the work of consumers

The workload and time commitment asked of Consumer Advisors varies depending on the type of roles they are in. It's not uncommon to hear of people volunteering with services for years and the cumulative knowledge that these consumers hold is invaluable.

Safer Care Victoria and other government agencies have [guidelines](#) in place that encourage public organisations to pay Consumer Advisors for their time. Paying people not only recognises the time and expertise they contribute, but it also enables people to participate that aren't in a financial position to volunteer for free. This promotes more equitable participation and ensures that services create opportunities for more diverse voices.

Attributes of a Consumer Advisor

Below are some areas of knowledge, values and skills that can support a consumer to be an effective partner in improving the health system. People bring a huge mix of skills and experiences when they become a Consumer Advisor and will grow their expertise over time.

Healthcare organisations can use this attribute table as a guide when recruiting people to different consumer roles.

Values	Skills and experience	Knowledge areas
Respect different consumer experiences and perspectives.	Lived experience as a patient or carer, or an interest in health as a potential user of health services.	The Australian Charter of Healthcare Rights .
Value patient-centred care and individualised, holistic approaches to health.	The ability to draw on one's own experience as a patient and the experience of others to identify solutions that improve the quality and safety of a service.	The various roles of health professionals and awareness of how different areas of the health system work together.
Embrace collaborative working with other consumers and healthcare staff in shared decision making and co-design processes.	Able to communicate effectively with diverse audiences, from listening to the needs of current patients through to asking difficult questions of executive staff members on committees.	Understanding the principles of Health Literacy and the responsibility services have to consumers to access, understand, and use health information.
Motivated to partner with health services to help them to improve the patient experience.	Effective use of lived experience storytelling to support services to develop insight into the consumer experience.	The National Safety and Quality Health Service (NSQHS) Standards and Partnering with Consumers Framework.
Champion equity in healthcare	Able to build strategic, productive relationships and influence decision makers.	Consumer and community engagement practices and principles.
Value diversity and inclusion of those who are seldom heard .	Ability to analyse and interpret information.	Awareness of the social determinants of health .

It's important to note that Consumer Advisors, especially those just starting out, are not expected to be able to show all of these. It is natural for some consumers to have more experience in one area and less in others.

Consumers can use the Consumer Advisor Skills Checklist to reflect on their current skills. It helps a health organisation to know the types of roles a consumer might be best suited to and also helps identify any areas where extra support or training is needed.

Development stages of a Consumer Advisor

Consumers fall under three levels of experience: Emerging, Evolving and Experienced¹. Healthcare organisations can use this table when considering the level of experience that a consumer needs to take on a particular role. It can also be used to plan training programs and support tailored to consumers at different stages of development.

Emerging consumers	Evolving consumers	Experienced consumers
<p>Typically have a desire to contribute based on their personal experience of using health services. They are keen to help services and researchers improve the consumer experience.</p> <p>Tend to take on roles of 'expert patients'. They speak from their own experience, rather than on behalf of others.</p> <p>May do 'one-off' style engagements like taking part in focus group, providing feedback or sharing their story to help other patients or families.</p> <p>Need support to engage in their role(s). Their focus is on learning, growing, developing through on-the-job experience, and finding their voice.</p> <p>Healthcare organisations encourage consumers at this stage through offering training opportunities. They may also connect them with an experienced consumer to act as their mentor.</p>	<p>Begin to connect their own experience to broader consumer issues. They are developing confidence to raise concerns and point out potential issues.</p> <p>Are expected to be independent knowledge seekers. Help from an expert may be required from time to time, but they can usually perform their role(s) independently.</p> <p>Will be familiar with the common language, terminology, acronyms, concepts, and content of the service they work with.</p> <p>They will be able to access a broad range of information sources available.</p> <p>Are likely to be contributing on a regular basis and are often engaged on committees, co-design groups, and working parties with a focus on relationship building and networking.</p> <p>Healthcare organisations can support evolving consumers to engage with other community members, so they can begin to advocate for the needs of consumers more broadly.</p>	<p>Combine their personal experience with their knowledge of the sector and system to provide high level strategic advice that can be generalised to the consumer experience.</p> <p>Use their expertise to influence policy, co-design solutions with health staff, and critically analyse proposals and papers. They may be able to deliver training sessions related to their areas of expertise and engage with other consumers.</p> <p>Are highly skilled communicators, influencers, and negotiators.</p> <p>Can adapt to different roles and environments with relative ease.</p> <p>They are often engaged as advisors reporting to the Board(s), co-chairs of committees, and have strong community ties.</p> <p>Healthcare organisations can pair experienced consumers with emerging consumers to provide them with mentorship in navigating the early stages of their journey.</p>

Assessing current stage of development

There is no obligation or expectation that a consumer will progress through the various stages, every consumer's journey looks different. Often consumer advisors wish to stay at the stage they feel comfortable with and don't necessarily 'move on' to more advanced stages. This will be a personal decision based on their own interests and situation.

Consumers can explore their current stage of development using Health Issues Centre's [Guide for Consumers to self-assess the quality of their engagement in health organisations](#). We encourage consumer advisors to share their completed tool with their support person or consumer lead. This will assist the service to know about their areas for development and training needs.

Consumers and their supports are encouraged to meet and review the self-assessment tool every 12-18 months.

Opportunities for consumer advisors

Levels of healthcare

Safer Care Victoria's *Partnering in healthcare framework* shows us that there are many opportunities for consumers to be meaningfully involved at all three levels of healthcare: the direct care level, the service level, and the system level.

Direct care level	Service level	System level
<p>This is the point at which a patient receives care.</p> <p>Consumers participate in their own healthcare and treatment, as do their family and carers. A health service enables and supports consumers to be equal partners in their care, including through shared decision-making.</p>	<p>This level focuses on service design, delivery, and quality improvement.</p> <p>Health services partner with consumers in decisions about the design and delivery of services, including through consumer advisory committees, working groups, quality and safety committees, and service co-design working groups.</p> <p>Consumers provide feedback, ideas, and personal experiences to drive change.</p>	<p>This level relates to governance, planning and policy development.</p> <p>Consumers, carers, and communities participate in system-wide quality and safety improvement in healthcare organisations and government health agencies. Healthcare organisations partner through hospital boards and clinical governance committees.</p> <p>Government organisations partner with consumers in governance, planning and policy development.</p>

Source: Partnering in Healthcare Framework

Domains of partnering in healthcare

The *Partnering in healthcare framework* consists of five domains, or qualities, that are important to partner in healthcare. These were developed with extensive consultation with consumers and health services and represent focus areas, where work could improve consumer experience and outcomes.

Figure 1: Five domains of Partnering in healthcare



Source: Partnering in Healthcare Framework

Activity areas across the health system

When starting out as a consumer advisor, it can be challenging to know what pathways exist to contribute. Consumers are engaged in various and changing ways. This depends on factors such as:

- The setting or environment
- The level of the health system
- Resourcing and timeframes
- Purpose and goals of the engagement
- Organisational culture
- The level of experience of a consumer

There are **four main activity areas** where consumers are engaged as partners by healthcare organisations. These include:

1. [Patient experience](#)
2. [Governance](#)
3. [Health and Medical Research](#)
4. [Public health policy](#)

The following section of the Consumer Model gives an overview of various roles that consumer advisors can be involved in across the four activity areas. It also includes case studies that show the real-world impact consumer advisors are having.

Health organisation staff, researchers, and government agencies can use these lists to expand the breadth of consumer partnership opportunities that could be embedded.

Consumers advisors can use this section to gain an understanding of the spectrum of consumer engagement in the health system. It can help with goal setting, thinking about what roles might be a good match for their current skills and interests, and what they might like to work towards in the future.



Patient experience

Growing evidence shows that patients' experiences of care have a direct impact on their health outcomes. Good patient experiences include access to timely and quality care, respectful relationships, appropriate information and communication, emotional support, and physical comfort and safety.²

Further, health literacy plays an integral role in the way health services provide safe and appropriate care. Health literacy refers to how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it.³

Consumer advisors are often asked to take on a range of sharing, review and development activities to help improve the patient experience.



Areas where consumer advisors may be asked to contribute include:

- **Patient information and communications** which includes reviewing and helping to create health information that is clear and easy to understand e.g., brochures, factsheets and videos on a range of topics from patient rights and responsibilities, through to treatments.
- **Codesigning** when consumers and other stakeholders come together as equal partners to the creation or redesign of services, program, processes or resources.
- **Collecting patient and carer feedback and research** where consumer advisors may interview or survey patients and carers to assess experiences of care; includes aspects of cultural safety and respect.
- **Delivering training** to health professionals on consumer experiences and expectations, which may involve lived and/or living experience storytelling.
- **Advising health professionals** on inclusive engagement with diverse communities which consumer advisors are linked with.
- **Public speaking** – sharing your story to improve service delivery or uptake.

Nora attended a Community Information and Consultation Session about the soon-to-be developed Joan Kirner Women's and Children's Hospital. There she had the opportunity to speak with Board Members. Nora provided feedback that the focus had been mainly on young children, overlooking that the service included children up to the age of 18. The service agreed with this observation and Nora took on the role of gathering consumer feedback to improve consumer experiences at the hospital.

Nora, using her personal background in social work, went on to interview 76 children of all ages, expectant mothers, new mothers and spouses from a range of diverse cultural backgrounds. Children talked about what they wanted, including amenities, technology, and menu preferences. Parents and partners said that they wanted to be able to stay overnight with their children or spouses and their newborns in hospital.

With these insights, the hospital created single maternity rooms with an additional bed so partners can stay. Parents who stay with their children overnight have a bed as well. The menu caters to various cultural preferences as per diverse cultural feedback. A children's menu was also developed by younger patients and parents of infants and young children.



CASE STUDY

Patient
experience

Governance

Governance covers the processes, policy directives, laws and customs which outline the way a service is directed, administered or controlled. Governance determines how health services are delivered and impacts on the safety and quality of care given. Consumer advisors play a critical role in ensuring the governance structures respond to the needs of health consumers.



Areas where consumer advisors may be asked to contribute include:

- **Developing, informing or reviewing organisational policies** such as clinical governance frameworks, fees for service or opening hours policies.
- **Board membership** involves taking on leadership and decision-making roles, including overseeing budgets and the efficient use of resources.
- **Participating in advisory and review groups** for service improvement and evaluation or program development; includes Community and Consumer Advisory Committees.
- **Being part of clinical governance reviews or quality and safety reviews and committees;** this includes participating in Root Cause Analysis reviews and Sentinel Events (when a patient's care goes wrong and causes serious harm or death).
- **Quality accounts** - contributing to the reports developed demonstrating health services performance and improvement work.
- **Contributing to strategic planning processes** that help to guide organisational decisions.
- **Participating in codesign activities** such as trialling new tools and programs.
- **Recruitment** of new staff by being part of interview panels.
- **Delivering training** to health professionals or other consumer advisors.
- **Mentoring emerging consumer advisors** so they can be more effective in contributing to the improvement of the health organisation.

Julian joined Peninsula Health's LGBTIQ+ Community Advisory Group. From the urgings and recommendations of the advisory group Peninsula Health went on to pursue Rainbow Tick accreditation. This involved working with other consumers and staff, helping them develop organisational policies and practices to improve services for LGBTIQ+ people.

Attaining Rainbow Tick accreditation helped to signal to both consumers and the health service that Peninsula Health is a safe, inclusive and affirming service for LGBTIQ+ patients and employees. Peninsula Health's efforts signalled the first public health service in Australia to be Rainbow Tick accredited in 2017 and they won the Improving LGBTI Health award at the Victorian Public Healthcare Awards. David Anderson, CEO at the time, recognised the efforts of all involved.

"I would like to thank all our staff who put so much effort into this project which will dramatically improve the health and wellbeing of our LGBTI community.

Our community representatives played a pivotal role in this success and I would like to thank them for all the hard work they have put in over many months and years."



CASE STUDY
Governance

Health and medical research

Medical research guidelines recognise that involving consumers in research as partners, not just as participants, is a must. It has been shown that where consumers are involved in the identification, design, and delivery of research, we see the following benefits:

- Issues important to consumers are identified and prioritised
- Sharing of research results are improved
- Research findings are better translated into strategic and system change, clinical practice, and implemented within health service delivery
- The money and resources spent on research benefits consumers, and
- Public confidence in research is increased.



Areas where consumer advisors may be asked to contribute include:

- **Review panels** to help inform the selection of successful grant applications.
- **Contribute to the development** of grant applications.
- **Assist to identify service gaps and consumer issues** that will benefit from research.
- **Participate in codesign** of research questions, processes, tools and activity.
- **Assist in communications and recruitment** for relevant consumers to participate in research.
- **Partnering with researchers** to improve the experience of patients participating in medical trials and research or improve the researchers' understanding of an illness or condition.
- **Joining the research team** – positions vary but are clearly articulated and can include conducting interviews, codesigning surveys or reviewing and interpreting data; evaluating research, methodology, implementation and outcomes; review of changes shaped by research outcomes.
- **Being a research advisor** – overseeing strategic and ethical direction of the research.
- **Assist researchers** to distil their research ideas, improve their communication skills and disseminate their research findings to the wider community.
- **Consumer-led researchers** – working toward identifying, prioritising, directing or leading research projects.

Melanoma Research Victoria (MRV) is a collaborative research program which aims to improve outcomes for melanoma patients through supporting research and meaningfully engaging with consumers. The program brings together consumers and researchers to build relationships and share understandings of the skills and abilities that each can bring to the research arena.

One critical way this happens is through the MRV Researcher Presentation Series where researchers are invited to informally present their work and consumers are invited to listen, learn and ask questions. Through this process consumers begin to understand research more but also have the chance to put forward their areas of concern and interest. The initiative fosters connections and has resulted in consumers joining a research team as lived experience experts. This means that consumers are engaged earlier in the research cycle and have greater input in research questions, methodologies and findings.

The MRV Researcher Presentation Series... “hit(s) the sweet spot of describing the trends and objectives of the melanoma projects together with enough scientific detail to remind us-consumers of the complexity of the work” –Geoff Lomdahl, MRV Consumer

“MRV consumer’s good understanding and enthusiasm for biomarker research will be important across multiple melanoma projects, given there are so many questions to be asked” – Dr Lewis Au, Melanoma Clinician Researcher



CASE STUDY
Health and
medical
research

Public health policy

Public policy reflects the actions and decisions of an elected government, such as introducing new laws and implementing programs, that aim to benefit the community and/or solve a particular problem. Policy in the health sector usually relates to promoting wellness and delivering healthcare. All levels of government develop, implement and review a range of public health policies that impact health consumers including funding for more nurses or doctors and improving access to health services.



Engaging people from the community with a lived experience of a health condition, including families or carers, help to ensure governments consider the real-world impact of health policy proposals. Genuine and timely engagement leads to better healthcare decisions and greater acceptance in the community, especially amongst those who will be impacted most by the policy.

Areas where consumer advisors may be asked to contribute include:

- **Preparing or contributing to a written submission** in response to discussion papers outlining policy options and questions about implementing proposed changes.
- **Speaking at public meetings** this includes participating in parliamentary hearings, speaking on panels, and presenting at public and government enquiries.
- **Participating in advisory groups** for the development of new policies, guidelines and frameworks at a State or Federal level.

Health consumers were integral in helping to inform the reform recommendations from the Mental Health Royal Commission in Victoria. As a result, the State Government recognised that the design and delivery of all mental health services needs to involve people with lived experience more closely.

Off the feedback and evidence of those with lived experience, the Royal Commission recommended that effective programs like HOPE (Hospital Outreach Post-suicidal after Engagement) move beyond trial stage to become implemented as best practice across the state. The HOPE program has a multidisciplinary team, including peer workers who deliver practical support and interventions to address the unique economic, historical and environmental factors that have contributed to a person's suicidality and the program has grown from 12 sites to 21 across Victoria.

In addition, the recommendations stated that the HOPE program needed to be developed and adapted for children and young people. The Child and Youth HOPE program has since been co-developed by young people with lived experience to ensure the program offers the same benefits to children and young people as the adult HOPE program.

“The people who often understand mental illness best are those who live with it, so it’s absolutely vital their voices are front and centre in any discussion about how the system is strengthened and remade,” Georgie Harman, Beyond Blue CEO



CASE STUDY
Public health
policy

Training and development opportunities for consumers

Consumer advisors are critical partners to health services, researchers, and government agencies in providing insights and advice to improve patient experience. Partnerships go two-ways. A vital part of these partnerships is the support and development opportunities that services provide to Consumer advisors in return. This support enables a consumer to feel more confident, valued, and comfortable in their role(s). It also results in more effective engagements.

In the [NSQHS Standards](#), Standard 2, Partnering with Consumers, health services are directed to provide support and education to consumer partners.

Training opportunities

- [Workshops for Consumer Advisors](#) on topics such as co-production, health literacy, corporate governance delivered by Health Issues Centre.
- Accredited [Course in Consumer Leadership](#) delivered by Health Issues Centre.

Resources

- [Consumer Mentorship Program Manual](#) for services interested in supporting consumers' growth through mentorship.
- Subscribe to health consumer newsletters such as [Consumers Connect](#) from Health Issues Centre and [Consumers Shaping Health](#) from Consumers Health Forum of Australia
- [Consumer Involvement Pack: How to get involved in health and medical research](#) developed by Australian Clinical Trials Alliance.
- [Guidelines for Consumer Representatives](#) for consumers on committees produced by Consumer Health Forum of Australia.
- [All of Us: A guide to engaging consumers, carers and communities across NSW Health](#) includes 'Six ways of working' for any type of consumer engagement.
- [SCV's Partnering in healthcare framework and Outcomes Summit 2023 recording](#) gives examples of the ways health services and consumers work together.

Background reading

- [The Australian Charter of Healthcare Rights](#)
- [What is health?](#) - Australian Institute of Health and Welfare
- Safer Care Victoria's [Partnering in Healthcare Framework](#)
- The [National Safety and Quality Health Service Standards](#), particularly Standard 1, [Clinical Governance Standard](#), and Standard 2, [Partnering with Consumers](#)

Glossary

Australian Charter of Healthcare Rights: specifies the key rights of patients when seeking or receiving healthcare services. It was endorsed by health ministers in 2008.⁴

Clinical governance: an integrated component of corporate governance of health service organisations. It ensures that everyone – from frontline clinicians to managers and members of governing bodies, such as boards – is accountable to patients and the community for assuring the delivery of safe, effective and high-quality services. Clinical governance systems provide confidence to the community and the healthcare organisation that systems are in place to deliver safe and high-quality health care.⁴

Co-design: A process that brings stakeholders together to design new products, services and policies, right from the start. It involves defining the problem, developing and testing solutions together. They are typically participatory processes that collaboratively explore consumer and staff experiences and ideas, consider how these relate to the care journey, develop, and implement improvements, and review what difference these make.⁵

Consumer Advisory Committee (CAC): Community advisory committees provide a formal way for health services to work with their communities and listen to their needs. They serve the role of advocating for their community and advising the board on the community needs. The committee is accountable to the health service board, which in turn is accountable to the Minister for Health⁶.

Consumer engagement: Consumer engagement reflects an approach involving the development of meaningful relationships with a shared focus. Consumer engagement is underpinned by trust and mutual respect, a commitment by all involved and active two-way dialogue. The term consumer engagement indicates that action is more than simply taking part.⁷

Equity in healthcare: Equity in healthcare means that all people receive care of equal quality that is safe, effective and is responsive to their individual needs, culture, language, ability, experience and preferences. This does not mean that everyone receives the same care, but rather that all persons have their healthcare needs equally well met, including through removing differences in the quality, safety and accessibility of opportunities, services and rights between groups of people.

Governance: the set of relationships and responsibilities established by a health service organisation between its executive, workforce and stakeholders (including patients and consumers). Governance incorporates the processes, customs, policy directives, laws and conventions affecting the way an organisation is directed, administered or controlled. Governance arrangements provide the structure for setting the corporate objectives (social, fiscal, legal, human resources) of the organisation and the means to achieve the objectives. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help align the roles, interests and actions of different participants in the organisation to achieve the organisation's objectives. In the NSQHS Standards, governance includes both corporate and clinical governance.⁴

Health consumer: Health consumers are people who use health services, their carers and family members. This includes community members who have used a service in the past, are current service users, or who could potentially use the service in the future.

Health literacy: the Australian Commission on Safety and Quality in Health Care separates health literacy into two components – individual health literacy and the health literacy environment. Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the healthcare system, which affect the

ways in which consumers access, understand, appraise and apply health-related information and services.

Informed consent: a process of communication between a patient and clinician about options for treatment, care processes or potential outcomes. This communication results in the patient's authorisation or agreement to undergo a specific intervention or participate in planned care. The communication should ensure that the patient has an understanding of the care they will receive, all the available options and the expected outcomes, including success rates and side effects for each

Lived and/or living experience: personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.⁸

Lived experience storytelling: the considered telling of a personal story with the intention of influencing changes to individual, organisations and systems. Listening to stories told effectively facilitates better person-centred care, can encourage help seeking, and promotes greater understanding, empathy and reduces stigma. Lived experience storytelling requires the teller to share their story in a way that is psychologically safe for themselves and others, and there are guidelines and training available to support this.

Kitchen table conversations: Meeting of people who know each other at someone's kitchen for morning or afternoon tea. Can be 5 to 10 community members. These informal sessions allow individuals and small groups to participate in discussions at a time of day, and in a place, that suits them. The discussions enable participation by community members who do not ordinarily participate in public consultations. The host of the session guides the discussion with a set of questions provided to them and reports back to the organisation.⁹

NSQHS Standards (second edition): The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care with the Australian Government, state and territory partners, consumers, and the private sector. The primary aim of the NSQHS Standards is to protect the public from harm and improve the quality of healthcare. They describe the level of care that should be provided by health service organisations, and the systems that are needed to deliver such care. The second edition of the NSQHS Standards was released in November 2017. Health service organisations will be assessed against the standards in the second edition from January 2019.

Open access board meeting: The board of a health service, hospital or multi-purpose service is required to hold at least one open access board meeting per year that the general public are able to attend. The aims of open access board meetings are to provide the public with an opportunity to participate in decision-making processes and to gain an understanding of the rationale, context and environment for board plans and decisions¹⁰.

Patient advocate - A consumer or patient advocate supports and promotes the rights of individual patients as they navigate the health care system. A patient advocate will make sure patients and their carers are informed and confident about the health decisions being made and will perform tasks like attending an appointment to assist the patient to ask the necessary questions and understand the answers, so they are better informed about their health care plan.¹¹

Patient-reported outcome measures (PROMs): PROMs are questionnaires which consumers complete. They ask for the consumers' assessments of how health services and interventions have, over time, affected their quality of life, daily functioning, symptom severity, and other dimensions of health which only consumers can truly know. PROMs promise to fill a vital gap in knowledge about outcomes, and about whether healthcare interventions make a difference to people's lives.⁴

Patient-reported experience measures (PREMs): PREMs are questionnaires used to obtain consumers' views and observations on aspects of health services they have received. This includes their views on the accessibility and physical environment of services (for example, waiting times and

the cleanliness of consultation rooms and waiting spaces) and aspects of consumer–clinician interactions (such as whether the clinician explained procedures clearly, or responded to questions in a way the consumer could understand).⁵

Person-centred care: an approach to the planning, delivery and evaluation of health care that is founded on mutually beneficial partnerships among clinicians and patients. Person-centred care is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Key dimensions of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of carers and family, and access to care. Also known as patient-centred care or consumer-centred care.

Policy: a set of principles that reflect the organisation’s mission and direction. All procedures and protocols are linked to a policy statement.

Quality accounts: All public health services and registered community health services submit an annual quality account. These reports provide the Victorian community with an open and transparent account of each service’s performance and improvement work.

Quality improvement: the combined efforts of the workforce and others – including consumers, patients and their families, researchers, planners, and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development. Quality improvement activities may be undertaken in sequence, intermittently or continually.

Rainbow tick accreditation: The Rainbow Tick is a quality framework to help health and human services organisations become safe and inclusive for the LGBTIQ community.

Seldom heard individuals or groups: Under-represented people who use or might potentially use social services and who are less likely to be heard by social service professionals and decision-makers. They are often referred to as 'hard to reach' groups, though this term has been criticised for implying that there is something about these people that makes their engagement with services difficult. 'Seldom- heard' places more of the emphasis on agencies to engage these service users, carers, and potential service users¹². Healthwatch have developed [guidance](#) on how to co-produce with seldom heard groups.

Shared decision making: a consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the patient’s values, preferences, and circumstances.⁴

Social determinants of health: The social determinants of health are the conditions in which people are born, grow, live, work and age that can and do influence their health. These circumstances are shaped by the distribution of money, power, and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.

References

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