Consumer Model - Partnering with Healthcare Organisations

January 2022
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Introduction

Aim

Health consumers play a critical role in improving our health system. The Consumer Model – Partnering with Healthcare Organisations shows health consumers how they can effectively do this. It aims to highlight the opportunities that exist for consumers to contribute, no matter their level of experience.

There are many helpful resources available to health services that outline ways to partner with consumers. However, Health Issues Centre (HIC) and Safer Care Victoria identified a gap - we needed to create a model that looks at this partnership journey from the perspective of the consumer.

The Consumer Model - Partnering with Healthcare Organisations (Model) has been informed by:

- The knowledge, experience and expertise drawn from HIC’s almost 40 years of collaborative work in consumer engagement.
- A review of national and international literature and best practice examples on consumer leadership and approaches to partnering with consumers.
- The competencies of the HIC’s Course in Consumer Leadership (10946NAT).
- Responses and feedback voiced by consumers from diverse backgrounds with varying levels of experience.

Acknowledgements

This Model was developed with funding from Safer Care Victoria (SCV).

Consumer input was essential to the creation of this resource. We especially thank the following consumers who provided feedback, attended co-production workshops, and generously shared their stories which were used as case studies:

- Mercedes Antunovic-Katinic - Western Health
- Julian Conlon - Peninsula Health
- Andrea Cooper - Alfred Health, SCV, DHSV, Soundfair
- Matthew Dale - SANE Australia, Bipolar Life
- Danny Elbaum - Ambulance Victoria, Monash Health, Mercy Health
- Angela Fitzpatrick - Eastern Health, St Vincent’s Hospital, SCV
- Lizzie Flemming - Eastern Health, SCV
- Sally Fraser - Bendigo Health, Loddon Mallee Regional Clinical Council, SCV, La Trobe Rural Health School
- Anda Llanaj - Royal Children’s Hospital
- Ray Newland - Djerriwarrah Health Service, Western Health, SCV
- Nora Refahi - Western Health, Eye and Ear Hospital, North West Melbourne Primary Health Network, SCV
- Natalie Ross - Walter and Eliza Hall Institute of Medical Research

The name of the Model was suggested by consumers, to acknowledge the importance of the partnership between health organisations and consumers, but from the consumer perspective.
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 Model. You will also find interactive links to the glossary throughout for terms that may be new or unfamiliar.

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 volunteer their time to health services, researchers, or government agencies and become important partners in improving outcomes for consumers. Consumer Advisors bring an outsider perspective to health organisations and are the voice for what really matters to health consumers and their communities.

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’.

*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 Representative’, ‘Lived Experience Expert’, ‘Consumer Advocate’, ‘Lived Experience Advisor’, and ‘Patient Leader’. 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.

“There needs to be significant cultural change to rebalance the system to include consumers as equal partners at all points in health care strategy setting and decision making and for them to be at the centre of their health care.”

Consumers partnering with healthcare

Better health outcomes happen when health services work in partnership with consumers. An effective, efficient, and safe health care 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.

Health services are 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.

Purpose of the Model

The Model goes one step further in supporting consumers and health services to work in effective partnership by:

- Supporting consumers to understand the types of roles they could engage in to contribute to the health system, and the skills and expertise that can help to fulfill those roles.

- Mapping possibilities for consumer leads, managers, researchers, and policy developers about the ways they can partner with consumers. This recognises the spectrum of skills and experiences that consumers bring.

- Prompting a two-way conversation between services and consumers. Together navigating the Consumer Advisor journey, supporting, and identify growth and development opportunities together.

- Demonstrating to executive leadership and Board how consumers should and could be fitting in to the decision-making hierarchy.

- Providing recognition of the accumulative knowledge that experienced consumers acquire and the value this has for the health system.
How to use the Model

The consumers who supported the development of this Model felt strongly that it should be shared with consumers by the health organisation they are connected to. The Model is intended as a high-level document that can provide a reference point for ongoing discussions around how a consumer can be supported.

Consumers and their supporters should make use of the interactive links throughout the document to access the sections that are most relevant or aligned with areas of interest. There is a glossary to help you understand new or unfamiliar terms.

It is suggested that the Model be used in conjunction with Health Issues Centre’s Guide for Consumers to self-assess the quality of their engagement in health organisations.

The two resources can be used at touchpoints throughout a Consumer Advisors’ journey, particularly when looking for ways to develop further or explore new opportunities to contribute to a service.
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.

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. Health services can use these as a guide when recruiting volunteers to become Consumer Advisors.

<table>
<thead>
<tr>
<th>Values</th>
<th>Skills and experience</th>
<th>Knowledge areas</th>
</tr>
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<tbody>
<tr>
<td>Respect different consumer experiences and perspectives.</td>
<td><strong>Lived experience</strong> as a patient or carer, or an interest in health as a potential user of health services.</td>
<td>The Australian Charter of Healthcare Rights.</td>
</tr>
<tr>
<td>Value <strong>patient-centred care</strong> and individualised, holistic approaches to health.</td>
<td>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.</td>
<td>The various roles of health professionals, the differences between primary, secondary (specialists), tertiary health services (hospitals) and awareness of health systems.</td>
</tr>
<tr>
<td>Embrace collaborative working with other consumers and healthcare staff in shared decision making and <strong>co-design</strong> processes.</td>
<td>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.</td>
<td>Understanding the principles of Health Literacy and the responsibility services have to consumers to access, understand, and use health information.</td>
</tr>
<tr>
<td>Motivated to partner with health services to help them to improve the patient experience.</td>
<td>Effective use of <strong>lived experience storytelling</strong> to support services to develop insight into the consumer experience.</td>
<td>The National Safety and Quality Health Service (NSQHS) Standards and Partnering with Consumers Framework.</td>
</tr>
<tr>
<td>Champion <strong>equity in healthcare</strong></td>
<td>Able to build strategic, productive relationships and influence decision makers.</td>
<td>Consumer and community engagement practices and principles.</td>
</tr>
<tr>
<td>Value <strong>diversity and inclusion</strong> of those who are <strong>seldom heard.</strong></td>
<td>Ability to analyse and interpret information.</td>
<td>Awareness of the social determinants of health.</td>
</tr>
</tbody>
</table>

Development stages of a Consumer Advisor

The Model identifies three levels of experience: Emerging, Evolving and Experienced. These are described on the following page.

Note: The journey of each Consumer Advisor will be different. There is no obligation or expectation that they will progress through the various stages. This will be a personal decision based on their own interests and situation.
Emerging consumers:
- 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.
- Tend to take on roles of ‘expert patients’. They speak from their own experience, rather than on behalf of others.
- May do ‘one-off’ style engagements like taking part in focus group, providing feedback or sharing their story to help other patients or families.
- Need support to engage in their role(s). Their focus is on learning, growing, developing through on-the-job experience, and finding their voice.

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.

Evolving consumers:
- Begin to connect their own experience to broader consumer issues. They are developing confidence to raise concerns and point out potential issues.
- 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.
- Will be familiar with the common language, terminology, acronyms, concepts, and content of the service they work with.
- They will be able to access a broad range of information sources available.
- Are likely to be volunteering on a regular basis and are often engaged on committees, co-design groups, and working parties with a focus on building relationships and forming alliances.

Healthcare organisations can support evolving consumers to engage with other consumers, to understand their experience, so they can begin to advocate for the needs of consumers more broadly.

Experienced consumers:
- 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.
- Use their expertise to influence policy, co-design solutions with health staff, and critically analyses proposals and papers. They may be able to deliver training sessions related to their areas of expertise and engage with other consumers.
- Are highly skilled communicators, influencers, and negotiators. They are often engaged as advisors reporting to the Board(s), co-chairs of committees, and have strong community ties.
- Can provide mentorship to emerging consumers and help them navigate the early stages of their journey.
Tool for assessing current stage of development

Consumers can assess 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 consumers representatives 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. The health service can then support the consumer by facilitating or seeking out training opportunities that directly relate to their needs and goals.

We encourage consumers and their supports to meet and review the self-assessment tool alongside this Model every 12-18 months. That way you can maintain and ongoing dialogue about any goals or opportunities to gain new experiences.

It’s important to remember that the goal is not necessarily to ‘progress’ through the stages and that every consumer’s advisory journey looks different. Often Consumer Advisors wish to stay at the stage they feel comfortable with and don’t ‘move on’ to other stages.

Consumer Advisors greatly appreciate being supported by health services to develop skills and knowledge that enable them to flourish in the types of roles that they find meaningful and align with their motivations for becoming involved.

Diversity and inclusion

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, young people, people experiencing homelessness and other socio-economic challenges, and isolated elderly people.

People in these groups experience health issues at a higher rate than the general population so it is vital they have a say in how our health system functions. By partnering and supporting consumers with different backgrounds and experiences, we can influence improvements that reduce health inequalities. Health services need to remove barriers to participation and create opportunities that support consumers to have a say in a way that is meaningful, inclusive, and accessible.
Opportunities for consumers to partner with healthcare organisations

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.

<table>
<thead>
<tr>
<th>Direct care level</th>
<th>Service level</th>
<th>System level</th>
</tr>
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<tbody>
<tr>
<td>This is the point at which a patient receives care.</td>
<td>This level focuses on service design, delivery, and quality improvement.</td>
<td>This level relates to governance, planning and policy development.</td>
</tr>
<tr>
<td>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.</td>
<td>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. Consumers provide feedback, ideas, and personal experiences to drive change.</td>
<td>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. Government organisations partner with consumers in governance, planning and policy development.</td>
</tr>
</tbody>
</table>

Source: Partnering in Healthcare Framework

Consumer Advisor roles focus on partnering at the service and system level and so these are the areas of focus of this Model.

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. This can be seen on the following page.
Activity areas of healthcare

Consumer participation is encouraged across a broad range of areas in health services. Seven activity areas where the contribution of consumers is highly valued include:

1. Information, communications and health literacy
2. Policy
3. Quality and safety
4. Patient experience
5. Research
6. Community engagement
7. Governance, leadership and culture

You can read more about how consumers at any stage of development can play an active role in each of these activity area by clicking the links provided.
Consumer Advisor roles in practice: a snapshot

Our aim is to enhance consumers’ ability to effectively partner in healthcare. The Appendix of this Model shows examples of the types of roles suited to consumers at the emerging, evolving and experienced stage in each of the seven activity areas along with a real-world example of consumer engagement in practice.

These snapshots are intended to:

- Support emerging consumers who are interested to explore ways they might want to start formally contributing to their health service.
- Enable evolving and experienced Consumer Advisors and their leads to work together to review and identify partnership opportunities that align with a consumer’s interests, skills, and experiences.
- Help Consumer Advisors at all stages to advocate for their training and development needs which in turn helps health services to resource more tailored and targeted support.
- Provide inspiration to health services, researchers, and government agencies about the breadth of best practice partnership opportunities that could be embedded to drive better health outcomes for all.

Recognising contributions through payments

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 accumulative 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.
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 consumers who are partnering in the governance, design, measurement, and evaluation of the organisation. This is pivotal to a Consumer Advisor’s experience. It assists to make sure people from all backgrounds, with all types of experiences, have the opportunity and support they need to shape our health system for the better.

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.
- The **Guide for consumers to self-assess the quality of their engagement in healthcare organisations** includes a Training Needs Assessment (TNA) on pages 11-14.

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.

Background reading

- **The Australian Charter of Healthcare Rights**
- **What is health?** - Australian Institute of Health and Welfare
- Safer Care Victoria’s **Partnersing in Healthcare Framework**
- The **National Safety and Quality Health Service Standards**, particularly Standard 1, **Clinical Governance Standard**, and Standard 2, **Partnering with Consumers**
Appendix

Information, communications, and health literacy

Health literacy refers to how people understand information about health and health care. It includes how they apply that information to their lives and use it to make decisions and act on it. As many as 1 in 6 people report that they struggle to understand health information given to them. If people can’t understand information given to them, or are unable to navigate health services, it makes it difficult for them to manage their own health and follow treatment guidance.

The National Statement on Health Literacy states health services have a responsibility to make it easy for people to know what services are available, how to access them and how to follow health care guidance. Unfortunately, health professionals often use jargon. Many health services have realised that they can improve leaflets, posters, websites, and forms by working with consumers to design and draft them.

Evolving consumer at service level

Natalie is a Consumer Advisor for Walter and Eliza Hall Institute of Medical Research and other health services. She wanted to give something back after her son received life-saving treatment.

“One of the things I bring to my consumer work is my professional experience with language teaching and communication. For many years I was a teacher of English as a Second Language,” she said.

“I am very aware that if we give people written language and they don’t understand the information that’s given – especially when they are sick and they are not in a position to check or clarify – then that leaves them really vulnerable and powerless to help themselves.”

“I have done things like check materials and apply plain English principles. Other people involved are IT people, or all sorts of other backgrounds, and they can contribute in unique ways.”

Emerging

A consumer might participate in activities like reviewing and developing health service communications materials such as brochures, forms and newsletters, to ensure accessible language and format or translation into community languages. Good English literacy skills come in handy, but services can provide accessibility support to those that need it. Having a foundational understanding of health literacy principles and techniques such as Check Back, Ask me 3 and 5 Questions would be beneficial to Consumer Advisors in these roles.

Evolving

A consumer has a good understanding of health literacy principles and how to relate them to information, communication and health service accessibility. Consumers can identify communication gaps and devise solutions, for example, wayfinding initiatives to aid clients navigate health centres or hospitals.

Roles that consumers might take on include helping to organise health service open days, or co-develop information about conditions, processes and pathways.

Experienced

A consumer demonstrates in-depth knowledge of health literacy principles and may be involved in training staff on how health literacy impacts on patient health and wellbeing and the risks of not implementing these principles.

At this development stage, consumers promote accessible information and understand a health service’s obligations for privacy and information security. Experienced consumers can identify the need for health literacy initiatives or projects within the service and communities.
Policy

Consumers should be involved in helping health services and government agencies develop policies, especially when these are relevant to how services are provided. These could be policies regarding opening hours, fees for service or the ways that a service partners with patients in their care planning. The policies may also be about organisation wide issues, such as how health services respond to the needs of diverse groups within our communities. Consumer-informed health policies ensure that we are providing equitable and accessible pathways to services for everyone.

At a systems level, local councils, the Victorian Government, and the Commonwealth often hold public consultations to help them develop plans and make decisions about funding priorities or what changes need to be made. The Victorian Government has a website - https://engage.vic.gov.au/ - which lists all the current consultations. You can read about what the Government is proposing and find out how to attend consultation meetings or submit your own views.

Emerging
Consumers may speak to the impact that an organisation’s policies had on their experience of using the health service. They may be able to help services identify gaps in the accessibility or equitability of policies. Consumers might choose to take part in public consultations conducted by government departments to influence policy at systems level. Consumers will typically participate in focus groups or provide written feedback on policy developments to influence change. Having existing knowledge of policy from previous personal or professional experience can be helpful but is not essential.

Evolving
A consumer understands the relationship between organisational or government policies and the delivery of services for consumers. They can analyse policies from a consumer perspective, identifying how they may impact consumers accessing safe and quality healthcare. Evolving consumers can discuss implications of changes to health policies, processes and procedures. This requires a working knowledge of the health care system and the broad issues experienced by consumers. Consumers at this level are typically engaged on advisory committees or take on roles as policy advisors.

Experienced
A consumer at this stage understands how the health system operates between jurisdictions and sectors. They appreciate the complexity and diversity of the healthcare system. This requires keeping informed with policy developments and supporting other consumers or staff in developing this knowledge and understands implications for service delivery. Experienced consumers can mobilise support from consumers and health professionals to influence decision makers. They are likely to hold roles in organisational governance committees.

Experienced consumer at system level
Julian had used Peninsula Health’s services and in 2010 he joined its LGBTIQ advisory group. He pushed for Peninsula Health to attain Rainbow Tick accreditation. This involved working with other consumers and staff, helping them develop organisational policies to improve services for LGBTIQ people.

This led to Peninsula Health being awarded the Rainbow Tick in 2017 – the first health service in Australia to get it.
Quality and safety

Clinical governance is a key element of quality and safety. It ensures the whole health organisation, from the governing body to managers and clinicians, are accountable to patients to deliver safe, effective and high-quality services. Despite these systems being in place, some people do not receive optimal care and unfavourable events occur. An adverse outcome might include pain, delays in care, short-term, permanent disabilities or death. It is estimated that around 3% to 15% of hospital admissions result in a patient safety incident.

Harm arising from care must be avoided and risks should be reduced across the whole care giving process, including providing care in the home. The NSQHS Standards ensure partnering with consumers is considered as an integral part of organisation-wide clinical governance and quality improvement systems.

From an emerging to an experienced consumer

When Lizzie joined the Eastern Health Consumer Advisor Committee (CAC), the service invested time, effort and resources in Lizzie’s development. “I was able to develop skills that make an effective consumer partner, I owe all that to Eastern Health” she said. The time commitment to become an experienced consumer can’t be underestimated. After five years on the CAC, Lizzie qualified for a place on the Quality & Safety Board. “By that time, I had accrued experience that confirmed for me the importance of quality and safety in healthcare for the broader community. This was fundamental for me to give an opinion, to evaluate how the decisions being made are going to affect patients.” She always kept her consumer hat on, saying, “if we are going to review clinical outcome data, what interest does the community at large have in looking at this?”.

Lizzie was then invited to be a Consumer Advisor with Safer Care Victoria. She joined a Collaborative group which examined how patients travelled through the health system to understand whether they received timely care - “this level of work is challenging, it requires the ability to think broadly... it’s not about me, it’s about the community”.

Emerging

A consumer might start their advisory journey by choosing to provide feedback or make a complaint if they’re unhappy with a service they received. Consumers can share their stories of accessing a health service to assist organisations to identify ways to make care safer. Becoming familiar with concepts like shared decision-making, informed consent, human rights, and complaints processes would be beneficial. Consumers may participate in quality improvement projects, for example they might volunteer to trial a new program or tool and then take part in an evaluation.

Evolving

Consumers at this stage are likely to be a committee member participating in the review of safety and quality incidents or other serious adverse events. To undertake this type of role it’s important to have the ability to undertake critical reading and to be familiar with quality accounts. These provide the Victorian community with an open and transparent account of each service’s performance and improvement work. Consumers could also be invited to take part in staff recruitment processes or could take on more responsibility in a quality improvement project working group.

Experienced

Commonly consumers at this stage are members of a clinical governance committee which involves periodic review of a services performance in quality improvement, risk management, incident management, feedback and complaints management. Services can implement forward-thinking approaches to improving patient safety through initiatives like the Collaborative Pairs Program. This brings together an experienced Consumer Advisor with a service, clinician, or manager to identify a joint healthcare challenge or project that they are passionate about and will work on together.
Patient experience

A patient, family member or carer’s experiences of a health service is influenced through physical, cultural, and social contexts. ‘Patient experience’ refers to what receiving care feels like to each individual and their family. This includes the quality and value of all interactions that patients have with the health care system across their journey. There is growing evidence which shows that a patient’s experience of care has a direct impact on their health outcomes.

Looking at all parts of an individual’s health experience assists health services to understand the patient’s journey. They are better able to assess the extent in which person-centred care has been received.

Person-centred care means being respectful of and responsive to an individual’s preferences, needs and values. This is also when patients and their families have their questions and or concerns answered and taken into account. The treating team showing genuine interest and they are able to work together to regain or maintain a good level of health. Consumers with a positive patient experience can be motivated to ‘give back’ to that service by becoming a Consumer Advisor.

Emerging consumer at service level

Mercedes came across an opportunity advertised by Western Health, asking to hear from younger voices through their new Western Health ‘WHY’ committee. After her own experience of being a patient and facing challenges supporting family members who have English as a second language to access care, she jumped at the chance to take part.

“I’m so passionate about making healthcare more patient-orientated.”

Mercedes and a group of other young people started meeting monthly online to brainstorm ways they would like to improve the experience of care for other young people in the West. One example Mercedes shared was that “We are brainstorming what a ‘buddy program’ could look like... It can be scary for a young person to be alone with a health professional, everything is fast paced... I don’t want people to feel scared to ask questions.”

Mercedes has attended training sessions to meet with more experienced Consumer Advisors and has learnt about the role of consumers on committees, the NSQHS Standards, and storytelling.

Emerging

A consumer may give feedback on what it is like to use a service with the view to improve the service for themselves and other consumers. They may go further and share their story as part of a service user journey mapping project, focus group or patient experience video series.

Consumers at this stage might be motivated to take part in a co-design service improvement project. It’s helpful for consumers to understand the concept of patient-centred care.

Evolving

A consumer at this stage will be demonstrating their ability to represent broader perspectives about experiences of accessing health services. They can conduct patient experience interviews on behalf of the health service or may do this through more informal discussions in places like waiting rooms. Consumers can do environmental walk throughs to identify issues and improvements that will enhance patients’ experience. Consumers on patient experience committees should develop an understanding of Patient Reported Outcome Measures and Patient Reported Experience Measures.

Experienced

Consumers are thinking strategically about the ways services can improve patient areas and are forming relationships and alliances in organisations. It can be helpful for consumers to draw on ABS Patient Experience in Australia Data along with patient experience stories as a way to influence decision-makers.

Consumers at this stage can also be involved in delivering education and training programs, to support the workforce on topics such as the importance of person-centred care to the patient experience.
Research

It is becoming more widely recognised that involving consumers in health research as partners, not just participants, is essential. When researchers apply for grants from funders like the National Health & Medical Research Centre, they must include information about how they have involved consumers and the community in developing their proposal, as well as how they plan to involve them in carrying out their research.

Traditionally, patients, family and carers have expressed feeling ‘used’ in research. There is now a conscious shift away from consumers being research subjects to being ‘team members’ and co-researchers. As a Consumer Advisor, you can work alongside researchers to help make decisions about what research gets done, how research happens, and how the results are shared and used in practice.

Benefits of partnering with consumers in research are widespread and include improved relevance of research to consumer needs, improved quality of studies and their outcomes, improved take up of research in practice, as well as increased public confidence in research.

Emerging consumer at system level

Matt was one of six Lived Experience Champions that partnered with the Anne Deveson Research Centre for their National Stigma Report Card project. Drawing on his lived experience of Bipolar Disorder, Matt was able to support the research team in several ways. This included supporting the distribution and promotion of the ‘Our Turn To Speak’ survey link through his networks in mental health and other areas so that it could reach as many people with lived experience of complex mental health issues as possible.

Matt attended workshops to help the research team interpret the findings of the survey, and to give suggestions on how the results and recommendations could be best presented in an accessible way. Matt also provided quotes relating to times where he had experienced stigma and discrimination in regards to having a mental illness, which were featured in the final report and on the internet page under the heading "Real people, real stories".

Emerging

Consumers most commonly contribute their lived experiences with a health condition or an illness to the researchers. Consumers can be involved in workshops that have an impact on the design and conduct of research, or they might help to develop strategies to share study results with interested consumers. They are not expected to have technical research knowledge. Completing online submissions to help identify gaps in research or health advice helps organisations to prioritise new research topics and guideline development.

Evolving

Consumers will be more familiar with the research process and terminology. Consumers can ensure written materials are clear, easy to understand and free from jargon. This includes reviewing surveys for language, length, relevance, and cultural appropriateness. Consumers may also become part of an advisory group with the role to connect research with community experiences of health conditions. Some researchers partner with a ‘consumer buddy’ to assist them with communicating their science in plain language and providing insight into how their research can make a difference in the community.

Experienced

A consumer at this stage should have a key focus on building productive relationships with researchers. They can influence the setting of research priorities, evaluate papers, help to write funding grants and reviewing research grants. A consumer can become a partner on a research team and conduct peer research, help to collect data and work with researchers to make sense of the results. Experienced consumers may have the opportunity to present research results at conferences, forums, and workshops. Sometimes consumers choose to take the step of leading research of their own.
Community engagement

It is crucial that services and governments listen to community needs, concerns and aspirations. Effective community engagement is key to building respectful relationships, and can result in strengthening communities and capacity building. Importantly it can help to support community members to develop trust in their health services.

Consumer Advisors act as a vital link between the health service, diverse population groups and condition specific groups including local residents and community groups. This includes priority communities such as those who are culturally and linguistically diverse, Aboriginal and Torres Strait Islander people, people living with a disability, people who identify as LGBTQIA+ and older Australians.

One important approach to community engagement is health promotion. Health promotion is the process of enabling people to increase control over the things that impact on their health. There is a growing body of evidence to support the effectiveness of place-based and collaborative health promotion. Consumer Advisors involved in community engagement, are uniquely placed to connect with people in the places where they spend their time. We know this plays an important role in shaping their health and wellbeing.

Evolution consumer at service level

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.

Nora wanted to help so she took on a role interviewing children of all ages, expectant mothers, new mothers and spouses - 76 interviews in total. 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 this insight, the hospital created single maternity rooms with an additional bed so partners can stay. Parents that 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.

Emerging

Consumers that are trusted and respected by their communities are wonderfully suited to these roles. Consumers can actively participate in community information sessions, community consultations and awareness events. They can encourage other community members to attend and act as spokespeople for why engaging in these types of events is important. They may be supported by a health service to be part of health promotion activities like sharing their story for the development of health education resources or present in health condition support groups.

Experienced

A consumer at this stage can navigate conversations about diversity and difference within complex, bureaucratic contexts. They can use their leadership role to influence health organisations to co-design solutions with seldom heard communities. Having strong ties across broader consumer and community-based organisations helps a consumer to be effective. They may input into staff training on the importance of partnering with consumers, cultural competency, or making consultations accessible.

Evolving

Consumers have knowledge of community engagement approaches, and equity and inclusion principles. They can take an active role by hosting ‘kitchen table conversations’ to enable participation by community members who do not ordinarily participate in public consultations. Consumers can support health services to design and co-facilitate community consultation and engagement projects so that they are tailored to the needs of specific groups. They can also advise services on how community needs can be translated into health programs or services.
Governance, leadership and culture

NSQHS Standard 2 states that health services must partner with consumers in organisational design and governance. As a Consumer Advisor involved in governance, you will help shape the way the health organisation operates to achieve mutually beneficial outcomes. Good governance systems promote the effective delivery of healthcare, empower patients and contribute to improvements in health outcomes.

Corporate governance involves establishing systems and processes that shape the way an organisation is directed and managed. Governing bodies (often Boards) set priorities and the strategic directions of the organisation. They establish policy frameworks, lead organisational culture, oversee management performance, prioritise resource allocation, monitor organisational performance and ensure accountability.

Supporting consumer engagement at multiple levels of governance is a key element for effective governance systems. It is also critical that the consumers involved in these partnerships reflect the diversity of consumers who use the service.

Advice to evolving consumers from an experienced consumer at system level

Ray, a motorcycle enthusiast, was flying all over the country representing the industry on road safety issues and compliance at government level. A severe stroke put a stop to this but started his Consumer Advisor journey. After years of dedication as a consumer on various committees, Ray was recently appointed to the Board of Directors at Western Health. “I’m a confident person who was used to dealing with Government Ministers, but you can imagine it can be very daunting for the average person” he said.

Ray’s advice to evolving consumers interested in being involved in governance - “Know Standard 1 on Governance inside out, internalise it, understand it. Take part in leadership training and build your confidence in performing at higher levels.”

He shares, “I have loved every minute of my consumer journey. I’d love to see more consumers coming on and participating at governance level.”

Emerging

A consumer might attend open access Board meetings which are open to the public. Health services are required to hold these at least once per year. Consumers should keep informed with organisational changes and opportunities through reading annual reports, quality accounts and subscribing to newsletters. Becoming familiar with the NSQHS Standards on Governance, leadership and culture is helpful.

Consumers can be involved in roundtable discussions or focus groups on the future vision or values of an organisation.

Evolving

Consumers are developing a working understanding of health service governance structures. They may have joined a Board of a small community organisation to gain real-world Board and governance experience. Consumers can demonstrate good communication and relationship building skills. They can make contributions to management through membership of committees and steering groups that work alongside staff. Consumers may hold a salaried role as a Consumer Consultant, bringing a professional level of consumer leadership to an organisation.

Experienced

A consumer at this stage is most commonly a member of a senior committee such as a Community Advisory Committee and advises the Board. They are able to provide the health service with high level consumer, carer and community views on health service development, planning and quality improvement. They provide leadership to ensure a culture of partnering with consumers and have highly developed skills in influencing and negotiation. They may take a further step to become a health service Board director.
**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.\(^5\)

**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.\(^3\)

**Co-design**: Is a method of human-centred design, where new approaches to services are created with the people who use or deliver those services. 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.\(^6\)

**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 Health.\(^7\)

**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.\(^8\)

**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.\(^5\)

**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 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 option.

**Lived experience**: personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.\(^9\)
**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 seek, 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.

**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 decisions.

**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 patients and their carers 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.

**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.

**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).

**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 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 users. 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.

**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**


7 Safer Care Victoria. 2020. Building your healthy community A guide for health service community advisory committees.


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