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# **Consumer Voices at the CEIH**

## Shaping Better Healthcare Together

IMAGINATION AT WORK

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Commission  
on Excellence  
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in Health



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# Acknowledgements

## **Acknowledgement of Country**

We acknowledge and respect the Traditional Custodians on whose ancestral land SA Health provides services. We acknowledge the deep feelings of attachment and relationships of Aboriginal people to country.

## **CEIH Community of Consumers**

We recognise and appreciate consumers, patients, carers, supporters and loved ones. The voices of people with lived experience are powerful. Putting people at the centre of everything we do in healthcare is essential to ensure our system works for the people it is designed to serve. The contribution of those with lived expertise is essential to ensuring we focus on the right problem and put in place the right changes to deliver change that makes a difference

## **About this document**

The Consumer Framework guides the work of the CEIH to ensure genuine, inclusive and meaningful participation by consumers in all aspects of health care, program and policy development, research and service improvement. The framework establishes a shared set of principles that inform how the CEIH partners with consumers and communities, recognising them as essential contributors to safer, higher-quality and more responsive services.

It provides a structured, sustainable approach to engagement that builds organisational capability while supporting the empowerment, leadership development and confidence of consumers. The framework outlines a spectrum of engagement, with increasing levels of influence and shared decision-making, alongside clear processes for initiating, supporting and embedding consumer participation activities across the CEIH.

## Foreword

Together, we are pleased to share and support the implementation of the CEIH Consumer Engagement Framework.

Consumer engagement is central to the CEIH's purpose. Meaningful, well-designed engagement strengthens the quality, safety and relevance of health services by ensuring lived experience genuinely informs decision-making across the system.

The CEIH is committed to partnerships built on trust, respect and shared leadership. Through co-design, collaboration and intentional relationship-building, we work to ensure consumers have the capability, opportunity and authority to influence change.

### **Empowered consumers are a strategic pillar of the CEIH.**

This means supporting leadership among people with lived experience, creating inclusive and culturally safe spaces, and actively removing structural barriers. We recognise the importance of creating systems, processes and structures that support safe and appropriate environments that elevate the voices of those who are often marginalised or even unheard. This includes but is not limited to the voices of First Nations peoples, regional communities, culturally and linguistically diverse communities. Building trust, addressing access barriers and adapting our approaches are essential to ensuring all voices are heard and valued.

This Framework outlines how the CEIH will continue to champion consumer-centred care, shared decision-making and system improvement through genuine partnership. It reflects the insights of consumers, community organisations and health partners, and aligns with broader priorities to build a health system that is equitable, culturally responsive and accountable to the communities it serves.



**Prof. Keith McNeill**

Commissioner  
CEIH



**Mark Haseloff**

Co-Chair and Consumer  
Community of  
Consumers

## What is Consumer Engagement?

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

Health Consumers Queensland, Consumer and Community Engagement Framework (2017)

The CEIH recognises that engaging consumers in health care decisions is widely recognised as best practice in health care policy, research and services. Consumer Engagement is about involving consumers and carers in decision-making, be it decisions at an individual level - around people’s own health, treatments and illness management (consumer centred care) or at health service level – around policy development, service design, delivery and evaluation.

## Why is consumer engagement important?

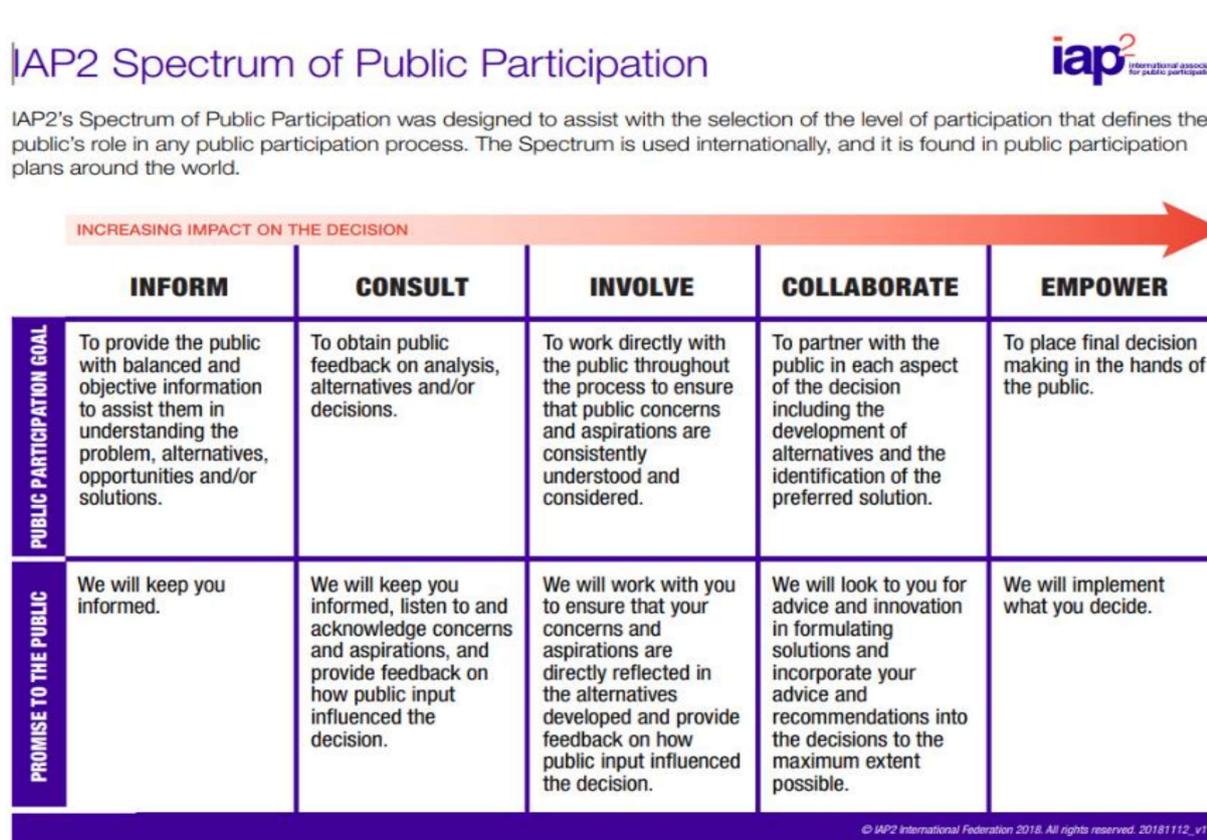
Consumer engagement is vital in health care as it promotes:

- Respect for ethics and democracy – participating in decisions that impact on people’s own health is an ethical and democratic right
- Improved health outcomes – engagement improves health outcomes for both individual and policy outcomes
- Improved service delivery – engagement ensures health services are delivered effectively and closely targeted to people’s needs
- Improved relationships – with health consumers, other services and the broader community
- Adherence to best practice standards of care – such as the [National Safety and Quality Health Service Standards, Standard 2: Partnering with Consumers](#).

Consumer engagement can occur at a range of levels from information sharing to true co-design. The IAP2 Spectrum of Public Participation provides an internationally recognised model of different levels of consumer engagement [<Figure 1>](#). Previous literature reviews have found that most consumer engagement strategies are delivered at the ‘consult’ level in the spectrum of public participation. This gives rise to concerns over the ‘tokenism’ of consumer participation and engagement. However, there is a growing call to move beyond consultation, involvement or engagement towards consumer leadership, where traditional engagement is expanded to build capacity for consumer leadership, including roles for consumers in agenda-setting and decision-making about policy, practice, education and research.

An important part of consumer engagement is understanding the roles that consumers play, where the engagement sits on the participation scale and being clear about this so both the consumer and the organisation ensure expectations are met. To this end, the IAP2 Public Participation Spectrum helps determine the most appropriate level of engagement by identifying how much influence consumers or the community will have on a decision or outcome.

**Figure 1: IAP2 Spectrum of Public Participation**



## Consumer Engagement at the CEIH

The CEIH commitment to consumer and community engagement is reflected in our Strategic Direction 2024 – 2027 [<Figure 2>](#). One of the key strategic pillars, Empowered consumers, highlights our focus on engaging with consumers and community to shape and improve healthcare.

**Figure 2: CEIH Strategic Pillars**



***‘Empowered Consumers’** - engage consumers, carers and community in design, delivery and evaluation of services’.*

The CEIH grounds its approach in a set of shared principles developed in partnership with consumers [<Figure 3>](#). These principles guide how we work, and the environments we create. They also provide the foundation for our commitment to psychological safety, sharing power, and embedding diversity and inclusion in every engagement activity. These principles are:

- Partnership
- Participation
- Respect
- Accessibility
- Diversity

The principles for engagement shape how we design, deliver and evaluate our consumer engagement activities, ensuring that our processes uphold safety, inclusion and genuine influence and shared decision-making.

Figure 3: CEIH Principles for Engagement

Our principles for engagement

Principle	Statement	In Practice
1 Partnership	We work in partnership with all those involved in healthcare, particularly clinicians, consumers, carers and other collaborators in all aspects of our work.	We will develop clear mechanisms to collaborate with people.  For example, for consumers and carers this includes the Community of Consumers, membership on Statewide Clinical Network Steering Committees and other advisory committees and engagement in projects. For others it may include formal partnerships or other clearly defined mechanisms for working together.
2 Participation	We support people to actively engage, participate and contribute to decision making and, in the planning, design, implementation and evaluation of all our work.	We will develop a person-centred process to understand people's needs and values and provide the required training or other support for active and meaningful engagement.
3 Respect	We value equally, the different experiences and skills people bring. This includes both the recipients of health care as well as the providers of health care.	We will undertake all engagement processes with mutual respect, demonstrated by treating people with courtesy and politeness, encouraging the open expression of ideas, actively listening and adopting a non-judgemental approach.
4 Accessibility	We recognise there are barriers to meaningful engagement and take action to remove barriers to ensure inclusion and accessibility for everyone, especially those people from marginalised or disadvantaged communities.	We will proactively identify barriers to effective engagement and do whatever we can to eliminate them in order to ensure that people are able to participate.
5 Diversity	We value engagement with diverse groups of people, including all sorts of clinical and non-clinical backgrounds, people with a disability, older people, young people, people from culturally and linguistically diverse backgrounds, Aboriginal people, people from rural or remote areas, and LGBTIQ+ people.	We will actively seek input from a diverse range of people. Where this is difficult, we will work with people and communities to develop strategies that support their engagement in our work.

## Psychological Safety and Sharing Power

At the CEIH, we recognise that when we design any interaction where we will be asking for input that touches on people's lived experience, we need to give time to think about how we do this safely and in a way that people feel comfortable and confident to share their views and speak up about their needs.

**Psychological safety** is essential to meaningful and respectful consumer engagement. At the CEIH, we are committed to creating environments where consumers, carers and community members feel safe to share their experiences, insights and perspectives without fear of judgement, harm, tokenism or negative consequences. This includes acknowledging the potential vulnerability and impact of discussing personal experiences in health settings, responding with empathy and respect, and implementing healing-centred and culturally safe practices. By fostering trust, transparency and mutual respect, CEIH enables honest dialogue, strengthens partnerships and supports consumers to participate confidently and authentically in shaping health care services and projects.

**Power, and the language** we use can impact significantly on people's ability and willingness to share information. When engaging with consumers at the CEIH we are mindful of how we share power and the language we use.

Ways we share power at the CEIH:

- We are clear about people's roles and responsibilities
- We make the language as relevant as possible and try not to use acronyms and jargon that maybe unknown to consumers
- We value experience and skills rather than titles and positions
- We are aware of where people are seated and how they are arranged in the room and online
- We consider the size of the group and what we ask of the group in that context
- When we chair meetings, we consider who is speaking a lot, who is speaking first and who is speaking less
- We choose spaces and environments that are welcoming, neutral, comfortable and easily accessible
- We welcome people to spaces we are engaging in by providing orientation and briefing about amenities
- We think ahead about the knowledge we will be sharing in a meeting or engagement and provide the suitable information ahead of time or at the time to those who need it without judgement.

**Healing-centred** focusses on strengths, moving from ‘what happened to you’ to ‘what’s right with you’. It builds beyond trauma informed care, with an intention to strengthen wellbeing and to support people to have control and power in their community.

Healing-centred care at the CEIH looks like:

- We build empathy
- We think about our mindset and our own biases when we are listening
- We listen without judgement
- We provide safe spaces for people to share in a way that they are comfortable with
- We plan for psychological safety and ensure we have contacts and resources available to anyone who might need them
- We focus and design our discussions, questions and workshops on what we can do rather than what is wrong.

## Diversity & Inclusion in Consumer and Community Engagement

Diversity and inclusion are fundamental to meaningful consumer engagement at the CEIH. We recognise that people’s experiences of the health system are shaped by culture, language, identity, ability, geography, socioeconomic position and lived experience. The CEIH is committed to removing barriers to participation and creating culturally safe, accessible and inclusive opportunities for people from priority and under-represented populations to contribute to, and influence, the design, delivery and evaluation of health services, networks and projects. By embedding inclusive practices and working in partnership with diverse communities, the CEIH ensures that the voices informing our work reflect the breadth of our population, leading to more equitable, responsive and effective outcomes.

### Key focus areas:

- Actively prioritise engagement with under-represented populations, including Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, people with disability, LGBTIQ+ communities, rural and remote populations and people experiencing disadvantage.
- Design engagement opportunities that are accessible, culturally safe, trauma-informed and responsive to individual needs (including language support, flexible formats and appropriate remuneration).
- Partner with community organisations, advocacy groups and cultural leaders to build trust and support authentic, ongoing participation.
- Support capacity building and leadership development for diverse consumers to enable confident participation and influence.
- Embed inclusive practice as a core organisational capability through staff training, reflective practice and measurement of diversity in engagement activities.

*Responding to diverse needs is complex. Many people want to be actively involved in their care, yet First Nations peoples, CALD communities and those in rural and remote areas are often under-represented in engagement opportunities and over-represented in clinical risk.*

*Guided by the World Health Organization’s definition of equity, we recognise that equity means removing avoidable differences in health outcomes between social, cultural, linguistic and geographic groups. In practice, equitable healthcare is not about giving everyone the same care, but ensuring all people can access safe, effective and person-centred care that meets their needs — including by addressing barriers in quality, safety and accessibility for priority populations.*

# CEIH Consumer Engagement Model

Figure 4 presents the CEIH Consumer Engagement Model, which has been adapted from the IAP2 Spectrum of Public Participation. It includes practical CEIH examples under each category or level, illustrating how the CEIH can involve consumers in organisational thinking, project work, and key initiatives. It also recognises that some activities and priorities may span across multiple categories on the spectrum, requiring multi-pronged engagement approaches.

In line with the IAP2 Spectrum, CEIH recognises that clear and transparent communication is fundamental to effective consumer engagement. When engaging people with lived experience, CEIH is committed to clearly outlining the purpose of engagement, the level of participation, and how consumer contributions will shape decisions and outcomes. This clarity supports trust, psychological safety and shared understanding, and underpins respectful partnerships that value lived experience as a critical source of expertise.

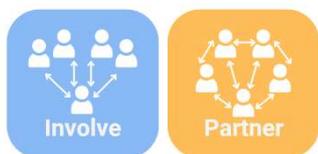
Figure 4: CEIH Consumer Engagement Model



# Consumer Engagement in Practice at the CEIH

Consumer and community engagement is embedded across the work of the CEIH, with different approaches applied depending on the purpose, context and level of influence required. The following sections provide specific examples of how this engagement occurs in practice across the different levels of the CEIH Consumer Engagement Model shown in [Figure 4](#).

## Statewide Clinical Network consumer representatives



Statewide Clinical Networks (SCNs) hosted by the CEIH bring together health professionals, consumers and subject matter experts to provide clinical leadership, strategic direction and drive innovation.

SCNs build partnerships and engagement across institutional and professional boundaries, allowing for improved working relationships and open sharing of information to solve system level problems, create excellence in care delivery and improve health outcomes.

To ensure broad representation, SCNs are constructed to reflect a balance of experience across metropolitan and regional areas, as well as both hospital and community settings. Each SCN is led by a Clinical Lead.

Across the twelve SCNs, membership includes two consumer representatives. Each SCN works collaboratively with these consumers, who contribute their voices and lived experiences to help deepen understanding of the consumer experience, inform and drive system change, and support better healthcare outcomes for South Australians within each of the Networks' twelve clinical specialties. In addition to the dedicated consumer representatives, the SCNs also draw on the knowledge and lived experiences of other consumers as needed, ensuring the perspectives involved are relevant to the specific piece of work or area of focus.

## Statewide Clinical Network Consumer Co-Lead



In 2023, the CEIH established a co-lead consumer role for one of its SCNs. The SCNs consumer co-Lead model championed a new way of leading and sharing decision-making with the Clinical Co-Lead.

The co-lead model was adopted for the Palliative Care Network to recognise the equality of the consumer and the clinician in palliative care. It was an innovative model that led the way for other projects.

The success of this model can be attributed to the:

- The design of agreed ways of working to ensure role clarity
- Knowledge and skills of the co-leads
- Ability of the co-leads to truly value each other's skills and abilities

An important part of the consumer Co-Lead role was to raise awareness and to advocate for people's voices to be respectfully heard so their needs were met according to their wishes.

A particular focus was on identifying ways to assess patient and carer experiences that support services to understand what is working well and where improvements may be needed. This was an emerging and innovative area, with growing recognition and advocacy at both state and national levels.

The CEIH would like to acknowledge and remember the contributions of the inaugural consumer co-lead for this network who passed away in 2025.

*\*Note – the Statewide Palliative Care Clinical Network is no longer hosted by the CEIH, however this remains an excellent example of good consumer engagement practice.*

## Consumer Involvement in CEIH-Led Projects



Projects and initiatives that are led by the CEIH engage specifically with consumers. Consumers may be part of the Project Working Group or governance committee, be consulted through surveys or engaged in specific ways that support inclusion of the consumer voice for that project.

### Case study:

#### Strengthening consumer involvement in healthcare

CEIH first consulted with consumers in the development of the 'CEIH Partnerships and Networks' approach, an internal document educating CEIH on best consumer engagement practices. This process established who CEIH would engage with and the principles of engagement [<Figure 3>](#). This process also resulted in an initial model to describe consumer engagement and many of the initiatives that are now in place. In 2021-2022, the CEIH facilitated a consumer-led, sector-wide series of consumer engagement activities to understand what meaningful engagement is, how it can be measured and what it could look like in the future. This resulted in a report with a range of recommendations for the health sector and CEIH.

The recommendations included:

- Continue to develop a culture that supports meaningful consumer involvement and use of co-design principles in a culturally respectful way across all stages of CEIH projects
- Commit to ongoing capability building in consumer engagement for Statewide Clinical Network Leads, Clinical Community of Practice Chairs and CEIH staff
- Continue to support CEIH consumer representatives through the Community of Consumers Committee
- Involve consumers in future consumer engagement design and strategic planning for CEIH
- Attract and involve a diverse representation of consumers across consumer engagement activities.

## Consumer representation on the HCEC Clinical Council



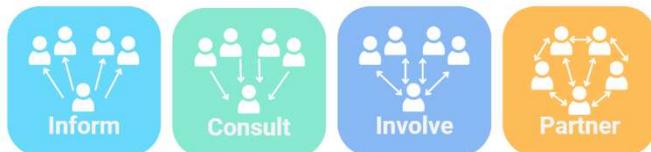
The HCEC Clinical Council has been established to act as the peak clinical body responsible for providing clinical engagement and input into statewide and strategic decisions that affect clinical care in South Australia.

It consists of a team of clinical leaders, consumer representatives and senior administrators to enable clinical improvement, based on the pursuit of excellence through innovation. The HCEC Clinical Council provides recommendations and independent, impartial strategic advice and advocacy to the Health Chief Executives' Council (HCEC), comprised of Chief and Deputy Chief Executive Officers of Local Health Networks (LHN) and the Department for Health and Wellbeing (DHW).

*"The clarity of vision of what is important is best found through the eyes of lived experience. Consumer engagement informs strategy, research, translation and clinical delivery to create the most relevant and effective decisions. The CEIH has surprised me with its open discussion and ability to think outside the box when working with consumers. It is so refreshing to speak to people who get excited about the things I think are important."*

Karen van Gorp - Chair of Cancer Voices South Australia and CEIH Consumer Representative on HCEC Clinical Council.

## The CEIH Community of Consumers Committee



The CEIH Community of Consumers formed to engage consumers, carers and the community in a meaningful way to ensure their experiences and expertise guide the CEIH in its program of work.

The overarching purpose is to:

- Provide a stronger voice for consumers, carers and the community in the work of The CEIH and other health organisations
- Provide consumer, carer and community connections and networking with other groups
- Support opportunities for capability development and greater understanding of clinical engagement.

The committee is co-chaired by a CEIH staff member and a consumer representative and is made up of consumers from each of the Statewide Clinical Networks.

*"Genuine consumer engagement is absolutely vital and helps deliver better outcomes for patients. Involving consumers in healthcare protocols adds a unique and important perspective. From making things more easy to understand and giving practical advice, strong consumer involvement helps all those involved. The saying 'nothing about us, without us' resonates greatly with me and these values are a cornerstone of what the CEIH does every day.*

*I have been privileged to be involved as a Consumer Representative for over 5 years now at CEIH and have been involved with many great projects. In the uncertain early days of Covid 19, it was great to help develop patient fact sheets which were set out to help navigate the complex health advice that we all experienced in that extraordinary time."*

Mark Haseloff – Co-Chair, Community of Consumers

## Youth Advisory Group



The Youth Advisory Group (YAG) is a joint initiative of the CEIH and the Adolescent Transition Care SCN to help the CEIH understand the voice and healthcare experiences of young South Australians, to drive change and improve their healthcare outcomes.

The group provides representation on the Adolescent Transition Care SCN and is available to provide input and advice to other SCN and relevant groups such as researchers. Members of the YAG show leadership by taking turns to chair their meetings with the support of the CEIH.

The YAG is for young people between the age of 12 - 25 years, who regularly engage with healthcare services.

### Vision

- To engage with and represent the voice and interest of young people engaged with South Australian healthcare services.
- To inform, advocate, and collaborate to improve health outcomes, services, and consumer engagement for young people in South Australia.

### Case Study

#### Statewide Adolescent Transition Framework

DHW consulted with the Youth Advisory Group in collaboration with the Adolescent Transition Care SCN, on the development of the Statewide Adolescent Transition Framework from a young person's perspective. Once the framework was established, the YAG then worked with the team to make a more youth friendly version of the framework on a page in infographic form which could be used to communicate with various stakeholders across the state on the framework and their transition plans and options. They also provided feedback on the look and feel of the framework document and suggested adding in youth related imagery within the document.

# Building Sector-Wide Consumer Engagement Capability

## Community of Practice (COP) for Local Health Network (LHN) Consumer and Community Engagement Professionals

Although not directly working with consumers, the CEIH brings together staff working in consumer engagement across the LHNs into a Community of Practice. The aim of the group is to share best practice across the sector, collaborate where appropriate and offer peer support to colleagues – all of which contribute to improving consumer engagement across the sector. The CEIH recognises the sophisticated consumer engagement practices in place at the LHN's across SA and acts as a vehicle for sharing and collaboration.

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