

Strengthening Consumer Engagement in Healthcare Summary Report 2022

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Acknowledgement

CEIH acknowledges the ongoing impacts of colonisation on Aboriginal people. These impacts include discrimination, reduced access to resources and opportunities to participate equally and equitably in all facets of life in Australia. In this light, CEIH will continually strive to remove systemic biases and disadvantage in our work on health system redesign, advocating for timely provision of culturally responsive healthcare for all Aboriginal people.

Please note that, in this document, the term Aboriginal refers to all people who identify as Aboriginal, Torres Strait Islander, Indigenous or First Nations.

Foreword

This report summarises the context, process and findings of the consumer-led engagement process undertaken by the Commission on Excellence and Innovation in Health (CEIH) throughout 2021-22.

We are very pleased to have facilitated this engagement process, working alongside consumers, carers, clinicians and other stakeholders to better understand how we can strengthen and improve the role of consumer engagement in healthcare in South Australia. Together, we are helping to drive the planning, design and delivery of better healthcare services and systems and, ultimately, better health outcomes for our community.

We would like to thank everyone who took the time to participate in these consumer engagement activities. Your input, the perspectives you provided and your unique experiences are important to us and will inform continuous improvements across our activities. We would also like to thank the CEIH Community of Consumers Committee for their input into the report recommendations.



A handwritten signature in black ink, appearing to read 'Katie Billing'.

A handwritten signature in black ink, appearing to read 'Paul Williams'.

Katie Billing

Executive Director, Consumer & Clinical Partnerships
Commission on Excellence & Innovation in Health

Paul Williams

Chair, Community of Consumers
Consumer and Community Lead
Commission on Excellence & Innovation in Health

1. Introduction

In recent years, there has been considerable growth in understanding and evidence around how improving consumer ¹ engagement in healthcare leads to better patient outcomes, service innovation and system development.

This includes identifying service gaps, system improvements, issues that are important to consumers and how their needs may best be met, so that health services are relevant and effective. Further, involving consumers builds trust and demonstrates a commitment to collecting, learning from and making changes based on their healthcare experiences, to continually adapt services and systems to better meet the needs of consumers.

For these reasons, the CEIH has been strongly focussed on consumer engagement since its establishment (see next page). In 2021, consumer representatives engaged by the CEIH identified there were opportunities for improved consumer engagement throughout the health system, which could assist the development of better healthcare for South Australians. This prompted the development of the engagement process described in this report.

The aim was to bring together a variety of stakeholders who could provide direction on approaches to strengthen and improve the practice of consumer, carer and community engagement. While the process was facilitated by the CEIH, it was initiated, designed and led by CEIH consumer representatives-

The engagement involved various opportunities to gather views and feedback, including an in-person Consumer Forum, an online survey (conducted via the State Government's 'YourSAY' platform) and opportunities for regional groups to gather and provide feedback via a 'Kitchen Table Pack'. Activities were targeted primarily towards consumers, but also invited feedback from clinicians, engagement professionals and other healthcare consumer advocates.

This report summarises the engagement process and its findings, including key opportunities and recommendations. It is intended as an initial phase in what needs to be a continuing conversation to guide ongoing improvements to consumer engagement activities across the South Australian healthcare landscape.

¹ In this report, the term 'consumer' refers to patients, healthcare users, families, carers, support people and community members.

2. How we engaged

The engagement process ran between December 2021 and September 2022.

Based on advice from consumer representatives, the following two areas were explored:

- What is meaningful consumer engagement and how do we measure it?
- What could the future of consumer engagement look like?

Three main activities formed the basis of the consultation.

Consumer Forum Event

In collaboration with CEIH consumer representatives, the CEIH facilitated an in-person Consumer Forum event on Thursday 14 December 2021 at the Adelaide Pavilion.

Registrations were open to anyone in South Australia interested in strengthening consumer involvement in healthcare. Promotion included:

- CEIH social media platforms
- Targeted email campaigns, including CEIH direct email lists, SA Health all staff email lists, and consumer groups who promoted the event among their networks
- Targeted phone calls to relevant key stakeholders and stakeholder groups, who also promoted the event among their networks.

There were more than 80 registrations, the majority of whom were consumers but also including carers, clinicians, consumer engagement professionals and others who work in health.

The consumer forum event included presentations from two healthcare consumer engagement experts, panel discussions and roundtable workshops where the two identified questions were considered. CEIH staff captured responses and discussion from the day. A full summary of the day including videos of the key note presentations can be accessed through the [CEIH website](#).

'YourSAy' Digital Engagement

To expand the opportunity for South Australians to contribute to the conversation, the two questions of interest were posed via the YourSAy digital platform across four weeks in January and February 2022. This opportunity was sent directly to those who were unavailable for the event, as well as promoted broadly via social media and email.



Regional engagement through 'Kitchen Table Packs'

As the Consumer Forum was an in-person metropolitan event, people living in regional and remote South Australia were supported to provide their input in written form. This process was developed in consultation with Consumer Engagement professionals across the six regional Local Health Networks (LHNs) based on what they felt would work best with their respective communities.

A 'Kitchen Table Pack' was developed for dissemination by the LHNs, again focused on the two key questions. It included information on the Consumer Forum Event (including access to the videos of the keynote speakers), the purpose of the engagement and a brief guide on how to complete and return the pack. The document was available in either an electronic version or as a hard copy, and the interested communities could either complete the exercise as groups or individuals.

3. What we heard

All perspectives and responses gathered during the engagement were collated and analysed by a trained CEIH research professional. Anonymous data was examined and collapsed into themes, which were then reviewed and revised.

This section summarises the broad themes and key points that arose during consultation.

QUESTION 1.

How do we know we're achieving meaningful consumer engagement and how do we measure it?

THEME 1.1: Co-Design and Feedback:

One of the strongest themes from participants' responses was around consumer co-design and feedback. This includes:

- The need for consumers to be involved in meaningful co-design from the beginning, ie involving consumers in designing engagement activities, assessing needs, service design and decision-making processes.
- Seeking consumer feedback at multiple points including following engagement activities and throughout health service delivery.
- Communicating back to consumers about how their feedback (from an engagement activity or through a health service) was used and resulting changes implemented, ensuring that communication methods are targeted and varied (eg consideration of cultural and linguistic needs).
- Using various strategies and methods (eg patient stories) to capture consumer feedback.
- Providing a safe environment for consumers to be comfortable giving negative feedback.

“Hearing people's experience is not engagement. Consumers need to be part of the co-design”

FORUM
PARTICIPANT

THEME 1.2: Evaluation and Measurement

“ Communicate outcomes and changes resulting from evaluation back to consumers ”

FORUM
PARTICIPANT

Participants want to see various measures and evaluation methods used to ensure meaningful consumer engagement, including qualitative and quantitative methods that include both process and outcome measures.

Participants highlighted the need for data to be collected from multiple sources – such as reports, audits, health system use and consumer feedback – when undertaking evaluation. Additionally, surveys should be relevant to the group they are targeting and take into consideration language, literacy and best mode of delivery.

The following activities were suggested as potential measures of effective engagement: audits, annual reports, board reports, surveys, stories, qualitative feedback, activity attendance, survey completion, complaints, participation/non-participation. Good outcome measures could include service/system improvements, policy amendments and changes to funding allocations.

Involving consumers in the design of evaluation was identified as important, as was taking the time to understand what consumers see as necessary to be measured. Communication of outcomes and changes as a result of engagement again emerged as an important element.

THEME 1.3: Capability Building

Capability building among consumers and organisations to support consumer engagement emerged as a key theme. Responses highlighted the need to build consumer capability to support their involvement and contribution to health care planning opportunities, as well as to be actively involved in the design, planning and delivery of consumer engagement activities.

A number of comments were made about building confidence, empowering consumers and making individuals feel valued. Further, responses identified the need to build organisational capability to engage with consumers, including building trusting environments and attracting a diverse range of consumer perspectives.

“ Building capacity and confidence for consumers to participate ”

FORUM
PARTICIPANT

THEME 1.4: Consumer Advocacy and Principles

“ Be honest and transparent ”

FORUM
PARTICIPANT

Consumer advocacy and principles for consumer engagement emerged as another key theme. This included establishing culturally safe environments for consumers.

Several principles were discussed such as being patient-centred, acting with respect, honesty, transparency and addressing power balance/dynamics. The need to provide appropriate resources to support consumer involvement (eg reimbursement, training) and to use a variety of methodologies for consumer engagement were also highlighted.

QUESTION 2.

What could the future of consumer engagement look like?

THEME 2.1: Communication and Feedback

Participants want open, honest and authentic communication between the health system and consumers, including when seeking and providing feedback. It is important to use various methods and mediums to engage with consumers, promote engagement opportunities, seek consumer feedback and provide feedback to consumers.

Participants were open to embracing technology and innovation to better obtain consumer feedback. They also identified the importance of ensuring input and feedback could be provided anonymously.

It was highlighted that the ways in which individual services undertake engagement or obtain feedback must meet the needs of their own unique consumers. While system-wide processes to seek guidance and recommendations from consumers can be appropriate in some circumstances, there also needs to be flexibility to allow individual services to tailor their approaches.

Although outside the scope of the question posed, participants also discussed the need for improved communication between services and coordinated care among health providers and health services.

“
Virtual meetings
to not isolate
”
FORUM
PARTICIPANT

THEME 2.2: Consumer Focus

“
Go to where
people are
”

Discussions stressed the need to ensure consumers are at the centre of engagement. This includes providing respectful environments that support, facilitate and encourage engagement (eg considered language around the use of ‘consumer’ or ‘patient’).

“
Bring people
together through
existing places
”

Participants called for processes that provide opportunities for consumers and the community to influence and contribute to strategic directions around consumer engagement and healthcare (eg consumers on boards). This includes at local, state and national levels. One suggestion was to have a dedicated peak consumer body, independent of government.

It was said that, to achieve meaningful engagement, interactions should start where people already are and communicate with consumers through existing places and platforms. Discussions also highlighted the need for more engagement with consumers throughout their care (eg access to their medical records, patient/family involvement in discharge planning) and consumer focussed care.

FORUM PARTICIPANTS

THEME 2.3: Culture, Diversity and Inclusion

Discussions on this theme centred around organisational or system level changes in culture and mindset, to ensure inclusive and culturally sensitive health services and methods for engaging consumers (eg yarning circles). Equitable engagement methods are needed to facilitate the diversity of consumers and groups, including vulnerable populations. At the same time, it is important participants are open to new and innovative ways to engage.

Some suggestions for improvements in this area included:

- Access to health professionals of the same culture
- Access to health services in first language and/or use of translators
- Using traditional methods/places for engagement
- Going into the community
- ‘Yarn in the garden’ – treatment outside

“
Equitable and
culturally
appropriate
methods”

FORUM
PARTICIPANT

THEME 2.4: Consumer and Clinician Education

“
Upskill people to
be better at
consumer
engagement”

Education and capability building for both consumers and clinicians was a key area of discussion (as also highlighted under Question One) in two respects. Firstly, to support consumers to develop skills around health system communication and navigation, aiming to support them to advocate for themselves throughout their health journey. Secondly, to support improved consumer engagement among clinicians through educational (eg professional development) opportunities.

FORUM
PARTICIPANT

THEME 2.5: System Coordination

Participants expressed the need for a better, more coordinated and systematic approach to consumer engagement in healthcare. Added to this was recognition that a greater number and broader variety of consumers across different areas of the health system should be the aim for consumer engagement.

Consumers feel there needs to be more acknowledgement across the health sector of the value of their time, experience and local knowledge.

“
Less repetition:
more coordinated
approach,
consumer fatigue
from over
consulted”

FORUM
PARTICIPANT

4. Recommendations

Acknowledging the work already being done across the South Australian healthcare sector, the themes presented in this report offer opportunities to build on existing consumer engagement practices.

Recommendations for the Health Sector

- Look for opportunities to provide system-wide learnings, reduce duplication of engagement activities, and broaden and diversify consumer engagement.
- Reflect on and review existing consumer engagement practices and involve consumers throughout this process.
- Build capability in staff and clinicians to enhance engagement with consumers and develop a culture throughout all levels of the health system to support and strengthen consumer engagement.
- Support health consumers and build their capability to confidently engage and contribute in health engagement processes.
- Support and provide opportunities to develop health literacy among consumers.
- Embrace technology and innovation to support consumer engagement activities.
- Develop consumer engagement strategies that provide a safe environment to support equitable, inclusive, diverse, and culturally respectful methods for engaging consumers.

Recommendations for CEIH

- 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 (eg consumer engagement within the Statewide Patient Reported Measures project) and through state level committees (eg Statewide Clinical Networks).
- 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 and the CEIH Consumer and Community Lead position.
- Involve consumers in future consumer engagement design and strategic planning for CEIH, including developing agreed actions based on this report and adopting appropriate metrics for measuring consumer engagement.
- Raise awareness of the importance of consumer engagement understanding, processes and learnings through CEIH communication channels.
- Attract and involve a diverse representation of consumers across consumer engagement activities.
- Disseminate knowledge and share CEIH engagement expertise across the health sector.
- Develop measures, embed evaluation and report on consumer engagement across all CEIH activities.

5. Next steps for the CEIH

Since its establishment, the CEIH has operated around the core principle that consumers are at the centre of everything it does. As such, the Commission has embedded consumer engagement into its operations from day one, seeking diverse consumer perspectives across all work to develop new learnings and innovative solutions for better healthcare for South Australians

The CEIH accepts all of the recommendations in this report and will build them into its future planning and activities. Progress will be regularly, publicly reported through the CEIH's communications channels.

The CEIH will also continue to promote the recommendations of this report with all its partners, as part of its ongoing commitment to ensuring South Australia's health system is truly person-centred.

Other consumer voices which influence the CEIH's activities in an ongoing manner include:

- The CEIH's [Community of Consumers Committee](#), led by the CEIH Consumer and Community Lead
- Consumer representation on each of the eight CEIH [Statewide Clinical Networks](#)
- A [Consumer Co-Lead for the Statewide Palliative Care Clinical Network](#)
- A new [Youth Advisory Group](#) to ensure young peoples' voices are heard
- Ongoing consumer involvement across CEIH led projects, forums and workshops
- Providing support to Consumer Engagement roles across the health system through a Community of Practice

Some examples of CEIH highlights in consumer engagement in 2021/2022 include:

- Funding of the [consumer-led research project](#) 'Minimising the burden of haematopoietic stem cell transplant through the CEIH Patient Reported Measures program (PRMs)'
- Consumer representatives on the Working Group for the [Germline Genetic Testing for Treatment](#) have been providing critical input and expertise in the co-design and development of the project activities, implementation and evaluation
- [Building capability](#) through:
 - Tailored stakeholder and consumer engagement training based on the International Association for Public Participation (IAP2) model for Statewide Clinical Network Leads, Clinical Community of Practice Chairs and CEIH staff
 - Training and capability building for CEIH consumer representatives, co-designed with IAP2 trainer