

**WHY QUEENSLAND
NEEDS HEALTH
CONSUMERS
QUEENSLAND**

Health Consumers Queensland ensures that the Queensland Health system benefits from a strong consumer voice.

The next Queensland Government will benefit from listening to and partnering with consumers so consumers are placed at the centre of the health system.

“ *Partnering with consumers leads to better health outcomes, reduced mortality and infection rates, reduced cost of care, decreased length of stay, and fewer readmissions, adverse incidents and complaints leading to litigation. The case for patient-centred care is compelling.* **”**

*National Safety & Quality Health Service Standards,
Standard 2: Partnering with Consumers Fact Sheet*

**HEALTH
CONSUMERS
QUEENSLAND
EMPOWERS
CONSUMERS**

Health Consumers Queensland empowers and amplifies the voice of health consumers, people with a lived experience of the Queensland health system.

Health Consumers Queensland links health consumers with health staff and decisions makers to prevent disease, unnecessary and futile treatment, and improve health outcomes.

Training and skills development programs are provided to consumers and health staff, to maximise opportunities for consumer representation at all levels of decision making. Consumers are empowered to become meaningful, health literate contributors. Health staff are trained to partner effectively with consumer representatives.

Health Consumers Queensland maintains a diverse network of health consumers across all regions of Queensland who engage with health services across the state. These consumer representatives are networked to support each other through peer to peer exchange.

Continuing to invest in Health Consumers Queensland will deliver a health system that is focussed on consumers, driving improvements in quality care that leads to better consumer experiences and efficiencies for the system.

Investment needed –

- **Remainder of five year Queensland Health contract honoured to June 2023**
- **Recurrent future funding of \$1,037,204 per annum from June 2023 (CPI indexed)**

HEALTH SYSTEM BENEFITS DUE TO HEALTH CONSUMERS QUEENSLAND

- ✓ A health system that is responsive to consumer feedback that builds stronger confidence from all Queenslanders
- ✓ Co-designed services between consumers and clinicians that ensures safety and appropriate design
- ✓ Skilled consumer representation to advocate for more integrated care and better health outcomes
- ✓ Health service staff trained in stakeholder engagement and skilled in involving consumers
- ✓ Linking the lived experience of the health system with the decisions making process
- ✓ Early warning about issues that may be missed within the health system
- ✓ Experiences of individuals are translated into meaningful feedback for health administrators
- ✓ Consumers are a visible reminder of who health services are for.

“ Here in QLD, [consumers] have been included and asked for our opinions. All because of Health Consumers Queensland and [the] advocacy you do in promoting the consumer voice and [this is] why QLD is seen as Gold Standard of consumer voices during [the] pandemic. ”

Looking Back: How effective has the Queensland COVID-19 response been? (HCQ Community of Interest feedback 25 June 2020)

QUEENSLAND'S PANDEMIC RESPONSE PLACED CONSUMERS AT THE CENTRE

“ Rather than waiting for data - better predictive capability could have been obtained by listening to real life people's experiences. Patient experience is data. ”

In conversation: Consumer engagement in Victoria and NSW – Lessons learned during COVID-19 (HCQ Consumer Conversation session 10 August 2020).

In the COVID-19 crisis, Health Consumers Queensland pivoted and began collaborating on solutions in early March.

- Rapid and diverse consumer consultation through existing Health Consumers Queensland networks
- 32 consumer conversations hosted with 514 consumers
- 20 rapid consultations on challenges not seen before and involving more than 100 consumers
- On-line forum for First Nation peoples with 83 consumer attendees
- Brought together highly skilled consumer representatives from Hospital and Health Services, Primary Health Networks, and the Statewide Clinical Networks to work on COVID-19 challenges.

Health Consumers Queensland ensured that the Queensland Government heard from hundreds of Queenslanders from the early stages of the COVID-19 crisis and used that intelligence to form a wider reaching response. Health Consumers Queensland provided leadership and rapid linkage to the consumer voice.

This did not happen in southern states that have gone on to experience poorer outcomes and lose opportunities to alleviate issues where hearing the consumer voice would have made a difference.

Jessica Bean is a health consumer and now patient advocate, who knows firsthand what it is like to feel powerless in the health system. At 21 she was told she would need a double lung transplant to survive the damage caused to her lungs by cystic fibrosis. She turned the hardest moment of her life into an opportunity to not only take greater control of her health but to better understand the healthcare system. Today she still breathes through her own lungs.

Empowering other health consumers became her passion. She wants to ensure that they are truly represented in decision making across the health system.

“The strength of Health Consumers Queensland is that they are experts in how to engage with hard to reach groups and understand consumer communities. They do it efficiently and are agile. During the COVID crisis they have been able to get meaningful feedback from consumers, and quickly feed it back to decision makers in the health system.”

“Health Consumers Queensland reduce the burden on individual health consumers by amplifying their voice and connecting them with other consumers and decision makers.”

**JESSICA'S
STORY
HEALTH
CONSUMER
ADVOCATE**



“ *The power of Health Consumers Queensland is their ability to bring together health consumers from diverse backgrounds and give them a strong voice. Many of these people would otherwise not be heard. They are often from hard to reach, diverse and vulnerable groups who have valuable things to say, but may not know how to voice them.* ”

**NICOLLE'S
STORY
HEALTH
CONSUMER
REPRESENTATIVE**



“ *The biggest thing that women with mesh injury needed was acknowledgement that mesh was causing their health problems and an apology. Without Health Consumers Queensland this would never have happened.* ”

Nicolle Germano says that without Health Consumers Queensland she and other pelvic mesh injured women would not have the support and services that exist now.

After having four children, Nicolle was keen to return to work as a nurse and midwife. Before returning to work she had pelvic mesh surgery which has left her suffering from chronic pain, mobility issues that make it hard for her to walk and mental fatigue. Returning to the work she loved has not been possible.

For many years women with mesh injuries were not acknowledged so Health Consumers Queensland brought them together. “It was the first time most of us met someone else going through what we were experiencing. To finally have someone listen was a pivotal point which led to changes in how things are done.”

“Health Consumers Queensland gave us the confidence we needed to tell our own stories. They took our small voice and amplified it, uncovering thousands of women to help link our health issues back to the mesh implants. It's the bridge that brought health consumers and clinicians together.

This led to consumers being invited to co-design, along with clinicians, the Queensland Pelvic Mesh Service, the first of its kind in Australia.

A HISTORY OF RAISING SAFETY AND QUALITY ISSUES

Health Consumers Queensland was born from the safety and quality issues uncovered in the reviews of the system in the wake of the impact Dr Patel had on health consumers and Queensland's health system. Since its inception, Health Consumers Queensland has forged strong partnerships with the health system to reshape it so it's safer and more transparent. Where issues do arise we help to ensure that consumers work to remedy them alongside clinicians and other key stakeholders. When the health system, that is meant to provide their healthcare, is responsive to their concerns and suggestions, ensures their safety, and works with them to co-design services and priorities, then it builds a stronger confidence in the health system for all Queenslanders.

COMPLICATIONS OF PELVIC MESH

Health Consumers Queensland heard a number of individual consumer stories of great concern, brought women together to amplify their voice and advocated on their behalf at a time when few organisations across the globe were responding to these concerns. This has led to the co-design of a new state-wide service to provide mesh removal for women affected, and it's an Australian-first.

YOUNG PEOPLE AND THEIR MENTAL HEALTH

Health Consumers Queensland advocated for young people and their families about the impact on the health and wellbeing of young people in a long-term stay mental health facility. The organisation has continued to provide on-going critical support for both consumers and staff in the co-design and development of new services including Jacaranda Place, two new Step-Up Step Down services and two Day Programs and the inclusion of youth peer workers. The process of involving consumers and their families as key stakeholders in the design of models of care, service delivery and building design have won international respect and acclaim, including Best Paper at the Asia-Pacific Conference on Integrated Care in 2017 in Brisbane, and are leading to better outcomes for young people in Queensland.

AGED CARE, END OF LIFE CARE AND DYING

Health Consumers Queensland with COTA Queensland, Palliative Care Queensland and Carers Queensland collaborated with Queensland Health's Clinical Excellence Queensland to facilitate a targeted process of statewide consultation on "What Matters to you in relation to ageing, end-of-life care and dying." More than 400 grassroots community members shared their hopes and concerns on these important issues.

CONSUMERS ARE AN ESSENTIAL 'EARLY WARNING SYSTEM'

The health system has faced significant crises in the past that have led to poor consumer outcomes.

Where experts have failed to address risk, consumers have seen it and lived it. Gaps and solutions have been identified.

Health Consumers Queensland has been first to hear concerns from consumers, and is positioned to provide strategic advice and amplify the voices of consumers.

QUEENSLANDERS NOW EXPECT TO BE INVOLVED IN THEIR OWN HEALTH CARE AND IN IMPROVING THE HEALTH SYSTEM.

WITHOUT HEALTH CONSUMERS QUEENSLAND WE COULD SEE

- ✗ Consumer voices unrepresented and unheard by clinicians and decision makers leading to an unresponsive health system
- ✗ Reduction in patient safety and quality
- ✗ Gaps in service overlooked and un-remedied
- ✗ Blind spots, that can only be seen by those with lived experience, not detected until too late
- ✗ Poorer health outcomes and poor experiences of care