

Consumer Conversation: A seat at the decision making table

How can consumers influence funding priorities setting?

Summary:

- When going through tough times and when hard decisions are being made, it is more important than ever to involve consumers.
- Involve consumers from the start in the tough decisions which need to be made over the next five years. This will help to reduce the risk of poor decision-making by ensuring that more perspectives are considered and in the knowledge of how this will impact consumers on the front line.
- There is a real risk that the gaps will get wider for the State's most vulnerable communities – by involving these communities and consumers in decision-making you improve the chances of reducing this gap (rather than making it worse).
- Building trust and establishing effective collaboration mechanisms required for this level of influence at the priority setting point across Queensland Health is one challenge.
- Getting a commitment from and establishing effective mechanisms with the Boards of all the Hospitals and Health Services (HHSs) for consumers to have a similar level of input will be another as Hospitals and Health Services are separate statutory bodies.
- Learn from examples of good consumer engagement and focus on engagement that makes a positive impact.

A watershed commitment for consumer engagement in deciding funding priorities

As the State faces an uncertain economic future with the pandemic draining the public purse, a looming recession and a significant burden of chronic disease and health inequity, key decisions about funding, resourcing and service priorities are only going to get tougher.

However, currently, consumers do not have a seat at the table to help shape these decisions even though their health care and health outcomes are directly affected by them.

At Health Consumers Queensland's latest Consumer Conversation on how consumers can have a seat at the decision-making table to influence funding priorities, 27 consumers welcomed a commitment from Nick Steele, the Deputy Director General of the Healthcare Purchasing and System Performance Division at Queensland Health, to approach the Leadership Board about involving consumers from the start in the tough decisions which need to be made over the next five years.

Nick said: "Consumer engagement is important all the time but it is even more important when we're going through tough times financially because we've got hard choices to make and to make those choices without consumer engagement is the wrong thing to do and a real risk...We need to be brave and have these conversations."

“It doesn't mean we'll agree but we have to understand what these decisions mean for consumers on the front line.”

Nick's commitment was a watershed moment for health consumer engagement and partnering. It came after the last Consumer Conversation*, where consumers told Health Consumers Queensland it is no longer enough to simply be informed that they are 'at the centre' of Queensland Health decision-making (link to Steven Miles letter). Consumers identified an urgent need “to have a seat at the table” - to be meaningfully involved in shaping Queensland Health's funding priorities wherever and whenever key decisions are being made. Consumers see an urgent need for this to happen to ensure the gaps don't get wider for the State's most vulnerable.

It's time for bold and brave conversations: What does this commitment mean for the future of meaningful consumer engagement across the public health system?

This bold and brave Conversation also highlighted the need for further courageous conversations because the current ways of engaging are not meeting consumers' or frontline staff needs at a time when the consumer voice is more vital than ever.

Consumers and Nick both agreed that building trust and establishing the effective collaboration mechanisms required for this level of influence at the priority setting point across Queensland Health is one challenge. Getting a commitment from and establishing effective mechanisms with the Boards of all the Hospitals and Health Services (HHSs) for consumers to have a similar level of input will be another as Hospitals and Health Services are separate statutory bodies.

One consumer expressed her frustration, “There is a disconnect between what we're hearing you [Nick] saying now and what's happening in HHSs. They are making decisions which consumers have no input in which are all about the dollar but it really impacts care.”

Another consumer who sits on an HHS Safety and Quality Committee added, “I believe without exception, [his HHS] is dedicated to providing the best healthcare they can... I'm not sure that necessarily translates into consumer-focused services at the doctor and nurse level.”

This level of disconnect and the lack of importance and value placed on consumer partnerships by some HHSs reveal a public health system which has become complacent about a model of consumer engagement which is no longer meaningful or meeting anyone's needs.

Although there are plenty of ways for consumers to be engaged across the State, consumers and Health Consumers Queensland reported that engagement can be inconsistent in quality, frequency and extent, and can be dependent on where you live and who is engaging with you.

Often consumers are brought together with engagement staff who are under-resourced, juggling different roles and have little influence in the decision-making arena. All too often, it is too little, too late, and nothing more than a tick box exercise.

This perpetuates a cycle of distrust, fear, disconnection and frustration amongst consumers, carers, frontline staff, engagement staff and the Department and can lead to care that appears, feels and, sometimes, is unsafe – and leaves consumers voiceless.

Yet, time and again, Queensland Health has demonstrated that it can be brave when it really matters:

- Jacaranda Place, the new adolescent extended treatment centre in Chermside, Brisbane and the Pelvic Mesh Service on the Gold Coast, were co-designed from the beginning with consumers. These services demonstrate the successful outcomes which can emerge from tough, traumatic starting points when consumers and health staff are empowered and supported to partner within a meaningful framework and mechanisms.
- The COVID-19 public health response. Following an exceptional example of professional courage from Health Consumers Queensland's Melissa Fox, when she issued a stern reminder to include consumers, Queensland Health has involved consumers right across the system to help shape its successful pandemic response. The wealth of innovation and level of flexibility to adapt to new models of care and keep listening to consumers has increased trust and confidence in the system.
- The historic appointment of consumers to all but one of Queensland Health's Tier 2 System Advisory Committees to enable greater transparency, accountability and scrutiny to help improve efficiencies and ensure the right decisions are being made.

It's time to do things differently: Recommendations from Health Consumers Queensland and consumers

During this year, we have all learned to guard against complacency and this extends to guarding against slipping back into a default approach to consumer engagement just as we head into possibly the toughest three to five year period in Queensland Health's history. Enough lessons have been learned as demonstrated by the bold and courageous consumer partnership conversations listed above. Whether we like it or not, there are going to have to be radical changes to the way everyone thinks, feels and behaves around health in Queensland.

Going forward, consumers want to be assured that the process of funding services is transparent and that priorities reflect their input. But the way we need to have these difficult and brave conversations needs to change. They need to be held in spaces which feel safe for consumers and the people who currently influence decision-making within the Department and amongst the Boards of each Hospitals and Health Service – and all the relevant people need to be around the virtual/actual table defining the questions, establishing the mechanisms, listening together.

How else can engagement be done differently:

- Increase the focus on outcomes: In relation to healthcare needs assessments: people are tired of being asked questions but never seeing any changes.
- Engaging with consumers early means starting even before priority setting. It means shaping the questions which needs to be asked in the first place together with consumers and following through to priority setting, implementation and monitoring of outcomes.
- Increase the number of consumers involved in a project or activity and make these more inclusive.
- Some consumers want to tell their story rather than sit on committees. It's time to start seeing the collective picture which these stories can represent.
- Start replicating the successful examples of consumer partnership.
- Accept that meaningful consumer partnership takes time but the outcomes are often better.

- Listen to consumers about what matters to them: For example, during today's conversation, consumers urged Queensland Health to focus on prevention, addressing health inequities and prohibitive parking costs, measuring outcomes rather than endless needs assessments. They also asked about the status of bundle pricing, partnering-style service agreements, the implementation of PREMS and PROMS
- *an incoming brief to the newly elected Labor Government was prepared by Health Consumers Queensland following this Conversation. It set out the key priorities and solutions as identified by consumers to shape the focus of the public health system during the next four years. (LINK)