

*We are still feeling lost. And we have questions.*

## What Queensland health consumers are saying this week

### Key consumer concerns

**Health consumers this week are worried that waiting lists are blowing out after Omicron.** They are asking *Why have some health consumers' or carer's voices been heard above others when they have been trying to access the care they need? Who is taking responsibility for following up with them now following delays, cancellations and closures? When will the health system re-design the waiting list system (with consumers) so it's more empowering, and facilitates consumers' informed choices and decision-making?*

**Many consumers are still isolating and concerned that a COVID diagnosis will be life threatening to them.** They are asking *How can the health system now work with consumers to reduce their fear, anxiety, isolation and stress around COVID-19?*

**They can't see that the health system has a plan for long COVID.** They are asking *How are consumers with long COVID or who develop symptoms linked to having COVID further down the track, being monitored, followed up and cared for?*

**They want to work with the health system to make sense of the past eight weeks.** They are asking *Why was the health system unprepared for Omicron, after a two year head start?*

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### Getting consumers back on track with elective surgery, treatment and screening

Following the postponement of surgery, treatment, screenings etc, consumers are now reporting being lost in the system even when they were previously already in the system. "No one is taking responsibility for following up and getting people back on track."— especially if multiple specialties or locations are involved. In turn this limbo state is creating other blocks e.g. being unable to get medications because they cannot get scripts.

One experienced consumer representative who had to advocate strongly for his wife's surgery, said that he pitied consumers who were less confident and who were not well enough to push for the surgery or treatment they needed at this time.

Pre-existing relationships with health staff also contribute to better care outcomes according to one consumer. For example: renal dialysis units across the State have reported good outcomes from patient care during the Omicron wave. She put this down to great preparation for COVID on the part of staff, high quality communication e.g. regular phone calls, and the fact that she sees the same staff constantly as the consumer attends the unit twice a week.

In contrast, a transplant consumer who sees health staff on a quarterly basis and has moved to a different HHS, described being left in the lurch. "I don't know what's happening or whether I'm going to hear from anyone. If they don't know you, they don't care."

### *Listening, advocacy, support*

The health system has been listening to some health consumers when getting care (those who are confident enough and well enough to push through the barriers) but other people when trying to get care have reported not being heard or feeling silenced e.g. people with brain injuries, people who have had ME or people from culturally and linguistically diverse backgrounds. One consumer who has faced discrimination said, “My voice doesn’t count. And I have had enough.” **Pathways to care need to ensure that every voice is valuable, every person deserves the opportunity to advocate for their own best health care, and to be heard and considered.** Consumers see nurse navigators and liaison officers as key allies at this time particularly when conditions may need multi-disciplinary care and across different locations. These key members of staff can be resourced and prioritised to further support consumers to advocate for their care more effectively.

### *Consistency, openness and transparency*

When turning services back on, **health care services need to ensure key decisions are being made that are consistent across the state** (to avoid a postcode lottery) and that **all consumers on waiting lists receive information about what’s to come.**

This has been an anxious time for many, and especially for those on waiting lists for care that will improve their health (and who are scared that more delays will lead to greater chance of poorer outcomes). **An improved waiting list system** will empower consumers to make informed choices and decisions about their health care pathways. There is an urgent need to consult with consumers and co-design a waiting list system which has openness, transparency and two way communication at its heart. A starting point is asking the question: “So, you’re on a waiting list. What now?” What does it mean to have been assigned to a category, who and how have your circumstances been assessed, what will happen next, who is involved in your care, and what do I do if I’m getting worse?

### *Putting a plan in place for long COVID consumers*

A consumer who developed further debilitating symptoms after previously having SARS, asked the health system to demonstrate its commitment to a plan for monitoring and following up people who have had COVID. **Consumers want to ensure treatment and support can be offered to those who develop long COVID or who develop symptoms down the track which can be linked to their original COVID diagnosis.**

### *Why was the health system so unprepared for Omicron?*

Consumers are angry, incredulous and feel let down and shut out by the health system’s response to the Omicron wave after it had almost two years’ to plan and learn from what was happening across Australia and around the world. For many, resources and care plans have come too late and now the health system has signalled it must move forward, whilst consumers still have many unanswered questions. **They want to work with the health system to make sense of the past eight weeks and feel confident about preparations for the next wave/variant.**

“Omicron has been overwhelming in so many ways” said one consumer and he described the difficulty of being able to let go of the fear and anxiety caused by the past eight weeks. **Evidence based, compassionate, co-designed information is needed to support vulnerable consumers to make informed decisions about continuing to isolate.**

For all HCQ Issues Papers: COVID-19 click [HERE](#). For more information: Melissa Fox, Chief Executive Officer: [melissa.fox@hcq.org.au](mailto:melissa.fox@hcq.org.au)