

HCQ listening to consumers during COVID-19: What's working & what's not

CONSUMER THEMES THROUGH COVID-19

Health Consumers Queensland has been facilitating Consumer Conversations since 25 March to hear directly from consumers during COVID-19. Since then we have held 26 sessions with more than 500 consumers. The early conversations were during a lot of uncertainty as public health restrictions were being imposed and we simply asked “what is working, what isn’t and what are you concerned about?” As the curve began to flatten, we refined the conversations to focus on specific topics, based on what we were hearing from consumers. Consumers routinely identified early key issues for the community, which we were able to feed through to the health system. This enabled the system to respond in the knowledge of consumer insights and expectations.

Since mid-April, HCQ has been writing an Issues Paper based on each week’s Consumer Conversations. These are all [available on-line](#) at www.hcq.org.au and include:

- Mental health
- Telehealth and virtual care
- Who is being left behind?
- Positives and innovations consumers want to keep
- Consumers delaying healthcare during COVID-19
- COVID-19 Testing
- QLD Health funding priorities 2020/21
- Safety in healthcare during COVID-19
- Re-balancing the health system: Providing care and being prepared for COVID-19

SUMMARY OF KEY THEMES FROM ALL THE CONSUMER CONVERSATIONS

Valuing the consumer voice and co-designing system responses

In a time of rapid change and uncertainty, consumers intuitively understand that their involvement in system-wide and local Hospital and Health Services (and other health provider) responses can help to increase the chances that the right decisions will be made, and communicated effectively, to consumers and community. Consumers understand that their living experience and insights can improve and strengthen the health system response during a global pandemic.

Consumers value the chance to come together regularly to discuss their living experience of receiving healthcare (or not) during these times, their concern for other priority population groups and to hear the perspectives of other health consumers in different circumstances.

Consumers want to co-design system-wide and local HHS (and other health provider) responses and decisions regarding policy, planning, service delivery, communication and more. Consumers understand that their collective experience is critical to the implementation of an effective pandemic response (while at the same time balancing the needs of those who continue to require healthcare that is not COVID-19 related).

Consumer representatives from across Department of Health committees and HHS committees report a variability of their involvement during COVID-19. Some consumers are more involved than

ever before on very important decisions, and some committees have completely excluded their consumer reps from critical decision-making.

Recommendation: Collaborate with consumers more.

Strong desire to use the disruption of a global pandemic to transform the health system

Consumers would like for the health system to use this opportunity to make significant changes to the health system including:

- the way in which consumers are viewed (from passive users of the system to active decision-makers of the system and of their own care). Consumers want to be actively involved in their own care as well as system-wide planning, policy and decision-making.
- more collaborative decision-making that is timely and less bureaucratic.
- decision-making that is collaborative, transparent, and focused on the greatest good. They are happy to see the demise of decision-making that is siloed, slow and overly bureaucratised.
- a more balanced perspective on risk. Pre-COVID-19 it seemed that decisions took a long time to be made as key health leaders worried about the risk of those decisions. During COVID-19 the view of risk shifted, with health leaders understanding that there was more risk in doing nothing. Consequently they made decisions knowing that if they didn't work out, they could adapt them, tweak them, learn from them. Consumers valued this responsiveness that saw telehealth suddenly unblocked and clinicians trying new ways of providing care.
 - In the early days of the pandemic there seemed to be a greater autonomy for clinicians and local service providers to do what they needed to do to ensure they were prepared for any over-demand on the health system.
- consider new ways of funding healthcare that focuses on people's health outcomes and experiences more than on just 'doing something'
- reprioritising the way people wait for surgeries and treatments so that those people can be involved in those discussions – currently it is all based on clinical need without looking at the impact on the whole person/family unit.

Recommendation: Capitalise on this major disruption and transform health care by working in strong partnerships with consumers.

Communication and consumer informed decision making about accessing care:

- People living with chronic conditions, or with complex care needs, or with a disability, identified in the early days of the pandemic they were not receiving the information they needed in order to keep themselves safe, and to help with their decision-making about when and where to receive care. Key messages were being largely prepared for healthy Queenslanders, not those people who were already 'in' the health system. We have fed this into various parts of the Department, however it continues to be an issue. The system needs to communicate the right individualised and localised messages to people with extra health care needs, for as long as COVID-19 is a threat.
- Improved levels of health literacy in the community as a result of COVID-19 require health staff to have different conversations with consumers. COVID-19 has required us all to become more comfortable with ambiguity, and consumers want to hear their options and make informed decisions about care together.

- Consumers are keen to hear the evidence behind decisions, not just what the latest rules, guidance or policies are.
 - Currently consumers want to know what groups of people are getting surgery, which aren't, what is being done to manage wait lists and to re-prioritise care if needed and the evidence/rationale for these decisions.
 - Consumers hear that hospitals are safe, but before going to hospital they want to know how they are being made safe, what screening measures are in place, the physical changes being made to waiting rooms etc. It's not enough to just 'trust' the system that adequate measures are in place.

Recommendation: Recognise the social capital and connections available from the consumer-world and tap into these to inform communication, particularly communication aimed at those who require focused health attention and are likely to be impacted most by these decisions.

Communication – mass

Consumers are keen to lead the next phase of messaging to show the importance of physical distancing for vulnerable people – consumers would like to put a face on what vulnerable looks like. One consumer said he is walking a fine line “between diligence and paranoia” and would like to contribute to messaging for people to understand the continuing importance of physical distancing, particularly when restrictions have eased for the mainstream community.

In fact, consumers have been very keen from the on-set of COVID-19 to be more involved in message framing. Consumers have been able to review messages and community campaigns once they are complete but are not involved in the early phases of the development. They are keen for this to change.


Consumers in regional areas have also highlighted that in previous emergencies such natural community members hear from trusted, authoritative locals. Receiving communication from trusted sources is important, and for many people those trusted sources vary. Consumers would like more opportunity for local health providers (whether it's a HHS or an Aboriginal and Torres Strait Islander Community Controlled Health Organisation) to tailor messaging specific to their local community, while noting the importance of consistency of messages between local, state and national sources. People from First Nations and culturally and linguistically diverse communities have a particular reliance on established trusted sources of information. Ensuring a mechanism that allows for consistent messaging across Queensland but using the right spokespeople is critical to ensure the messaging is understood and acted upon.

Recommendation: Create communication campaigns with consumers playing a leading and active role.

Concern for others – an inclusive and equitable system

Many consumers are concerned for people who are being forgotten about or left behind during COVID-19. This includes people living with a disability and/or chronic condition including people who are immune-suppressed. It also includes First Nations consumers who are also living with a disability and/or chronic condition, and culturally and linguistically diverse consumers.

Consumers are also concerned about others whose circumstances have changed and created new challenges for them including those people who are at risk of homelessness, international students or new arrivals who do not have access to Medicare-funded health services, and people who have recently lost their livelihoods/incomes.



The digital, financial and communication divide can increase the risks for those who are already vulnerable. Those who need to remain in isolation to protect their own health as restrictions ease for others are of particular concern. This needs to be actively monitored and measured, and those groups included in decision-making wherever possible.

Recommendation: Monitor and measure the impact COVID-19 is having on the people most at risk of being left behind. Involve these consumers in co-design to ensure the health response meets their needs.