

Positives and innovations consumers want to keep after COVID-19

Health Consumers Queensland has been running a series of Consumer Conversations for the last 2 months to hear directly from consumers during the global pandemic. We have previously produced summaries of consumer feedback on the key themes on *Rebalancing the health system* and *Delaying healthcare*.

During the week beginning 4 May, Health Consumers Queensland ran three separate consumer conversations with 37 consumers from across Queensland on *success stories which are coming out of the public health system's response to the crisis*.

- Experienced consumers (10): Statewide HHS CAG Leaders, consumers members of the Health Consumers Collaborative of Queensland and HCQ's consumer advisory group
- Community of Interest (15): comprising more than 120 consumers from across the state, very diverse group with cultural, geographic, financial, and (dis)ability and health experiences.
- Consumer representatives of Statewide Clinical Networks (12): A group of experienced consumer representatives

Consumers outlined what they would like maintained during COVID-19 and beyond:

Improved consumer engagement

- Online video conferencing has opened up and democratized opportunities for consumers to engage more frequently, more meaningfully and on a much broader range of issues with more diverse range of health consumers and carers than traditional engagement methods.
- Opportunities such as HCQ's Consumer Conversations and the Director General's VideoCast have signalled that the health system wants to listen and respond to consumer input.
- Timely consumer involvement from the early stages (of some key projects) has made a huge difference.
- Efficiency and speed of consultation turn around.
- Improved access, equity and transparency in decision-making. Consumers highlighted the need to maintain this level of consumer involvement.
- Groups with some of the greatest health needs have been able to engage in conversations that shape decisions including First Nations and rural and remote people, people living with a disability or chronic health conditions, or culturally and linguistically diverse people have been given a seat at the engagement table.
- Consumers are better informed and better connected e.g. information sharing into consumer networks and into local HHS groups.
- COVID-19 has created a sense of urgency and a need to collaborate with all stakeholders. For this level of consumer engagement to continue consumers identified the benefit of shared goals and mechanisms/willingness to continue to partner.

Decision making – at system level and point-of- care

- Consumers can see that the health system has changed its decision making and value the new: collaboration, speed, transparency and shared vision.
- The Renal Clinical Network and AKC2026 have come together almost as a single entity to make decisions and ensure care for people with renal/kidney disease is fit-for-purpose during these changed times.
- A new maternity decision-making group has formed with Directors of Midwifery, Obstetrics, consumers and key Department staff. Consumers value this group's ability to make decisions on clinical care, pathways, place of birth and communications to families receiving maternity care.
- HCQ has a seat at many decision-making tables, which allows the organisation to provide timely, and diverse consumer experiences and perspective on issues on the agenda. This effectiveness supports better real time understanding of the experiences of consumers in response to the health system across the state.

Queensland Health has shown greater transparency and collaboration between staff and leaders across the system

- Consumers recognise that the COVID-19 pandemic caused massive levels of change in the health system. Disruptive change on many issues that have been discussed for years was implemented rapidly. Collaboration and inter-professional relationships between staff has made decision-making more efficient and effective. People in the health system now value learning from each other and can see what they are gaining through collaboration and openness. They are growing in confidence that it is safe to do this and want to hear this from consumers.
- Consumers have also seen health staff working collaboratively with each other and across different health sectors. In contrast where there are pockets of staff that are (still) working in silos, it is now glaringly obvious.

Consumer vignette:

A mother shared how a decision about her child's care that would normally take a few months to make was made in 30 min. The head of each department providing care for this child, simply got on the phone and talked to each other to collaborate on decision-making about her care and treatment. This bypassed many messages, delays and enabled shared understanding on the needs of the child leading to an efficient and effective decision.

What are the efficiencies of care to keep?

- Access to telehealth (discussed further in the next section)
- Development of new models of care and guidelines that will serve beyond COVID-19 e.g. end of life, dementia care.
- Great opportunity to have long-overdue conversations on low-value care treatments/ surgeries and to drop these in favour of high-value care that optimizes investigations and to de-prescribe medications.
- Ethical decision making framework – co-design between consumers and clinicians. Involvement of clinical ethicists (it was even suggested that one be available in every health service). Real awakening of decision making and dilemmas that need to be discussed and resolved in a collaborative way alongside consumers and carers. Innovative processes to

ethical dilemmas especially on equity and access. Ensure that organizational values are aligned with staff behaviours and actions.

- Elective surgery – Use principles of value based health care to rethink and reprioritize surgery and wait lists.

Telehealth and virtual wards and hospital in the home

- Telehealth has been a success story on many levels.
- It has enabled rapid access to care and equity of access in both metropolitan areas and particularly across rural and remote Queensland. The ability to have a consultation or assessment with a health professional has saved consumers time and money.
- It does not replace the importance of human connectedness or the need for appropriate face-to-face appointments and examinations but for certain consultations it is valuable.
- Consumers want to keep Telehealth and continue to improve it. Going forward the lack of internet access for many people must also be addressed.
- Health Consumers Queensland has suggested that Telehealth could co-design information for consumers about telehealth including what it is, how to use it, what are the costings for consumers etc. Telehealth is keen to work with consumers to further improve both the current experience of receiving care via telehealth and information about it.
- Consumers also identified a need to continue Medicare funding for telehealth post COVID-19. Additionally, they would like longer consultations via telehealth funded by Medicare.
- Technology to enable medical care and monitoring in the home is supported by consumers especially those who live with a disability. This means people can receive the care they need from the comfort of their own home with enormous benefits for them.

Consumer vignette:

A consumer with significant disabilities from the Townsville region normally has to access his specialist health care in Brisbane which means having to travel down a couple of times a year. He requires high intensity support to be able to attend these appointments and it can take up to two months to organise with doctors, NDIS and care workers. As he is high risk he has been told he must isolate for many months but he can now speak to his specialist and GP regularly via telehealth from the comfort of his lounge. He is still unable to have MRIs, specialised testing or planned surgery locally but telehealth has relieved the considerable strain of having to travel regularly to Brisbane for consultations.

Increased health literacy has changed the conversations consumers want

- Levels of health literacy have increased and become more sophisticated amongst consumers. There has never been this level of respect for science and maths.
- Improved levels of health literacy require health staff to have different conversations with consumers. COVID-19 has required us all to become more comfortable with ambiguity and to be able to present different options and make informed decisions about care together.
- Consumers want more nuanced information including the evidence behind key decisions. This is reflected at both a whole of community level and at the point of care.
- In a post-COVID world, the ability to communicate authentically and to make information relevant will be critical in building continued trust and collaboration with consumers and community. Consumers no longer want to be told. Instead they want to explore the issue or problem alongside a health professional and take on board information which has been made relevant to us. It's time to talk "with" us and not "at" us.

- This in turns means that consumers will be expecting to have different conversations with their health professionals around the benefits, risks and alternatives of proposed treatments
- People are now in the habit of looking at QH sites and platforms for trusted information on COVID-19. There is an opportunity for QH to capitalise on these new behaviours and levels of trust to increase people's awareness about chronic conditions and how people can look after their own health. Many spoke of the opportunities for prevention and well being.
- Part of the uncertainty, confusion and reticence from some people who feel unsafe accessing care in hospitals and primary care at this time comes from unclear messaging and the overwhelm of COVID-19 TV programming. Consumers would like one daily, short, sharp briefing from Queensland Health (eg. 5 minutes). They would like to know they could tune in at the same time each day (television or Facebook) and be told any new, important information that would guide their decision making about accessing care and moving about in the community.

Mental health given equal weight alongside physical health

- Stigma associated with mental health has been reduced.
- Amount and availability of high quality information and support has signalled the importance of a holistic approach to healthcare.