

## Where are we at right now?

### Consumer experiences of health services as COVID-19 restrictions ease

17 July 2020

In late April 2020, Health Consumers Queensland asked consumers about their experiences of healthcare during the very first easing of the COVID-19 lockdown. Procedures that had been delayed or cancelled were restarting, but consumers shared that they were unsure about accessing care safely. Many reported feeling uncertain and confused about when, if and how they could have their healthcare needs met.

Ten weeks later in Queensland, restrictions have eased significantly and healthcare services are beginning to return to almost full operation.

At the same time, parts of Victoria have gone back into lockdown and parts of NSW are seeing an increase in positive testing results, with community spread in both states.

Against these opposing backgrounds, Health Consumers Queensland asked 28 consumers and consumers representatives from our COVID-19 Community of Interest, Health Consumers Queensland's Consumer Advisory Group, the Health Consumers Collaborative of Queensland, Primary Health Networks and Statewide Clinical Networks steering committees about their current experiences of health care.

Consumers were asked:

1. If you were waiting for treatment that was delayed due to the pandemic, have you received updates on when that treatment will be available to you?
2. Who provided you with care during the pandemic?
3. Are you getting the information now that you need to support you, such as information about how your health service is being kept COVID-19 safe, or alternative ways of receiving care?
4. Every Hospital and Health Service is responsible for developing their own plan to re-open services. Have you been involved as a consumer rep in these plans for your local HHS?

Consumers highlighted a range of concerns that were top-of-mind for them at the moment. These included:

- Inconsistent approach from hospital to hospital of informing patients about their expected wait times for surgery, procedures and outpatient appointments. There is a need for clear and transparent information about what is 'back on', what isn't and the timeframes involved on various waiting lists.
- Are hospitals doing all they can to protect us?
- Importance of clear communication and provision of information in language that is easy to understand for CALD consumers and those with low literacy
- Concern about the impact of complacency by some members of the community around social distancing and a subsequent increase in transmission.

### **Updates and information about treatment are inconsistent**

A number of consumers reported significant variation in the level of communications and updates from hospital and health services. *"I have been on two different hospital wait lists for cat 2 and 3 at two different HHSs. It has been interesting to observe that for my more urgent surgery I hear nothing. [The other] hospital is really regular at communicating to me and updating."*

Timely support for current patients is important but one consumer reported that clinics are not responding to requests from GP or patient regarding treatment, options and symptoms.

Consumers also reported that in the case of public dental services, all services just stopped with no information given. However, one consumer also reported that she was able to get an appointment for an urgent dental matter very quickly.

Some consumers felt the onus appears to be on them to find out and ask for information and updates rather than this information being provided in a routine or consistent way by service providers.

### **Barriers to information for CALD consumers or consumers with low levels of health literacy**

Placing the responsibility for information gathering on the consumer has considerable implications for CALD (culturally and linguistically diverse) consumers or those who may have varying levels of health literacy and be unfamiliar with navigating the public health system.

Concerns were raised about the provision of up-to-date translated information and the availability of interpreters for consumers whose first language is not English. Consumers also raised concerns about the complexity of the messaging around COVID-19 health service protocols and urged the health system to consider the health literacy levels of all members of the community and tailor these accordingly. One consumer suggested: *"At the very least put phone hotline numbers in different languages so CALD persons can ring. This could be done immediately, rather than wait for other communications to be translated."*

Currently there does not appear to be a standard protocol for requesting a translator and consumers explored how this could be improved. *In Townsville, for example, when a member of the CALD community visits a GP, the Townsville multicultural support group has pre-booked the CIS interpreter for them.* Another consumer suggested that an interpreter option should be automatically ticked on a booking form if appropriate.

During the conversation consumers said that HHSs don't consistently record languages that consumers speak in the electronic medical record. According to other consumers, information about disabilities is not captured either. Consumers consider this is incredibly vital data which can give rich information about consumers and their needs to enable health service communications to provide the right information in the most effective ways.

Another consumer said he would welcome and like to be a part of a working group which engages with community groups that relate to those people to help facilitate the flow of communication from the health service.

### **Services not yet back to full capacity**

One consumer was quick to praise the public health system's care during the past ten weeks. *"Thumbs up to the system – [I] had three family/friends in surgery. We were delighted with the care"*

*we received for my husband. Lots of telehealth appointments and phone calls – all this worked really, really well.”*

However, the experience of other consumers highlighted the need for the health services to be transparent about services that are still suspended or will take more time to get back to pre-COVID-19 levels of activity. This includes a lack of support state-wide for women who are breastfeeding, a significant drop in cancer diagnoses and an ongoing suspension of transplant programmes.

### **Ongoing confusion about wearing face masks – making hospitals feel safer**

Uncertainty about whether hospitals and other health services are safe still exists with one consumer stating that she felt that businesses are being more proactive than hospitals, in visibly demonstrating the protective measures that are in place to protect themselves, customers and their businesses.

In terms of the system demonstrating COVID-19 safety measures, a consumer attending an outpatient appointment at a hospital noticed: *“We have been concerned about going out without a mask – there was no medical staff wearing masks but [the hospital] had in place all other hygiene protocol. But we were concerned that there was no use of masks. The fact that I was wearing mask – [meant] others backed away from me!”*.

After her husband was admitted to a ward, she also noted: *“The wards in hospitals are fairly enclosed spaces, often with quite a lot of people coming in and out. The patients themselves have various levels of health which may include transmissible diseases e.g. one of the blokes had a heavy duty cough. In the present COVID climate, it would be more than reasonable to consider providing people with masks to reduce the risk of transmission, including from one patient to another.*

Consumers are looking at Queensland Health to take the lead on signalling that its facilities are safe. This is particularly important as there is a growing sense amongst consumers that hospitals should not take people’s word for it when they say they do not have COVID-19 symptoms. These signals could take many forms including the physical and visible presence of protective measures, and clear communications about the hospital’s position on staff and consumers wearing masks.

### **Consumers on waiting lists are falling through the cracks**

Yet again, the responsibility for ensuring that consumers are still on the waiting list sits with the consumer who must contact a service if they are concerned they have fallen off the list.

*“I needed to call the hospital to ask when my appointments that had been postponed during the lockdown would happen. They called me the next day apologising that I’d slipped through the cracks and they acknowledged I should have been seen and needed to be seen urgently. They did then get me appointments for the two urgent areas I needed to see within the next week.”*

Some consumers shared how in the past (pre-COVID-19) that it’s possible to fall through the cracks.

*“I had the experience of disappearing from waiting list with dental general checkup. Expected waitlist was 12 months. Called after 13 months and told not on list. Added to list but still another 12 months plus wait.”*

The system needs to give urgent consideration to improving both the waiting system processes and communications to consumers about this, to maintain consumers’ trust and faith in it in light of:

- Waiting lists having grown during this time

- Waiting times will now be considerably extended
- It is expected to take up to 12 months for the public health system to address the backlog

Consumers are keen to get information about how referrals will be prioritised: *“Can we have it certain and explicit that priority will be based on historic date of referral, rather than currently denoted by new referral?”*.

Another suggestion to improve the current system is to automate a monthly update on a consumer’s position on any waiting list.

One consumer, who attends hospital regularly and sits on many committees, wondered how Queensland Health could support a clearly exhausted workforce whilst ensuring that consumers who have been on waiting lists for years do not miss out on the care they need.

### **Consumers and services are interpreting changing rules and guidance to suit their own circumstances**

With new advice from the CHO on hospital visitors (patients can now have 2 visitors at the same time, for as long as they want during visiting hours; and no age restrictions on visitors) consumers discussed how these kind of directives are interpreted and implemented (by consumers and organisations).

*There is significant variation in how aged care establishments implement visitor numbers and procedures... to be fair, those that are over-the-top-restrictive e.g. have to book in at least 24 hours before, are operating with fear - a slipup can be catastrophic - but [residents] are typically very isolated from what outside circumstances are, they just see it's more difficult for their visitors to get in.”*

Fear of having services withdrawn is also driving consumers with disabilities who require support services to make decisions about what they will disclose on COVID-19 questionnaires and surveys. *“Asking if we have any flu like symptoms? People would lie to get the service. They aren’t going to disclose every sneeze in the disability sector or we will lose our support workers.”*

### **Is complacency setting in?**

Consumers shared the view that COVID-19 is like “a ghost” which will be with us for a few years until there is a vaccine.

*“All the older people I have been talking to - we are thinking that we will have a big second wave. This will be a big and a real problem. We are opening up too fast in QLD.”*

Despite this fear, they observed that complacency was setting in throughout the state, social distancing is not taking place in public spaces and guidelines are not being imposed consistently across Queensland. *“People are not wanting to listen to the messaging now. There's little attention to social distancing and hand hygiene happening in rural and regional communities.”*

Another consumer representative reported that testing numbers are down at her HHS – *“people see it as an inconvenience and don’t go [to get tested] as they have to self-isolate till they have results – this is a barrier.”*

Consumers feel that in order to avoid finding Queensland in the same circumstances as New South Wales or Victoria, we need strong messaging around not being complacent with social distancing, hand hygiene and staying home when sick.

## Recommendations

- Queensland Health needs to take the lead in providing consistent, cohesive affirmation and reassurance that the safety, health and wellbeing of every Queenslander is the driving force behind its pandemic response.
- Communications which address key concerns such as safety, what services are operational, waiting lists and response times could be part of an over-arching, state-wide system response rather than making it the responsibility of individual HHSs.
- Then, as part of a tailored, individualized response, individual hospitals and clinics could manage their own communications (based on key consistent messages) as part of keeping consumers informed and up-to-date.
- At all levels, high expectations around communications need to be set and maintained to prevent consumers having to take what can feel like sole responsibility for managing their health care.
- Communications teams should also pay particular attention to narrowing the digital divide at this time and avoiding an over-reliance on digital media and ensure all communication channels are utilized (including local radio, print press, appointment letters).
- Consideration of how the workforce can demonstrate and embody these messages around safety and a sense of “we know what matters to you” is a further important step which will build confidence and trust amongst consumers at this difficult time.