

“We are not just statistics. We are people.

And we need to keep telling our story.”

What consumers are saying this week

This week’s HCQ Issues Paper brings together information from health consumers, consumer organisations and NGOs, and some professional organisations collected by HCQ via:

HCQ Coffee and Connect On-line Session #6: consumer attendees from SEQ, Townsville, Mackay, Cairns and Roma.

How you are going living with COVID - Tell HCQ what is happening is an on-line engagement tool for consumers.

HCQ Consumers, Community, & Clinicians COVID (C4F) Forum (3 meetings/week) a HCQ online forum for consumer representatives, consumer organisations and professional organisations .

Key issues

- People with disability and other ‘at risk’ people including residents of RACFs are feeling a **sense of abandonment and disregard for their lives. They are increasingly angry** at the perceived lack of inclusion in decision-making and communications.
- **Consumers are concerned about how backlogs and waiting lists** for elective surgery following cancellations, closures and deferrals are being managed. Need transparent communications about this.
- **Telehealth and virtual care** have huge potential but is it always safe, consultative and high quality?
- **Learning lessons for future COVID strains** Consumers have an expectation that the same mistakes are not repeated. Take the time to identify key lessons from the Omicron wave, so when the next wave of COVID comes, the system is prepared and ready to protect our most vulnerable. Ways to ensure rapid policy decisions are made to ensure timely to models of COVID care and communications which are co-designed with consumers, carers and clinicians.

We have every right to feel angry

“Please do not feel for a moment that we are unjustified in feeling as we do. We are not being negative. We have every right to feel angry. As the wider community goes back to life as usual, that can and will not happen for many of us. When we have feelings that are not in line with the wider community, we are not being pessimistic, we are being realistic and pragmatic.” Consumer.

People with disability and vulnerable people feel neglected and disregarded by both levels of government. Many feel they are left with no choice but to remain locked down at home given the life-threatening risk to many if they are infected with COVID-19.

There was further frustration that additional money is being made available for aged care support workers, but not disability support workers. *“It is just dividing people who are already disadvantaged into smaller groups. Heaven help you if you are living at home.”* Consumer

However, even being confined to home is now another source of concern and fear to people who need disability support workers because they are being asked to bear the responsibility for providing Personal Protective Equipment (PPE) to their workers or care will not be provided. *“I was told that I wouldn't be able to have in home support and/or support workers support at home if I could not provide staff with my personal [supply] of PPE masks.”* Consumer with disability

Action

Need an equity-based approach and/or principles co-designed with consumers, clinicians and health leaders to visibly underpin pandemic planning, prioritisation, healthcare decision-making and development of models of care and communications.

Priority access for older people, people with disability and First Nations people to vaccines, PPE, RATs, boosters, antivirals, enteral feeding products.

These groups need a clear understanding of their level of priority and methods of accessing the above. Communications for these consumers needs to urgently include:

- clear list of risk factors that might lead to increased illness
- the value/need of doing the symptom checker to link them to care and get antivirals
- to know what symptoms to escalate and to whom.

Governments to address the unresolved issues presented in the [open letter](#) to the state and federal governments from HCQ, QDN, consumers, consumer organisations and professional organisations and unions issued 2 weeks ago with a clear list of actions to meet the needs of Queenslanders with a disability.

What does regular health care look like now?

“Except for a four-month period of reprieve last year when I was able to leave home and seek hospital treatment, I haven't been able to have any face-to-face treatment with clinicians and allied health since the beginning of COVID. I had four surgeries planned but I'm still waiting. The longer they are kicked down the road, the greater the impact on my health and quality of life.” Consumer with disability

Consumers are increasingly concerned about the backlogs and waiting lists for regular care, elective surgery and screening. There are reports of being removed from waiting lists without consultation or follow up about whether they will be re-instated or even re-instated at the same position as before.

People are being expected to navigate multiple systems and services alone without any sense of shared responsibility or accountability. They are concerned about the lack of safety and quality of non-COVID health care now.

“Friend has recently moved to Queensland after a bone marrow transplant last year. She has been having difficulty getting in touch with a new doctor at the [hospital] although she has a referral from [interstate].” Consumer

"I recently had a serious flare of my own lung condition but hesitated to contact my GP as I expected to be referred to the fever clinic which seemed like a risky environment. Patients with respiratory conditions are reporting this sort of dilemma." Consumer

Action

Need for transparent planning and clear communications to primary care and consumers about how to access to on-going health care and treatments. This needs to include information about what consumers may need to do next in regards to previously delayed care e.g. wait for a letter to confirm their next scheduled visit, phone the clinic/health professional, or do nothing.

Varied experiences of telehealth / virtual care / Hospital in the Home (HITH)

Consumers' views on telehealth and Hospital in the Home (HITH) ranged from optimistic to cautionary. Consultation about what care option pathway to choose is key. For example:

During the pandemic, telehealth and virtual care in the home has transformed the world for one consumer who is completely bed-bound: *"It has finally brought people, connection and the health system to me. With ME [Myalgic Encephalomyelitis] it can be quite unsafe for people to go into hospital, with HITH it is wonderful to have this service at home but why didn't they bring it to us sooner? There is so much potential and a new mindset with the COVID pandemic. The strategy is there – need to get the good systems happening. If there is a will then anything is possible."*
Consumer

However, another consumer cautioned about ensuring the telehealth phone call does not become a tick box exercise for doctors. *"There is no [human] connection/ (routine physical) assessment with a phone call. At least if video call there is more connection."*

"A person with [condition name] is having experimental drug treatment but now is only able to see their treating specialist in [place name] via telehealth which they are finding pretty unsatisfactory/anxiety provoking."

A benefit of HITH for one consumer who is treated at home for infections when possible is, *"Being in hospital for more than 2-3 days always results in me leaving in worse shape than when I arrived. The health system of the modern age does not respond well to people with chronic health complaints and the needs you have every day just to maintain your health."*

There is a perception that HITH is unsafe for one consumer: *"For very vulnerable people even HITH is considered a risk because of visiting nurses who may have seen 20 other patients exposed to COVID during the week."*

Actions

If there are patient reported experience and outcome (PREMs and PROMs) measures being collected right now on telehealth and HITH models of care, consumers and carers they should be published and drawn on for continuous improvements.

If these are not being collected, the system could look to do this and implement the learnings (and publish).

HCQ's COVID-19 response

For all HCQ Issues Papers: COVID-19 click [HERE](#).

What are Health Consumers Queensland's weekly Coffee and Connect Sessions?

Different to HCQ's Consumer Conversations and Webcasts, this new format of HCQ's online consultation session is simply listening to consumers sharing their experiences in a safe, respectful space about what it's like to navigate the health system at this time and flag up whether they are getting the care they need.

What is HCQ's Consumers, Community & Clinicians COVID Forum (C4F)?

A newly established forum for key stakeholders outside the public health system for rapid:

- high level info sharing, with an equity lens i.e. gaps in the COVID response for vulnerable communities
- agreement on burning issues to collectively escalate
- identify consumer-focused solutions to resolve and the role our organisations can play to support
- advocate for immediate resolution by Government / system / other stakeholder

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