

“There is no time”

What health consumers and carers are saying today

HCQ Consumer Coffee and Connect Session #2 and on-line engagement

Coffee and Connect #2 held Thursday evening (20 Jan 2022), an on-line session to hear from consumers across Queensland. Who attended: people from across Queensland - majority live in SEQ but there were also attendees from across the state including Toowoomba, Cooktown, Cairns, Barcaldine, Townsville and Mareeba. Attendees included young people, First Nations people and people living with a disability and/or chronic and complex health conditions.

How you are going living with COVID - Tell us what is happening? an on-line engagement tool for consumers to let us know how things are going. 7 responses from staff and consumers across the state in the last 24 hours, from Brisbane, Gold Coast, Townsville and Tully.

Summary of key issues:

Key themes emerged including how the system doesn't support people with any vulnerabilities, including those with a disability, and a sense that “there is no time.” A sense that both consumers and health staff want a plan forward rather than crisis management – no one is looking at the horizon – need a medium to long term plan **and need hope.**

- Access to care and care for COVID patients
- Testing
- Vaccinations
- On-going health concerns (not COVID-related)
- Long COVID
- Be open and transparent

Access to care and care for COVID patients

- A health consumer shared their difficulty in getting care for her daughter with COVID. The family struggled to access GP care or any kind of care, the information available to them didn't consider that the person providing the care might be a person with a disability and/or at high risk of COVID and what care should then look like.
- Another consumer shared her experience of being in hospital with COVID. She said the only personal contact she had was with staff, and this was often done by phone (rather than in-room care). She knows staff are struggling, but wanted those providing care for COVID patients to remember how important connection is with others.

Testing

Many issues were raised around testing. It was observed that if this was early in the pandemic it would be understandable, but not in the third year.

- Cutting waiting times, making waiting more comfortable and efficient for people queueing who are not well. At the very least, we need toilets and amenities and shade where possible.
- Little consideration given for those with a disability and their needs.
- Lack of access to RATs in communities across QLD.

- Information on how to use RATs – small font, very technical, those with vision impairments cannot see the result. Need support with this.

Vaccinations

- Huge difficulties and barriers for people who are immuno-compromised to get vaccinated in a safe and efficient way - lack of knowledge of pathways by GPs and specialist clinicians and system workers of process to organise a medical exemption - lack of follow through from a single person in the health system to advocate and ensure the person receives information, resolution in a timely way.

On-going health concerns (not COVID-related)

- Multiple outpatients appointments cancelled and many individuals in the community are at high risks of long hospital stays in the future, whilst chronic health conditions deteriorate and even become life threatening, none of this data is being presented.
- Is there a plan to manage this? Including constraints on workforce going forward.

Long COVID

- Need to provide people with COVID with timely information on signs/symptoms of long-COVID and when/how to respond.

Be open and transparent

- There should be a more open dialogue & communication with the actual truth regarding Covid-19 Virus. Especially within the communities & smaller county towns with limited services & information when those have limited or no internet.

We also heard:

- We hear – where do I need to go, who can I turn to right now - so many people need support and advice for complex situations. Where do they go when they have exhausted every possibility. Hitting dead ends every time and these are people with high literacy.
- Difficulties for people with disabilities and carers to get essential supplies
- Self-mobilising e.g. A consumer in Central West not waiting for official response but mobilising the community to help with food and medication.
- Relying on health system to give us advice and support but they are failing us
- Media need to back off and stop discriminating against people who are unable to get vaccinated.
- Consumers are clear that there is no time now – these issues need to be addressed now.
- There should be a dedicated specialist hotline for people with complex needs.
- How can we meaningfully thank our staff and let them know consumers stand with them.
- Real concerns about people who are in aged care for their mental health – if lockdowns continue because residents are confined to their rooms. Their whole picture needs to be looked at not just keeping people safe from this illness.

What are Health Consumers Queensland 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. No presentations or guest speakers.

- Share their experiences in a safe, respectful space with people who can relate to their experiences and circumstances
- Tell HCQ what it's like to navigate the health system at this time and flag up whether they are getting the care they need

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