

In conversation: Consumer engagement in Victoria and NSW - Lessons learned during COVID-19

Key Points for action:

1. **Value consumer engagement at every level:** Health organisations must genuinely value consumer partnerships and the voice of health consumers, by embedding consumers in decision making at the service and system level
2. **Recognise that patient experience IS data:** Rather than wait for epidemiological data, the system can get early warning on risks and breaches by listening to consumer's current experiences
3. **Be responsive to communities:** Involve consumers in the planning and implementation of a sustained, fresh and ever-changing and nuanced communication strategy to ensure long-term community commitment to protective strategies including staying at home if sick, getting tested, social distancing, hand hygiene and wearing a mask in crowded environments.

Here in Queensland, Health Consumers Queensland is uniquely positioned to amplify the consumer voice. We are fortunate to work with a Government, health department and health services that welcome consumer engagement and values the consumer voice. Importantly, this commitment is matched by action, not just lip service, with consumer/HCQ participation facilitated at almost every level of decision making in health, and our organization being funded to pivot our work to support the response to COVID-19.

Since March, we have hosted regular Consumer Conversations and bespoke consultations to share consumer feedback to Queensland Health and influence key policy frameworks such as ethical decision-making and testing. We have brought together different consumer networks to work on COVID-19 issues. We collaborate closely with NGOs in Queensland along with the Queensland Clinical Senate. We represent consumers on the Public Health Response Implementation Advisory Group, and the COVID System Leadership Forum. Melissa Fox, HCQ's CEO is also a member of the Reform Planning Group expert panel and the Queensland Health Leadership Board.

While consumer engagement and action has by no means been perfect and in every part of the system, it has been this openness by those in the health system to listen to consumers and act, which has set our state's response apart from the majority of the rest.

Queensland's current community transmission rate also contrasts starkly with the situation facing our friends south of the border.

We invited the CEOs of our equivalent state health consumer peaks, Danny Vadasz, CEO of Health Issues Centre in Victoria and Anthony Brown from Health Consumers NSW to join a conversation with our CEO Melissa Fox, to share their perspectives on their Government and Health Departments' engagement with consumers during COVID-19 and the

subsequent response at our regular Consumer Conversation session on Monday, 10 August 2020. We also invited some key QH staff (including Prevention, Strategic Communications and Healthcare Improvement Unit), the other state and territory peak consumer organisations and several Queensland consumer NGOs, to listen directly.

The views shared by Danny and Anthony made for “a sobering session” according to one Queensland consumer. Ultimately, their reflections, and the responses from their counterparts in South Australia, Tasmania and Western Australia, point to one key question: **How do we get health services to truly value the consumer voice?**

How does your experience of engagement compare to the situation here in Queensland?

It's a total contrast. We have been comprehensively ignored... and left out of any participatory role. All commitments from the system about the importance of consumers have disappeared as government moved to a command and control approach. Victoria

We haven't been able to pick up on multiple areas in the health system where HCQ has been able to link. Linked with central planning but consumer voice is still quite modest there. NSW

What do you believe is missing or needs to shift in order for these doors to open?

- **See consumers as partners who are part of the conversation and can act as ‘the canary in the coal mine’. Not as subjects who just need to listen and respond.**

Enable consumers to share their lived experiences to make a positive contribution to highlighting policy gaps and implementation failures e.g. forewarning about vulnerable contexts like public housing and residential care facilities. Currently the role of consumers is “just to behave themselves.” Victoria

- **Funding, resourcing and pre-existing relationships.**

Queensland is very fortunate to have best funded and resourced consumer peak in Australia and you've been able to leverage those connections and resources. NSW has been able to leverage resources and connections but from a lower starting point when COVID hit. NSW

We thought we had a reasonably good pre-existing relationship with the government department but they chose to go down a command and control pathway rather than a consultation pathway. ...can't dismiss the fact that a more collaborative approach could have alleviated some of the issues. Victoria

- **Flexibility within the funding envelope**

In contrast with Queensland and NSW, Victoria was not allowed to use their existing funding to pivot their work towards a COVID-19 focus.

What are some of the issues you can see that would have benefited from greater consumer involvement?

- **The current situation in residential aged care facilities, public housing and meat works could have been anticipated and foreseen**

Although unable to pivot their work towards COVID-19, Health Issues Centre went on to self-fund and organise national consumer forums on key COVID-19 issues in March and April which attracted +300 participants at each event. These conversations pointed to a range of urgent matters to be addressed: confusion about social distancing and social restrictions at home as well as inherent vulnerabilities in certain workplaces in terms of traffic flow and hygiene. These concerns were tabled in reports to the government. *Had the government been listening, [it] could have done something pre-emptive.*

- **Over-emphasis on data and compliance**

“Rather than waiting for data - better predictive capability – could have been obtained by listening to real life people’s experiences. Patient experience is data.” Victoria

“The focus has been on consumers not complying but the current inquiry into hotel quarantine has found evidence that nearly all infection can be traced back to hotel quarantine.” Victoria

- **Communications**

“They continue not to involve consumers and community in the development and nuancing of messaging Politicians and CHOs, medics and researching, etc giving good advice but not often in language people can hear and in a way people can work with right now.” NSW

A lot of messaging is for people who are well. Those discussions with people who are regular users of the health system would have saved a lot of angst.

Following one of national consumer forums organised by Health Issues Centre, the clearest message they reported to the government was the need for the government to acknowledge the difference between messaging e.g. CHO delivering directives at press conferences, and communication – the nuancing of those messages to be understood by targeted groups and communities.

Governments need to ensure communication is current and up to date and there are processes for withdrawal if out of date. e.g. a Victorian consumer received a leaflet on what to do after testing two days ago which instructed that masks were not efficient and shouldn’t be worn when they are now mandatory.

- **Lack of engagement at local level**

A lot of existing Consumer Advisory Committees at a facility or district level were stopped early on and this has impacted on non-COVID care. NSW

- **Unresponsive systems not providing care or information around delayed care**

Complications for people who have ill-health unrelated to COVID-19 will be one of the lasting impacts from this time and it is not because people are choosing to delay care but the systems are not addressing people's concerns about whether they are at increased risk or how changes to services will affect them. NSW

Can you reflect on the governance, structure and approach of your health care systems, and how they may have helped or hindered consumer engagement?

Health services are doing things at local level through local initiatives rather than coordinated approach. Now – all hands on deck to try to bend curve back down again.
Victoria

Nothing like degree of organisation in Queensland appears in Victoria. Opportunity was lost between March-June.

The consumer engagement system works pretty well in normal circumstances with each of the [NSW] agencies. However, COVID-19 is highlighting flaws in a system under pressure.

The difficulty is that there has never been a well-established, systemic way for consumers in each part of system to come together. *“When the system went into command and control there was no established mechanism to link in with consumers so consumer voice wasn't considered and consumers became invisible.”* NSW

How have you seen Commonwealth and State approaches align, in terms of policy and messaging out to the community?

- They've maintained Cabinet solidarity. Victoria
- The response has been consistently slow with inexplicable delays to delivering sensible precautionary policies after infection rates are out of control. Victoria
- Coordination of consumer engagement between State and Commonwealth level has not been as good as it could be – even pre-COVID. No one has been identified as a strategic leader (within the system) for consumer engagement nationally. NSW

Key lessons learned for Queensland consumers, consumer organizations, and State and Commonwealth governments

- Beware of hubris – *“we've contained it, let's move on to life after virus.”* Victoria
- Look now at government processes and emerging competing issues e.g. high infection rates and entering bush fire season. Victoria
- Invest in robust planning and structures and foresight based on participation and collaboration rather than command and control. Victoria

- *The government was given huge amount of licence in the early days to act in our best interest. That's been squandered certainly in Victoria by reciprocally failing to pay back our trust by taking the consumers and community into its decision making process. Now is the time for other states to grab it. Victoria*
- As a consumer movement, we haven't been good at knitting together State and Commonwealth activities. We need to establish mechanisms for consumer engagement nationally which we can fall back on during health crises. NSW
- Work on cross-border issues together. NSW
- Establish a streamlined, single source of contact with government for a coalition of high risk population groups to warn about emerging issues, failures and impacts of policies. Victoria
- Use existing relationship and connections and build on them. NSW
- As health consumer advocates, we feel we have to wait for permission to say something. We need to get over that and need to be proactive and if something is happening we don't like or closed down at a local level, we should be acting up and creating more of a stir than we used to. NSW
- The whole way consumers have been sidelined in Victoria has caused us to rethink the way we work in the future. Our inclination has always been constructive, advisory process - this is what happens when we rely entirely on the goodwill that underlines that process. Have to take a more aggressive and leadership role. Hold authorities to account when they don't act in best interests of consumers. The pandemic has been a forceful, unhappy example of what happens when we allow ourselves to be marginalised and almost seen as being an impediment. Victoria

The final word, from across the country – reflections from other state and territory peak consumer organization CEOs

Since pivoting to online engagement, we have been filling the gap in the lack of consumer engagement by health services with hosting online activities. Though the re-initiated Sustainable Health Review we are looking to see if we can leverage lessons learned to inform how we can future proof our state's health consumer engagement activities, so it would be unthinkable to shut consumers out again. Western Australia

Terrible awakening here in SA. Thought consumer engagement was committed but it turned out it wasn't. It's further complicated in SA because we receive no state government funding, so pivoting has been done on a shoe string. We are now putting to the vote to close the organisation because without state funding we cannot survive. South Australia

State peaks have all raised question with the Australian Commission on Safety and Quality in Health Care: What is role and responsibility of the government and each state jurisdiction in terms of making sure consumer advocacy does input into statewide policy? There is actually no formal way of making sure this happens. The pandemic has really shone a light on this gap. South Australia

We were ignored initially, so we adopted the "we will tell you anyway approach", which has worked to the extent that they are now coming to us for information on how the community is feeling and feedback on some areas - it has opened our doors. Tasmania