

27 January 2022

What are consumers and consumer organisations saying?

Health Consumers NSW convened two extraordinary meetings of our COVID consumer taskforces to discuss the current issues impacting consumers and consumer organisations around Covid-19. We spoke to consumer leaders and consumer organisations from around NSW.

Health consumers are grateful for the efforts of front-line staff. They recognise the great challenges front line staff are dealing with during this phase of the pandemic.

Consumers also expressed their concerns around the current COVID-19 situation and their need to have that discomfort communicated to the health system and receive ongoing support from each other and the system.

Consumers are very aware of the difficulties and challenges faced by the health system. They feel their involvement in planning would have prevented some of these challenges and want to return to being involved in shaping solutions going forward.

Key issues:

Consumers feel they are disenfranchised, disconnected, and no longer feel like partners in care.

People expressed feeling burnt out and left out.

They feel their voices are not being heard and the human stories are missing.

"I want to hear stories not opinions."

Current messaging is stigmatising, isolating and confusing.

Consumers said that they felt the health communication had too many inconsistencies, changed too often, and left people confused about what they are meant to do. Consumers also reported a change in messaging away from the importance of keeping vulnerable members of the community safe from infection. Current messaging has left older people, people with disabilities, and people with chronic health conditions feeling unsupported, stigmatised and expendable.

Consumers are very concerned that the current confused messaging will erode ongoing trust in the health system.

"What happened to 'we're all in this together'?"

Consumers are feeling disenfranchised and disengaged from health planning.

People and organisations who previously had been involved in health service planning are not involved in pandemic planning. They feel ignored and there is a growing cynicism and negativity when so many of the consumers or consumer organisations have worked so hard to have positive relationships with health.

"I'm starting to wonder if the 20 years I spent as a consumer representative was worth it. If they won't involve me in this [planning for the pandemic] then why I am doing this?"



Consumers want to know what the plan is to move forward in health for the next 3-5 years.

What is the plan to address Long Covid? How are people going to be able to return to face-to-face appointments and have health care in their homes? Consumers expressed that they felt the 'Communities of Practice' were in a good position to develop processes for planning forward, however, they need to be regular and more actively engage consumers.

Access to ongoing treatment for non-Covid health issues.

Consumers told experiences of last-minute cancellations of elective surgery, monthly injections, cancer scans, and other appointments due to not being able to get PCR tests and cancelled pain clinic appointments. People are concerned about the serious consequences and long-term impacts on people's health and quality of life, as well as the impact on patients' mental health.

Continuity of care.

Consumers reported not getting connected to rehab, NDIS, mental health services or any follow up after discharge, or being kept in hospital weeks longer than they would normally have been because they couldn't be referred to rehab services. Families reported setting up their own rehab programs at home as access to telehealth or physical rehab is limited. People are reporting decreases in functional capacity due to not having access to physiotherapy and hydrotherapy.

"Give people the autonomy to make their own assessment about what they're comfortable with."

Access to Rapid Antigen Tests (RATs). Consumer organisations expressed concerns that their members cannot access RATs. These members are unable to wait in queues or drive to multiple locations to try and find tests for themselves or to test people before they enter their homes.

The burden on carers and family members.

There is a burden of increasing expenses on the community, including the cost of RATs. Carers are unable to organise respite care. Carers are unable to access support in getting their loved ones vaccinated if they are living with psychosocial disabilities in community settings.

Restrictions on visiting health services mean families are locked out of their role as partners in care. Patients with a lack of communication abilities need carer support/voice. Carers and families fear they are being dismissed for asking for information about the person being cared for.

"Carers feel they are being told it's none of their business"

Covid self-care in the community.

Current experiences being shared included patients being unsure when to escalate the need for further healthcare to their GP or hospital. Reports of long wait times on phones, equipment not arriving or arriving long after it was needed. Patients report being uncertain how to register positive diagnoses and not receiving adequate and timely information about self-care, in a format and language that is useful. People are struggling to get access to things they need while they isolate e.g. how to get food into the household.

Isolation/lack of connection and the mental health impact.

Vulnerable people have been in long term self-imposed lockdown. Patients are being re-traumatised by the stigmatisation of their illness and having to isolate. Some are forced to isolate themselves with challenging family dynamics and can't access their usual supports.

What do consumers and consumer organisations say they need right now?

- An emergency strategy that involves consumers and consumer organisations
- Actively bring consumers and consumer organisations into planning for COVID-19 responses and health messaging, at both NSW and local level
- Return to messaging emphasising working together to protect people who are medically vulnerable and not overloading the health system
- Assistance for consumer organisations to access RATs
 - ideally by facilitating the supply of free RATs from NSW Health stocks directly to consumer organisations,
 - assistance in accessing bulk supplies of RATs

Stories of Resilience

Consumers and consumer organisations are also sharing their experiences of mutual support and resilience in the face of these challenges. The next consumer report from Health Consumer NSW will focus on what people are doing in the face of these challenges.

Health Consumers NSW will continue to listen and respond to consumers experiences with Covid-19 and will work closely with health consumers and organisations to capture and share those experiences. We will deliver future communications as we hear key issues raised and ensure the consumer voice is heard.

