

Omicron Outbreak – Winter 2022 Consumer Insights

Executive Summary

These themes emerged from our discussions and consumer feedback:

- Concern about apparent COVID **complacency** in the general population which is affecting attitude to protective measures
- Concern about the risks, impact and treatment of **long COVID**
- **Lack of clarity** about where to go for the latest information, and what that information says – for example, about what to do if you're a close contact
- **Lack of quality, consumer friendly clinical advice** –
 - Clinical advice for Long COVID treatment
 - Advice on (oral) antiviral medications for COVID including qualification and access
 - Advice on infectious periods for people with COVID
- **Seeming lack of awareness or concern** for the particular needs of people who are medically vulnerable – it's not clear from Government communications that this group is prioritised in health and communication planning
- The need to **maintain compassion** in how protective measures are being applied in hospitals
- Concern for **staff and workforce availability**

At Health Consumers' Council we're aware of the challenge of moving towards living with COVID as business as usual, while also recognising that the consequence of living with COVID are still being understood. For example, the perceived complacency in the community about COVID being in the past is at odds with the warnings about an expected rise in case numbers, as well as with the experiences of people who have developed and are living with long COVID.

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Consumer concerns

Complacency

The majority of consumers we spoke to were worried about vulnerable people, medically vulnerable people including immunocompromised people and elderly people. They commented that they felt West Australians had become complacent and were acting as if the pandemic is over.

"It's like people have forgotten we are in a pandemic."

The majority of people felt restrictions eased too suddenly and were concerned about the effect of this on spread and on vulnerable people. Of particular concern of note was the lifting of the mask mandate.

Lifting the mask mandate and the impact on medically vulnerable people

A number of people felt the mask mandate was lifted early. Others were sympathetic to the need to move from mandates to the onus being on the community. While mandates have been lifted, a campaign to highlight the benefits of masking and to reduce mask stigma may encourage the community to accept masks as "the norm" – particularly in higher risk situations (when unwell, unable to distance etc).

"Because people are free not to wear a mask they no longer seem to think about whether their freedom TO go out without one actually means others are no longer free FROM harm and so are staying home and shielding."

Some people expressed concern about people who are medically vulnerable – including older people – who have opted to significantly reduce their social activities in order to reduce their risk of exposure, and the risk this may have for mental health and social isolation in this group. As online options decline, this group risk being excluded from social and community activities.

"The apathy of people in Perth thinking that it is just a flu frightens me as I am vulnerable."

Many consumers highlighted that mandates being dropped created a feeling that "the danger has passed, the pandemic is over".

Concerns about developing long COVID

Many consumers were concerned about contracting Long COVID and worried about what health services and treatments would be in place for them if they did. One consumer recounted hearing of a colleague who believes they have long COVID but whose primary care physician questions the existence of such a condition.

Confusion and mixed messages

Our recent consumer and community engagement shows that people are challenged with where to look for WA Government communications – (noting that there is similar – but sometimes different information on the Department of Health website and the Department of Premier and Cabinet website). While this feedback has been consistent since early 2022, the current issues seem to be around isolation rules and also clinical aspects of the disease including infectivity and infectious stages and oral medication to treat COVID.

Consumers also complained of mixed messages from health professionals on vaccination (who qualifies for how many doses), antivirals (qualification and effectiveness) and long COVID (with some consumers being told it doesn't exist).

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"It is very difficult to obtain reliable information on what is the right way to 'be' in the community."

Reducing public health protections in EDs

We note there are plans to reduce the need to undergo a Rapid Antigen Test (RAT) on arrival at Emergency Departments (ED). We understand the need to move towards integrating living with COVID into business as usual. However, our concern is that medically vulnerable people could be high users of the ED and if that's not identified as a high-risk area, then the issue becomes how to ensure people at high risk know that, and know what they need to do to protect themselves if they need to attend ED.

Questions about RATs

Consumers reported a lot of confusion amongst RAT reliability in their networks resulting in community distrust of the test. People raised concerns about the cost of RATs (note, this was before the expanded free RAT program).

Mixed perceptions about COVID death announcements

In the consumer and community conversation, the topic of burden of disease was raised and when it would be appropriate to stop announcing COVID deaths. Consumers discussed other health conditions which cause high numbers of deaths which are not published daily. We discussed that COVID is a global pandemic and a communicable disease, preventable to some extent and controlled by public health measures.

Clinical advice

Our consumer engagement showed a lack of accurate and easy to understand advice for consumers across various aspects of COVID but in the main at present on:

- oral medications for COVID-19
- infectious periods
- long COVID.

Oral medications for COVID-19

In our discussions with health consumers it is clear there is very little awareness or clarity about the availability and eligibility of oral medications to treat COVID-19. Some had not heard of the treatments at all. Others had heard but had no idea if they qualified or how they would access (or when they would need to do so).

One consumer reported that a close family member trying to access antivirals was incorrectly told by COVID Care at Home that he did not qualify and then incorrectly told they are ineffective so to avoid by his GP.

Medically vulnerable people may not understand their risk or available treatment options

From HCC's discussions with a range of health consumer groups, we believe that many people do not know how vulnerable they are (or are not). While others may believe they are more vulnerable than they are in reality as they recall the announcements of 2020 which often labelled anyone with any underlying health condition as "high-risk".

HCC believes there would be a valuable in a targeted direct campaign to reach people with chronic conditions and who are immunocompromised with some clear messages about:

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- who is at risk
- what treatment options are available
- what they should do
 - to protect themselves from infection
 - if they become infected.

This campaign could be promoted through existing groups such as HCC, Connect Groups, and the NGOs dealing with relevant conditions including Diabetes WA, Cancer Council WA, Donate Life, and Arthritis Australia, Lung Foundation Australia. Rare Voices Australia and others.

Protecting others after a COVID infection

Some people feel the rule of being able to leave isolation after seven days if “symptom free” is ambiguous and therefore could lead to people leaving isolation when they are still infectious, which might mean they expose vulnerable people to the risk of infection.

“I really struggled to find out if I was likely to be infectious if the RAT is still positive. Also, what symptoms are acceptable and considered post-COVID and what are still part of my initial bout of COVID-19?”

Vulnerable people

In the consumer and community conversation, complacency and the casual attitude towards COVID which society has adapted was the biggest concern for this group. Whilst society has moved on and, in many instances, acts like the pandemic is over, vulnerable people find themselves even more isolated than ever before. Mental health is a concern for this group given the increased social isolation and difficulties experienced in living with COVID.

The seeming lack of control of the outbreak, the end of contact tracing and removal of the listing of exposure sites makes it very scary for many vulnerable people to leave the house at all, as there is COVID any and everywhere. As society provides less online and alternative options for attending events (work and social) and accessing services, this group are becoming excluded from many aspects of daily life.

Financial support is also a big issue with the cost of quality masks and past and future cost of testing as well as indirect costs associated with non-attendance to work and shielding (in the more extreme cases).

Maintaining compassion while maintaining protection

Hospital visiting was an issue raised in the group discussion as well. The group understood the complexities of rules in this area but were supportive of some more flexibility in the system. There was good agreement that vetting visitors to hospitals and aged care is required to protect vulnerable people but that at this stage, more flexible hours are needed.

“we’ve moved from person-centred care, to COVID-centred care”

After this community conversation took place, Health Consumers’ Council staff met with Chief Health Officer (CHO) who explained significant relaxing of hospital visiting rules recently. The office of the CHO and the HCC

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found the consumer access to this updated visiting information was the issue and the group saw an opportunity to clarify the most up to date public advice about visiting hours.

While restrictions remain in place, there was discussion about the opportunity to emphasise the opportunity for rules to be relaxed in compassionate circumstances.

System readiness and workforce availability

Capacity of the system (equipment and workforce) remains a concern, particularly in the regions. This is both due to the high demand for COVID related care, as well as the impact of staff absences due to ill-health.

Some people have the perception that the system cannot cope outside COVID so then becomes unmanageable in COVID. People are concerned about wait times (particular Emergency Departments), elective surgery and people choosing not to access care because of real or perceived wait times or real or perceived COVID risk.

We know that many frontline staff are tired and may feel under pressure and the impact that this can have on the quality of the care and the experience that people have when they attend hospital.

Health Consumers' Council Recommendations

We reiterate our call for the involvement of consumers and community members in planning COVID-19 responses and in developing accompanying communications. We have a COVID Community of Interest as a ready resource of engaged consumers. These are some of the ways we believe that consumer concerns could be addressed:

- 1) Involve consumers on developing future iterations of COVID related rules – for example, a small time limited advisory group could provide rapid advice on areas of concern to consumers
- 2) Work with consumers, behaviour change specialists, and WA media on a campaign to reduce mask stigma, raise awareness of the benefits of masking and increase mask usage.
- 3) Work with consumers to develop consumer information on antiviral medication and effective distribution of this material, targeting medically vulnerable groups.
- 4) Develop a health system plan – involving consumers – for dealing with long COVID and share this information with the public.
- 5) If it doesn't exist already, HCC would continue to advocate for a cross-sector working group with a specific focus on medically vulnerable people. The group could involve clinicians, consumers and health service planners across hospital, community and primary care – with a focus on scoping and developing care pathways and developing specific supports including financial, mental health and specific communications for this cohort.

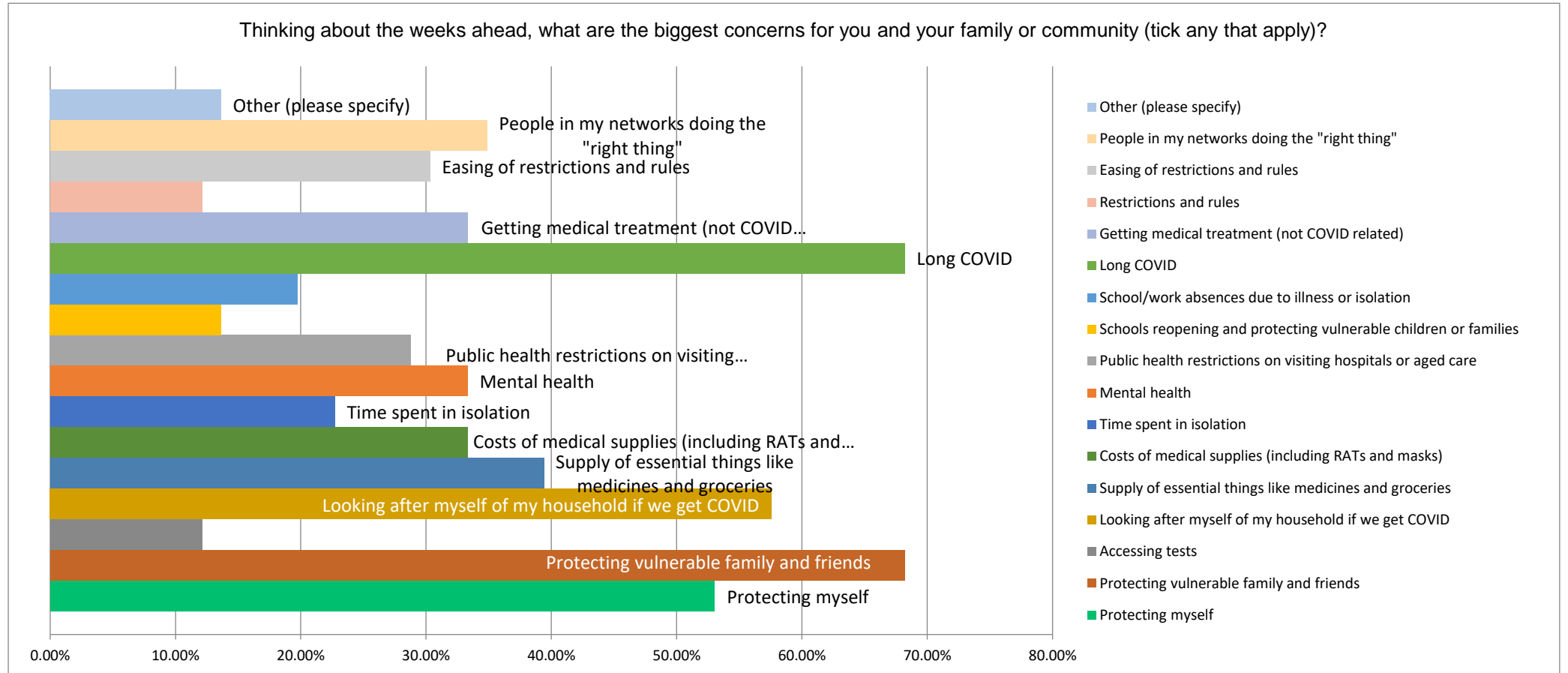
How we gathered this information

Health Consumers' Council WA (HCC) asked consumers for feedback on their perspectives on living with COVID-19. This included a survey and a virtual consumer conversation with consumer leaders. HCC staff also engaged with consumer facing organisations and informally monitored a number of community groups on social media. This document summarises the main issues raised in our recent discussions with consumers.

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Appendices

Additional detail from survey



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What is top of mind for you and your family / community at this stage of the pandemic?



Do you have any particular comments or concerns regarding healthcare or access to healthcare for COVID or during these COVID times?



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Do you have any particular concerns or see any particular gaps in terms of communication about/around COVID? That is, anything that concerns you that you feel you can't get answers to?



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