

## SUBMISSION

# Commonwealth Government COVID-19 Response Inquiry

I welcome the opportunity to make a submission to the COVID-19 Response Inquiry. I am making this submission as a member of an "at risk" family - my [REDACTED] who works full time to financially support our family, has had a [REDACTED]. He has a professional background in science, and due to this and his health position, we consider ourselves highly health-literate. I have Long COVID as a result of an infection in early 2022, and we have [REDACTED].

## Introduction

The COVID-19 pandemic has been stressful for our family, and other families like ours. We watched as healthcare systems overseas struggled and buckled under the pressure of COVID-19 cases. Aside from the damage and risk of an acute infection, my greatest fear was strain on our healthcare system would mean rationing of treatment. If there was a choice between ventilating a healthy person in their 40s and my [REDACTED] would they treat him? This was not a hypothetical situation in places like Italy, the US and the UK. It was also a very real fear that a dysfunctional healthcare system would impact his care in other ways - as a [REDACTED] he relies very heavily on a well-functioning hospital system. Each wave was stressful, particularly those during winter as this is when we need the hospital most.

## Protecting the vulnerable

### Plans for 'reopening'

It's clear that the plans for reopening did not factor in at-risk families. There was a huge RAT shortage. We were not able to access RATs through the transplant clinic, the risk of infection was too high for us to repeatedly go to the chemist to hopefully purchase a test, stores would not check stock if we called and there was no stock online. This meant our family (including our [REDACTED] spent most of the 'reopening' completely isolated to avoid infection.

Schools were reopened before children had access to vaccination. At the time we seriously considered whether or not my [REDACTED] should move out in order to protect himself from our [REDACTED] bringing COVID into the home, but decided against this because of the impact this would have had on our [REDACTED] and also because we couldn't access or afford alternative accommodation. Our school was very clear that it would not support continued at-home-learning for children of at-risk parents. Children who are under 5 still do not have access to vaccination, and

our children do not have access to boosters. The strategy for children seems to be "immunity through infection", which poses an obvious risk to our family (if not our children themselves, with the risk of post-covid adverse health effects, for which there is ample evidence). It is also at odds with the 'protect the vulnerable' approach that we cannot access vaccination for our children.

### Ongoing management

Protecting the vulnerable was a stated aim of the government's management framework, but it seems to be based on the premise that vulnerable people are somehow siloed from their community; don't work, live with other people, have children, volunteer for organisations, etc.

In theory, this approach sounds admirable. In practice, it is essential that any plan to protect the vulnerable should at least include their first degree contacts.

For example, with the removal of walk-in test clinics, my [REDACTED] can get PCR testing slips through his [REDACTED] clinic, but it is much more difficult for the rest of the household - the clinic cannot supply testing slips to us. Obviously, it is very important for the rest of the household to have access to prompt, accurate testing, so we can isolate from him if positive and hopefully prevent infecting him.

In another example, HCWs have been required to wear N95 masks while treating him due to his [REDACTED] status, but there is no such requirement if he is attending healthcare as a caregiver or parent. Whether he is in a hospital emergency department as a parent or patient, his risk profile has not changed so the infection control protocols in place should be consistent across all health services.

It should be a priority that at-risk people are able to safely access workplaces, education, healthcare and other public spaces. In particular, workplaces and schools are legally required to provide safe environments, and the ACSQHC charter of healthcare rights states that every patient has a right to access healthcare in a safe environment. Over the course of the pandemic, my [REDACTED] and I have both had our careers directly impacted because we are unable to work in "normal" workplaces because of transmission risk.

Our children have each caught COVID twice, a total of 4 times they have brought COVID into the home. Each time has been a crisis-like event, where we must work incredibly

hard (because of what is at stake) to ensure there is no onward transmission to my [REDACTED]. We have largely educated ourselves about methods on how to do this, and the safety net of emergency accommodation for at-risk families was removed long ago. It's incredibly hard work to isolate successfully in a single bathroom residence.

### Ongoing waves

The government has regularly predicted there will be several COVID waves per year for the foreseeable future, but doesn't seem to preventatively work to reduce the impact to the community. With each wave there have been many obvious impacts to businesses and hospitals, not to mention the health and wellbeing of the community generally, these impacts are direct evidence that relying on vaccination only is not enough.

We are vulnerable, we don't feel protected. And as evidenced by the number of times we've had COVID in our home despite our best efforts, we are *not* protected.

### 'Protect yourself'

There has also been a shift over the course of the pandemic for people who are at risk to look after themselves. Government officials have even stated at various points that vulnerable people should make plans for themselves.

Even though this shouldn't be the case, timely access to case levels allowed my family to do this. In particular, daily and then weekly information allowed us to dial up and down our family response as needed. Now that testing is discouraged by some governments, and reporting is not possible, the government should be using other means to determine prevalence and publicising it frequently so the general public is aware of levels but also so at risk people can protect themselves.

While we were told to expect a "vaccination plus" strategy, or even a traffic lights system where mitigations might increase and decrease with risk, transmission reduction has largely been left to individuals to manage themselves..

### Mental health of young people

In the time since lockdowns and school closures, there has been a lot of attention on how these measures affected young people. What seems to have been missing from these conversations is the mental health effects of living through a major pandemic event given the fear, stress and uncertainty at the time in general. It seems impossible to me to weed out a single cause of mental health impacts. I have no doubt that if schools were kept open it still would have been an incredibly fearful and stressful time for young people which would have impacted their wellbeing and education.

What has been completely absent from the conversation is the mental health impacts on young people who live with someone who is at risk, particularly with the rolling back of protections and increase of transmission in the community. What is the toll to them if they bring COVID into the home from school, infect their loved-one? What if their loved one is permanently affected or dies?

Over time, the government has minimised the impacts of COVID, as a direct result of changes of community attitudes our [REDACTED] have experienced peer pressure and bullying because they were wearing masks, or taking other protective measures. Our [REDACTED] routinely explains his behaviour to friends using these exact words: "I have to be careful because COVID might kill my [REDACTED]" I cannot begin to process the long-term mental health impacts this is having on him, despite his protests that "he's fine with it", and our efforts to minimise them.

These mental health impacts increase as transmission in the community increases.

We are now in the very difficult position of allowing our children to participate in activities that we know put them at risk of catching COVID, to allow them to experience a somewhat normal life alongside their peers, but despite this there are still things they must miss out on because the exposure risk is simply too great. I cannot overstate how stressful and isolating it has been to constantly be assessing and reassessing risk, or advocating directly to each organisation, or friends and family members, to try and make things safer for our kids over the course of the pandemic. I believe this has impacted relationships with these organisations as well as friends and family, with comments such as "everyone has to die sooner or later", "as long as my business isn't affected", and "if there was a real risk to your [REDACTED] I'm sure the government would be doing more".

Lockdowns and closures were a tool used at a time when there was little knowledge about the virus, how it was transmitted, we were an un- or under-vaccinated population, and when death and permanent disability or prolonged acute illness was a risk for even young and healthy people.

### Decision-making transparency

The structure of national cabinet means my family has no insight into the evidence supporting decisions that deeply and directly impact us. It is vital that in a democratic society that information like this be freely shared, and I've been disappointed that there has been a lack of interest from the media and politicians on this point.

## Long COVID

The long-term societal, economic and health effects of Long COVID are as yet unknown, and the best way to prevent Long COVID it is to prevent COVID infection in the first place. It's known, through anecdotal and scientific evidence, that even previously young and healthy people are at risk of Long COVID. With each wave, more and more people are affected by Long COVID.

While we had many approaches to transmission reduction early in the pandemic, few remain now - as referred to earlier, the onus is largely on the individual to advocate for and protect themselves. This is problematic due to the nature of the condition - though I am highly motivated to advocate for myself and my family, during times of a flare I may not have the mental or physical energy that is required to do this.

It seems an oversight of the government to allow wide-spread transmission in this context, since the risk of adverse health events post COVID and Long COVID has been known about since relatively early in the pandemic.

Long COVID has greatly affected my health and my life. The hard-won gains I had made over the course of two years have now been reset since a recent reinfection, making it clear that I must now avoid COVID not just because my health is at risk, but also my own.

## Education and awareness

There have been a number of very good transmission reduction initiatives throughout the pandemic, for example HEPA's in schools and excellent ventilation policies and the Victorian HEPA grants scheme. The success of these initiatives seems to have been hampered by poor education and communication from the Government.

Lack of general awareness in the community has also meant we have had the personal responsibility of educating both the organisations we interact with as well as our family and friends. To be blunt, our lives are complicated enough just dealing with the demands of living with chronic illness without this added burden.

It has been difficult to watch various government officials and politicians "other" people who are at risk, as if it's obvious by looking at someone who is at risk. Many people may find it an invasion of their privacy to be disclosing health information widely. Many of my colleagues (and indeed some of our friends) were not aware of his status in the past because he didn't want it to "define him", but he needs to make this information widely known now. He spent most of his life trying to live as normally as possible given his immense health challenges (for example he could easily qualify for but has built a

successful career in science), so this has been a difficult adjustment.

Therefore there is greater education needed in the community about *who* is at risk (including of Long COVID and other post-acute health effects), the fact that could include anyone around them or they may acquire Long COVID. There needs to be better awareness of what the primary mode of transmission is and transmission reduction strategies that the whole community can and should employ.

From a communication perspective, COVID was often positioned as a political rather than health issue, both by politicians and the media, damaging health education opportunities for the community.

## Summary

- People impacted by policy change should be consulted
- Children should have access to vaccines where it is recommended by their or their parent's treatment team
- PCR testing should be freely available to first degree contacts of people who are at risk, for example immediate family and household members
- Proactive measures to reduce the impact of forecasted/expected COVID waves on the community.
- Indoor public spaces, such as education, healthcare and workplaces, should be safely accessible by those who are at risk and organisations supported to make this change. For example supported isolation, testing, HEPA, ventilation strategies etc.
- Transparency in the decision-making process, ensuring insights into the evidence supporting decisions.
- Widespread education about the risks of Long COVID
- Education campaigns about dominant transmission modes, e.g. air, and strategies for risk reduction

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Thank you again for the opportunity to make a submission, and your time taken in reviewing it. My family is not unique, I personally know several who are in a similar situation. Based on the government's own vulnerability criteria for initial vaccination access, there are millions of Australians who are at risk, who matter, live full lives, and need to be considered and consulted properly in the current ongoing and future pandemic responses.