INTRODUCTION

My family is one of about 500,000 Australian households affected by severe [redacted].

My partner has [redacted] disease and severe [redacted] conditions, which are managed with [redacted] medications.

He was unable to work for most of [redacted] due to the risk of contracting COVID in the workplace, and has recently switched to a new line of work that is mostly outdoors and much lower risk.

Our family spent most of 2020-21 at home, with [redacted] remote teaching our [redacted] young children while I worked from home.

KEY HEALTH RESPONSE MEASURES

Our initial experience of the pandemic was positive, as we felt well supported to work and study from home, and received financial support from the government.

But we became increasingly concerned throughout 2021 when it became apparent that the vaccine roll-out was not working as intended. The priority system collapsed and my partner was not able to receive his first vaccine until well after he was originally supposed to.

Australia's opening-up plan was also largely predicated on vaccines being able to control transmission of the Delta variant and Paxlovid protecting high-risk people (1). The public was assured by government that if a new immune-evasive variant emerged, we could manage it by tweaking our pandemic controls.

However when Omicron arrived, Paxlovid was still many months away. Unfortunately Australia did not change course and the country went into election mode, minimising public conversation about the pandemic and opting for a politically expedient approach.

The country adopted a vaccine-only strategy with little consideration of long-term systemic and structural changes, especially in regards to airborne transmission. Existing sick leave provisions were inadequate and the country was and is facing stalling booster rates among elderly and low child vaccination rates, plus a looming long COVID burden.

We also observed little government engagement with high-risk communities and [redacted] individuals. Targeted public health messaging was close to nil, and we had to search ATAGI technical documents to find the relevant information, which often changed arbitrarily overnight, often unknown to our doctors. Several [redacted] families and their specialists in our circles were unaware children were eligible for booster doses months after ATAGI approved them because no one from government shared that information with them.

When schools and workplaces reopened in late 2021, my family sought accommodations to continue learning and working from home until [redacted] was able to receive the full course of primary vaccines for [redacted] people and antivirals became available. However, there was almost no support, consultation or communication from government and authorities at this time about the ongoing risk to severely [redacted]. Essentially, we were at the whim of the educators and employers, most of whom were poorly equipped to be making clinical decisions on our behalf.

Financial support from government was prematurely withdrawn, leaving my family living below the poverty line. Work and school accommodations were refused for many vulnerable people, and we received no guidance on how to assess individual risk, often waiting months for expensive annual specialist appointments.

Antivirals only became very belatedly available to desperate families such as ours. Three days before the 2022 federal election, Professor [redacted] revealed in a primary care update that only 1000 or so Australians had received the antiviral medication Paxlovid through their GP (2). That meant up to a

million doses, each worth more than $1000 and with a short shelf-life of nine months, were stockpiled in warehouses while people died (3).

Clinically vulnerable people were not prioritised for PCR during the Omicron surge and rapid tests were difficult and expensive to source. Pleas for help from patient groups were all but ignored (4).

Treatment pathways were opaque, and [redacted] people never received free or subsidised P2/N95s or rapid tests like other vulnerable groups. Proper P2/N95s were prohibitively expensive and only available to the public at large mark-ups with long waiting lists. Even if you had the financial means to buy them, most P2/N95s were strictly rationed to healthcare workers for most of the pandemic – it was illegal for [redacted] people to buy them.

[redacted] people were very belatedly permitted access to antibody testing in Australia, and monoclonal antibodies were often rendered ineffective by the time they were finally approved for use. Many severely [redacted] people remain ineligible for antivirals due to contraindications.

Even by March 2022, a significant proportion of NDIS participants had not received their second vaccination, having been deprioritised for vaccination in 2021 (5, 6, 7). Some disabled people were among the last to be vaccinated, when they were meant to be at the front of the queue.

The federal government at that time did not quantify disabled deaths, with the Federal Minister for Social Services telling parliament in February 2022 they were not collecting the relevant data (8).

Plans to form a National Schools Plan with federal air purification/ventilation standards and hybrid learning systems collapsed, as did attempts to streamline antiviral and PCR access via methods used overseas such as “Test to Treat” (USA) or back-pocket scripts (New Zealand).

Now, in 2023, hospitals are winding back PPE protections in clinical environments, in direct opposition to the wishes of high-risk patients and Australia’s National COVID-19 Health Management Plan for 2023, which purportedly prioritises “those at risk of severe illness, including through targeted supports” (9).

The shift to “personal responsibility” ignored social, political and commercial determinants of health, and governments fell into the trap of “ecological fallacy”, drawing conclusions about high-risk individuals based on group data. As Dr Cecilia Tomori says, “‘Personal responsibility’ rhetoric allows corporations and governments to absolve themselves of the responsibility they actually hold for the health of the public. And importantly it allows for locating moral blame at the individual level.” (10)

MECHANISMS TO BETTER TARGET FUTURE RESPONSES

In future, pandemic responses should include specialised consultation and communication with [redacted] people. This should be systemic and structural, and be streamlined using up-to-date technology.

As the July 8, 2022 AHPPC statement says: “The AHPPC reiterates the shared responsibility of individuals, employers and governments in minimising the impact of COVID-19.” The document outlines a number of steps that communities, business and government should take in regards to vaccination, treatment, testing, hygiene, ventilation, sick leave, masking, business continuity and OHS.

A National Schools Plan is crucial for identifying the different risk profiles of school families. A national hybrid schooling system will help children from high-risk families to learn remotely from home, while national ventilation and air filtration standards will minimise learning disruptions and help accommodate high-risk families in face-to-face settings.

The COVID-19 consensus paper published in Nature journal on 03/11/22 also summarises essential steps governments should take to control an ongoing public health threat such as COVID (11, 12).

Another useful resource is Advocacy for Inclusion's white paper and Shared Statement, which includes suggestions such as a COVID Inclusion Guarantee, which allows high-risk people to access essential services in a COVID-safe way (13).

Workplace regulators should also promote better understanding among employers (including hospitals) of their legal obligations under OHS laws and disability anti-discrimination legislation (14).

Most importantly, Australia needs an organising framework for community consultation and response to represent and communicate the needs of high-risk and marginalised communities most affected by the pandemic, namely elderly, immunocompromised and disabled patients.

These state or federal peak bodies should not be filled with clinicians or academics. They should be community-based and patient-led.

The organisations could be modelled on the AFAO and NAPWHA, which emerged in response to HIV. Similarly, a national COVID-19 commission could be modelled on NACAIDS, which operated in the 1980s-90s.

SOURCES

1.https://www.thesaturdaypaper.com.au/news/politics/2022/01/29/hospital-plan-try-very-hard-avoid-getting-covid-until-march/164337480013222

2.https://www.health.gov.au/resources/webinars/covid-19-response-update-for-primary-care-19-may-2022

3.https://www.smh.com.au/national/people-dying-of-covid-while-life-saving-drugs-go-unused-doctors-say-20220519-p5amvs.html

4.https://pwd.org.au/disability-sector-slams-national-cabinets-omicron-response/

5.https://www.bradhazzard.com.au/vaccination-boost-for-people-with-disability/

6.https://www.theguardian.com/australia-news/2021/sep/27/unconscionable-to-lift-lockdowns-before-all-australians-with-disability-can-be-vaccinated-inquiry-says

7.https://disability.royalcommission.gov.au/system/files/2021-09/Public%20hearing%2012%20-%20The%20experiences%20of%20people%20with%20disability%2C%20in%20the%20context%20of%20the%20Australian%20Government's%20approach%20to%20the%20COVID%2019%20vaccine%20rollout%20-%20Commissioners%27%20draft%20report_0.pdf

8.https://x.com/criprights/status/1494177602713849856?s=46&t=liSV0rnMz-wKKD0eDKR9zw

9.https://www.health.gov.au/resources/publications/national-covid-19-health-management-plan-for-2023

10.https://twitter.com/drtomori/status/1514600635798196235?s=21&t=VzXLwqKXJyNco0Vb46dA0A

11.https://www.nature.com/articles/s41586-022-05398-2

12.https://twitter.com/jvlazarus/status/1588202954850504705?s=46&t=F8pCdC8lWuMxiqFKft2OKw

13.https://www.advocacyforinclusion.org/wp-content/uploads/2022/08/White-Paper-COVID-19.pdf

14.https://covid19.swa.gov.au/doc/improving-ventilation-indoor-workplaces-covid-19

My first submission outlined my family's personal circumstances with [redacted] and how we have been affected by the pandemic.

I would like to make a short, second submission underlining the importance of maintaining inclusive healthcare and accessible essential spaces and protecting vulnerable Australians.

Australia's National COVID-19 Health Management Plan for 2023 purportedly aims to protect "those at risk of severe illness, including through targeted supports".

Yet all over the country, hospitals and clinics are winding back PPE protections or ignoring air quality, often with the excuse that patients will acquire COVID in the community anyway.

Many places are not even tracking nosocomial infections (2).

This overlooks the fact that our most vulnerable may take precautions in the community but often cannot protect themselves while unwell in hospital or seeking care, resulting in a much higher death rate among hospital-acquired cases (3, 4).

I personally caught COVID while attending a [redacted] public hospital ED while seeking treatment for [redacted]. While I tried my best to wear an N95, I was forced to remove it to drink water and take pills. I was surrounded by obviously symptomatic patients and staff, in a poorly designed ward with no natural ventilation and no apparent air filtration. A COVID-dedicated ward had recently shut due to lack of staff. After being sent home, I was later taken back to hospital via ambulance due to COVID symptoms. It has taken me many months to recover at the cost of my personal health and finances.

This story is being repeated all over the country. Vulnerable people are being harmed and dying because Australia does not have a good grasp of the "network topology" of transmission (5).

Academic and HIV researcher [redacted] provided an excellent analysis of this concept in an article called, 'Lock down smarter, not harder', which outlines the heterogeneity of networks and social groups, and the importance of investing in the capacity of affected communities to respond to outbreaks.

To truly protect our most vulnerable, we need to redouble our efforts to reduce transmission in hospitals, especially EDs, high-risk wards, and aged care settings.

Stalling booster rates in aged care are of particular concern. At last count only 39 per cent of aged care residents were up to date with boosters (6). Anecdotally I have heard this is because many aged care facilities are pooling their booster sessions, and require a minimum of 20 residents to offer on-site boosters.

These systemic failures are largely a result of our poor understanding of the network epidemiology of COVID.

Conversely, we must truly understand who and how COVID is mostly likely to harm if we want to protect our most vulnerable Australians.

1. https://www.health.gov.au/resources/publications/national-covid-19-health-management-plan-for-2023

2. https://youtu.be/Erahy9wknjA?si=ziMuJNrFrYuE2YAE

3. https://www.theage.com.au/national/victoria/hundreds-die-of-covid-after-catching-virus-while-in-hospital-20230330-p5cwjx.html

4. https://www.theage.com.au/national/victoria/a-death-sentence-more-than-600-people-die-after-catching-covid-in-hospital-20230621-p5di7x.html

5. https://insidestory.org.au/lock-down-smarter-not-harder/

6. https://www.health.gov.au/sites/default/files/2023-11/covid-19-vaccine-rollout-update-10-november-2023.pdf