

Alexandra Paine Submission to the Covid-19 response inquiry.

Introduction *(please note all links are coloured blue for accessibility)*

My name is Alex, I'm a 24 year old living in [REDACTED] I live with multiple Disabilities; [REDACTED] and more. In December of 2020 I was diagnosed with [REDACTED] the treatment, [REDACTED] that I am on to stop the progression of the disease makes me severely immunocompromised by the [ATAGI's standards](#) (See table 2a, CD-20 Antibodies). Because of this I am at high risk for serious illness due to Covid 19. I am also on [REDACTED] which means that any and all mitigations that I use to lower my risk of contracting Covid 19 need to be cheap or government funded. I have had 5 vaccine doses, and one course of [REDACTED] I still wear an N95 everywhere I go.

I will be exploring my personal experiences with regard to the terms of reference of;

-Key health response measures

-Broader health supports

-Mechanisms to better target future (and I would argue CURRENT) responses to the needs of particular populations

With this in mind, I share my experiences as a poor and Disabled person during the ongoing pandemic;

My first issue is access to healthcare, due to the complete lack of proper safety mitigations for at risk and immunocompromised people I have not been, and still cannot, access healthcare safely; to outline this I share a recent experience I had when attending my [REDACTED] at [REDACTED] in [REDACTED] [REDACTED] on the 27th of October 2023. I entered the hospital and got into the elevator to head up to the [REDACTED] [REDACTED] (or medihotel as it's more commonly known), after I entered the elevator I was followed by 3 staff members. two completely unmasked and one in a surgical mask being worn incorrectly. The two unmasked members started asking the third why he was masking, "have you got it" "no" he answered, "just my wife and kids". So he's an extremely close contact of 2 cases, could be carrying an asymptomatic infection, coming to work in a hospital full of vulnerable patients and can't even wear a surgical mask correctly. Once on the correct floor, I head down the hallway to the reception area for the medihotel. Only to be greeted with a big sign on the door saying "surgical masks required, Staff may elect to wear an N95" once I made it through check in and into the actual infusion centre, the nurse taking care of me was wearing her surgical mask inside out. With the white part facing out. She then asked me if I had taken my rapid test (a negative test is required for entry, and they send text reminders beforehand) I replied yes, it was negative. She then said she didn't need to see it and she "trusted me". She then repeated that for every person in the four person [REDACTED] room. So nobody was properly checked to have a negative RAT. I was the first person there, but throughout the day people arrived, and took off their masks after they were sitting down. No members of staff made any effort to ask patients to keep their masks on. I was then stuck, as a severely immunocompromised person, in a room with a group of unmasked people, getting my [REDACTED] that makes me severely Immunocompromised, for over five hours. All of this means that I was unable to safely access critical healthcare that is vital to my wellbeing as a disabled person. For the following week, and for the entire day, I was constantly afraid that I would catch Covid and become seriously ill or hospitalised.

My second issue is lack of access to proper mitigations, firstly due to lack of affordability since the axing of government funded programs, but also due to the fumbling of designing said programs properly. As a person who catches public transport and can't drive due to my Disabilities, once the state funded free RAT tests through pharmacies was ended, I was not able to access free RATs through the library and community centres program as there were no accessible options for me that were feasible for me to get to on public transport, with most over an hour of travel away.

Being classed as severely immunocompromised, I was one of the people who was classified as eligible to access [REDACTED] but due to multiple factors I was only able to receive one dose before the government stopped funding it through the PBS scheme at the end of 2022. One of the main reasons I was unable to access doses prior to that date was lack of proper education and awareness for medical practitioners about measures to take to protect their immunocompromised patients. I presented the TGA website to my neurologist showing my eligibility and asked him to prescribe it, he was happy to do so but asked to see the rest of the website so that he could learn which of his other patients would be eligible. If there were better

recourses and awareness for medical practitioners, more patients could easily and efficiently access recourses that can help to prevent serious illness or death due to Covid 19.

Inability to access proper precautions that I am entitled to has been an ongoing theme throughout the pandemic. This year on the 8th of February 2023, ATAGI released recommendations for a booster dose after 6 months for all vulnerable and at risk groups. I was part of that group, but I was not made aware of the updated booster availability until the 22nd of September 2023, after the SECOND round of 6monthly booster advice was released which I only found out from Twitter. Because of the fact that booster advice was not shared widely through the medical system or mainstream media, I was not made aware of this. In fact I had actually asked my GP about this and she was not aware there was any indications that another booster dose was available. If I had fair access to this information easily and reliably I could have had another booster by now and almost be eligible for my second of the year in December 2023. Instead I have not had a single dose since December 2022. As a severely immunocompromised person this simply is not good enough. It is also completely unacceptable that this kind of important and life saving information is only available to those of us who are media literate and can find this information online. Doctors need to be fully aware of this information so that they can be the ones to advise their at risk patients who are not as media literate, especially when one of the main groups of people advised to have a booster are those aged over 65 & Disabled at risk people. We should not bare the burden of having to source this information ourselves, This is not acceptable. I am not medically allowed to get vaccinated within 30 days pre or post my [REDACTED] So I was only able to get my first dose of 2023 on the 1st of December. The last month of the year.

Another point I would like to raise is the ridiculous system to access antiviral treatment. [The PBS website](#) clearly outlines that in order to even receive PBS prices, you must test positive and get your script within 5 days, otherwise you pay full price. The full price of Paxlovid is 1,159\$ someone on Disability pension like me could simply not afford that. In order to do this, you need to realise you are sick, try a RAT, if that doesn't provide you with a positive you have to organise an appointment with your GP to get a referral for a PCR test. Neither RAT's or PCR tests are [100% reliable](#). I personally tested negative on a PCR only to test positive a few days later in 2022. Even if you manage to test positive, you really need to test positive on days 1 or 2, in order to see your GP for an antiviral script, within the first 5 days? I don't know a single person, including myself, who can get a GP appointment within 3-5 days. Then you still have to arrange to somehow get the script and have it sent to you? For someone like me who lives alone and has no family nearby, absolutely none of this is accessible to me. Even if I could arrange a referral to a PCR, I can't access one. And I couldn't during 2020,21,22 either. There was absolutely nowhere near enough walk in centres and getting the at home service to come and test you was a nightmare and they definitely didn't have enough staff to see people within a 5 day window. At home testing is now no longer even available, so someone in my position who does not drive or have anyone who can drive them to a pathology centre, cannot even properly access a PCR test. This forces people to be heavily reliant on RATS, which are much harder to test positive on in the first 5 day window.

In order to give people with Disabilities and immunocompromised people access to safe and adequate care when it comes to Covid 19, there needs to be better organisation and awareness of Covid 19 information and materials. Hospitals and medical practices need to be better equipped with the correct information and tools to provide adequate care for at risk groups.

The current (and previous) system for care means that people who are at risk to Covid are currently being forced to carry the entire responsibility of their care and mitigations completely on their own, and given the lack of access to the proper and correct and consistent information this means that vulnerable groups are currently not being afforded the correct tools to keep themselves safe or get the correct care if they catch Covid 19. And given the complete lack of public messaging about correct and useful mitigations to take to protect oneself from Covid, this means that at risk people are currently at a very high chance of catching Covid. I still see elderly people at the supermarket dousing themselves with hand sanitiser, but they are not wearing a mask because they are not being given fair access to the correct information (hand sanitiser will not save them from airborne virus particles.)

Staff of high risk essential environments should be [required to wear N95s](#), ESPECIALLY when in spaces with high risk patients (eg Oncology wards.) Employers should be required to give staff proper information and education on what steps they need to be taking to keep patients safe. Specialists and Doctors should have access to a portal for the clearest and best information about what to do to protect their patients, what patients are eligible for booster vaccines, antivirals and protective treatments like Evusheld so that they can properly care for their at risk patients. Patients should have access to a clear and concise website to determine their own eligibility for such things and what steps they should be taking to protect themselves if they so wish. You cannot have a personal responsibility strategy if you are not giving people the tools to even take that responsibility in the first place. But at the absolute bare minimum disabled and at risk people deserve to be able to safely and effectively receive their medical care without having to fight for the most basic safety precautions.