

1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;

I write from personal experience as both a long COVID sufferer and a physician who has both a research interest and track record in COVID-19 guidelines in immune-suppressed patients as I am a haematologist and bone marrow transplant physician. I was diagnosed with COVID in the first week of March of 2022. I had a mild respiratory illness while the rest of my family succumbed to a much more severe version. My three daughters and husband were bed bound, experiencing fevers, gastrointestinal symptoms and extreme fatigue. I took on the carer role for my family despite my mild COVID symptoms, which included muscle aches and pains and some fevers. Over the ensuing week, I recovered and returned to work. Unfortunately, three weeks later I began developing progressive shortness of breath which became severe and required hospitalisation. I was diagnosed with adult-onset asthma, which was not part of my medical history in the past. I was extremely unwell, bed bound, breathless and unable to walk more than 100 to 200 m without stopping. This was in stark contrast to my prior level of fitness, which was typically running three times a week, 5 km in 30 minutes, and two hours of Pilates a week. I began to recover with a course of high-dose steroids and inhaled bronchodilators and steroids. My fatigue levels did not particularly improve but I was able to participate in low-volume work. I noticed that my heart rate was relatively high for my own baseline but at that stage this was thought to be associated with my new diagnosis of asthma. I was surprised by how badly I was affected given I was immunocompetent and had 3 doses of the COVID vaccine.

Just as I was beginning to improve in terms of my exercise tolerance, I acquired COVID again through work in May of 2022. On this occasion, I experienced a much more severe respiratory tract illness with a productive cough, fevers, rigors, muscle aches and headaches. It took a week for me to recover after taking the antiviral Paxlovid. I returned to work briefly. I had to stop working due to a progressive light-headedness that resulted in fainting episodes on three occasions. I was sitting in my clinic awaiting my next patient when I fainted from my seated position and woke up on the floor. Nobody was aware of this as the clinic room door was closed and I was by myself. I recovered relatively quickly and thought perhaps I had not drunk enough fluids as I was wearing personal protective equipment while I saw patients. I had a waiting area full of bone marrow transplant and blood cancer patients and so brushed myself off and persevered despite not feeling quite normal. The staffing pressures at the time were extremely high and I minimised my symptoms as “normal recovery from COVID” as many of my colleagues around me were also experiencing symptoms like mine. I then fainted again a couple of days later while I was in my office and again there was no one there to assist me or had noticed that I was on the ground. I woke up and I felt this time I had to do something. I was reviewed by a cardiologist who diagnosed me with postural orthostatic tachycardia syndrome. This is an autonomic nervous system dysfunction which means my heart rate goes out of control as I stand up and I lose my blood pressure and therefore lose consciousness. It progressively worsened within a few weeks of my second infection to the point that I was not able to stand for more than 30 to 60 seconds. My life was entirely ruled by where the next chair was. I had to crawl into the shower and turn the tap on and shower myself on the floor. I would have to crawl back into my bed to get dressed and try and sit up and make it to my car to get to work. You may ask how I was able to manage this safely and the answer is I normalised my symptoms and I normalised this kind of disability in the setting of a recent COVID infection. I started to become more breathless even at rest while in bed. I started waking up in the middle of the night with palpitations and a heart rate as high as 160 when my resting sleeping heart rate is normally in the low 50s. This was extremely alarming and sometimes made me feel like I was about to die. I was admitted into hospital with severe breathlessness, low blood pressure, severe headaches and an inability to even walk 100 m without having to stop. I received numerous investigations of my heart, lungs, brain and I was given another course of antiviral therapy. My symptoms did not improve and I was offered a rehab program while I was an inpatient.

for a week. This was extremely limited as I was unable to be upright even in a seated position without feeling lightheaded and my heart rate rising dramatically. I was bound to a flat position as much as possible and even toileting had to be completed in 30-to-60 seconds or else I might find myself on the floor without any witnesses. Doctors offered symptom controlling drugs that were not based on any evidence but educated guesses. Something to make my heart rate slow down which would make my breathlessness worse. Something to increase my blood pressure which made my headaches worst. Antibiotics for the inflammation in my sinuses which made my gut symptoms worse. The lack of evidence for effective treatment strategies was galling as a physician who highly values evidence based medicine.

This was an extremely difficult time in my life as I have experienced illness and the experience of being a patient before but never to this extent and never with such a level of vulnerability. This is because the clinicians around me knew very little about what was happening to me or how to assist me. I could see on the clinicians' faces a sense of helplessness and over time this evolved into a look of frustration on their part for not being able to see improvements while I was in hospital. Our hospital systems are not designed for illnesses that cannot be solved. I was surrounded by numerous nurses who would do my blood pressure, notice that it was low and have nothing to offer. I would ask nurses to not leave me by myself when I knew that I was about to faint even while I was lying down. While I was in hospital, I lost time on numerous occasions indicating that I had fainted in my bed. I had one of those episodes while I was in fact inside an MRI machine. I did not even think that it was important to let anyone know that that had happened because it had already happened. I was becoming very accustomed to the episodes of fainting and the lack of control I had over my body. I was aware that all the tests and all the observations that were occurring every four to six hours during my day looked abnormal but no one had anything to offer in terms of intervening or improving my symptoms. I would repeat my story to every doctor, to every nurse and every physiotherapist and occupational therapist who came to see me. I had a moment where I felt sharing my story over and over was actually more draining than the actual illness. My energy levels were extremely low and even the act of speaking and sharing my story was becoming draining. I reflected as a doctor how cruel it was to ask patients who are extremely fatigued and vulnerable and have no energy to even stay awake to have to share their story with accuracy and repetition because that is how we are trained. Every doctor and every nurse had to corroborate every single piece of information repeatedly. There were times towards the end of my admission where I felt despite the sadness of leaving my children behind that it would not be the worst thing in the world for me not to be alive anymore. I was neither depressed, nor teary, nor anxious, just aware of the limitations of my profession and what it can offer. The pervasive advice I was given was "to wait because most people improve". When I asked "how long" that is when the expression on people's faces was more telling than what they said. "A year perhaps, the majority of people return in a year." When I explained that I was unable to look after myself and my children in the current state there was no offer of help or solutions to that problem. I was advised "not to get COVID again" and when I asked how I could do that, there was always a shrug and a look of inevitability in me getting COVID again. What I would love to hear is, if you get it again, we will give you antivirals and will monitor you very carefully. Unfortunately, I would not be eligible for antivirals under current criteria as I am informed by general practitioner and would not likely get an appointment for weeks to see him.

As the pandemic progressed and public health restrictions eased, I noticed that people around me treated me like I was not only fragile but a reminder of a distant past where things were disturbing, difficult and abnormal. I would hear comments about how "COVID is over" and was a "mild flu" and that there was no reason to mask. People would casually ask, "can you please remove your mask?" and I would say, "I am sorry, but I cannot," and I had to disclose that I had very good reasons for needing to be masked. It was not even a matter of preference, it was a matter of life or death for me. I did not know how to protect myself from COVID again with three children under the age of 10

who would come home with viral symptoms on a daily basis. I was essentially isolated from my own family in my room on a regular basis wearing a mask and ensuring that if any of my children had a viral illness, they were very far away from me in our own home. My daughter remarked one day, "Mummy, your room looks like a bat cave," because I preferred the dark with the headaches and the sensitivity to light and because I was asleep a lot of the time and lifeless compared to who I used to be. They would ask, "When is long COVID over for you, Mummy?" and I would say, "I don't know. That's why it's called long COVID." I reflected on how difficult it was for me to be at home and a shell of who I used to be. I valued my intellect, my physicality and my love of socialising. My intellect had diminished as I found it difficult to read or write an email, read a book, watch a TV episode or sustain a conversation. My physicality and love for running had completely disappeared as I was unable to even walk to and back from the shower without severe breathlessness. I would have people offer to visit and show me pictures of their RAT test to prove that they were COVID negative so that they could come and see me. I was humbled by the love that I found around me but also saddened that even those interactions were extremely draining. This meant having to choose a phone call or a visit with a friend over being alert enough at the day to be with my children.

I was not able to get access to a long COVID clinic for months after my discharge from hospital as the clinics were overbooked. My brain did not compute appointment times and I often forgot what they told me. I would ask them to repeat the appointment times over and over and sometimes email me so that I could read it again and enter it into a calendar with a reminder so I did not forget. There were so many appointments. I saw a cardiologist, a respiratory physician, a neurologist, a physiotherapist, an occupational therapist, a dietitian and an infectious diseases specialist. Most of the time, I found the numerous appointments confusing and difficult to coordinate and manage as I did not have the physical, mental and emotional capacity to orchestrate and organise all of these appointments. My care was discussed by my various clinicians at multidisciplinary team meetings. These meetings happen without the patient. Decisions were relayed to me through various routes which was very confusing. Most of the time, there were no decisions to be made other than remarks about my slow improvement and how that is "expected". There was some investigations around my lung function that were dramatically abnormal at the time of my second hospital admission that were improving, which was reassuring. My heart rate lability, however, was no better for a very long time, so my lightheadedness symptoms did not really improve until six months later.

I am now able to stand up for five-to-seven minutes at a time but am always conscious of where the next chair, or ledge are so that I can hold on, lean or fall safely. I cannot be outside for long periods of time in case I fall. I have a falls alert on my watch. I am always wearing a mask. I have a portable CO2 monitor for when I do medical centre visits or doctor visits to keep an eye on the quality of the ventilation in those spaces. I was concerned that the ventilation were so poor in those waiting areas with many patients waiting not wearing adequate masks. I was aware that I was also at potential risk of acquiring COVID again waiting for my clinicians to see me. I began to realise with my repeated visits that no one could change the course of my disease but they could offer support and validation that what I was experiencing was real and that others were going through this also. It was in their expert opinion that the majority improved and all I could do was trust that. One of the biggest gaps in my care was a plan of what to do if I were to be exposed to or acquire COVID again, or how to protect myself from getting COVID in the first place. That is what I needed to help me navigate a world where COVID waves were going to be a norm and children who would come home in the future with COVID, which is now my reality. One of my children had COVID only two weeks ago and had to be isolated in our upstairs room while I was in our downstairs room locked away to ensure I did not acquire it. One of the other challenges of having long COVID is the incredibly immune-suppressed state one is in. I would get every viral illness that my children picked up including non-COVID viruses and these would hit me harder than I have ever been hit by viral illnesses. All of the long COVID symptoms would be amplified all over again. I would be bed bound for days, unable to move, unable to do anything

including eat. In eight months, I lost 25 kg due to poor nutrition, low appetite and essentially being asleep a lot of the time I was unwell.

2. The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;

Prior to contracting COVID, as a haematologist and bone marrow transplant physician, I spent the early parts of the pandemic trying to protect my patients from COVID. Haematology and bone marrow transplant patients had the highest risk of mortality from COVID with a risk of death between 30% to 50% in those infected in that population. As the president of Australia and New Zealand Transplant and Cell Therapies, I led the coordination of guidelines around how to protect patients from COVID, including how to implement alternative ways of storing stem cells that are usually transferred across the world from benevolent donors. This was suddenly no longer a reality as the borders were closed all around the world. I was contacting Commonwealth officials to discuss how we could together ensure transplant patients were as minimally affected as possible. My colleagues and I have contacts all over the world who had experienced much more severe waves of COVID and spoke of the horrors of the majority of their patients on a ward who were being treated for curable blood cancers dying so rapidly and so uncomfortably. Many of them were alone. I have even lost colleagues to COVID around the world.

I feared for my patients not only because COVID meant transplant products coming across international borders was a challenge, but also that those who had received their transplants were extremely immunosuppressed and at an extremely high risk of dying from COVID. I observed the pain and suffering of my patients who were isolated in hospital during catastrophic diagnoses of fatal blood cancers who did not have loved ones around them as we would be accustomed to for physical and psychological support. The moral injury associated was high. I started to question the ethics of offering patients life-saving immune suppressive therapy for blood cancers and transplantation in a world where the risk outside of my clinic was so high especially when society at large was unaware of that impact on my patients. The messaging my patients heard on the news was that if you got vaccinated you would be safe and that it would be a mild illness. That was not the case for the kind of patients that I saw. COVID vaccination was not routinely effective in this population of patients. There was never a suggestion that it would be, but patients did not see themselves as anything different to anyone else. I spent a lot of time counselling patients to explain why despite vaccination, which was the best protection offered for everybody else, was not the best protection for them. I counselled them on how they had to wear N95 masks and avoid socialising despite all the public health precautions that were in place. The amount of energy spent counselling patients on this was enormous. It was always met with confusion, disbelief and despair. I had to do this 50 to 60 times a day. I answered phone calls from concerned patients and family members about whether to be vaccinated, the risks of vaccination, the success rate of vaccinations with their underlying diseases and on a regular basis had to answer questions about specific social gatherings and advice on how to protect themselves from acquiring COVID as they desperately wanted to connect with their friends and family. When antivirals and monoclonal antibodies became available, I had to spend hours staying behind at work until 9 and 10 pm so that I could call my patients and explain to them that they had access to antiviral therapies, so they needed to contact me within five days of symptoms if they developed COVID. Some nights I had lost my voice from all the phone calls I was making and all the conversations I was having with patients well in excess of what I would normally do prior to the COVID pandemic. Nevertheless, many of my patients did not call or come to hospital when they acquired COVID. Some died and some languished in hospital unable to clear the virus despite antivirals offered and were in hospital for weeks and weeks as their bodies were unable to combat the virus or clear it. Inevitably, this meant that some could not continue their life-saving blood cancer therapies or the

treatments had to be truncated or doses reduced, all of course which had the effect of limiting their expected survival compared to prior to the pandemic. For my patients who got COVID, they would express their post-COVID symptoms, and if I am honest, despite my knowledge of long COVID as a researcher and a clinician with an interest in COVID in my immune-suppressed population, I still could not understand what they were describing before I experienced it myself. Some would use words like extreme tiredness, inability to get out of bed, breathlessness, chronic cough, lightheadedness and headaches. What I did not appreciate at the time was how all of the symptoms were likely happening all at the same time. We are not used to patients describing symptoms that may not necessarily be severe but in combination are debilitating and essentially are a complex disability that requires a more holistic approach and understanding of the impacts of COVID as a multisystem disease rather than a respiratory illness.

I remember the long days and exhaustion after being in PPE all day. Prior to COVID, I was always proud of carrying my water flasks and coffee and tea flasks to make sure I was hydrated and could maintain a high level of energy even through my very long clinics of 30 patients or more a day. I started to notice that I was barely getting a few sips of water a day and getting home. It is very subtle because it is much easier not to touch your mask or take it off during the day to avoid contamination. It was hard to wear PPE in patients' rooms with full gowns that were made out of plastic. It did add to the pressure of needing to leave a patient's room, which is not something I have ever had to experience before outside of the pressures of time.

I recall a patient who was very dear to me with a lot of sadness. He was incredibly strong towards the end of his life. We spoke in broken Russian to each other for a human interaction. He was in hospital with his second COVID infection. He was isolated from his family who could not visit. He was mildly unwell needing oxygen but every week a new complication would arise. He could not clear his virus because he had an underlying blood cancer that immunosuppressed him. Both he and his family were in disbelief. They could not understand why the second infection was worse than the first. They would repeat how they heard it was the opposite and that "hybrid immunity" was better. They could not understand how this could happen after being fully vaccinated. He died after a miserable 9 weeks in hospital alone, slowly acquiring complications and organ dysfunction. Watching a patient die is never easy, but I have always taken pride in being part of their journey and allowing them to face dying with dignity, comfort and the love of their family around them. The fact that I was unable to facilitate that for this patient was one of the hardest things I have ever had to experience. After that experience, I had to protect my mind and my heart from this type of moral injury. As clinicians who look after patients with fatal illnesses, we learn how to do this but never with callousness. I started to notice that over time it became harder and harder to manage the excessive demands made of us physically to see many more patients as many of the staff were away due to illness, including nurses and doctors. The demands from our patients were well above what we would normally expect even under fully staffed circumstances and the psychological burden and fear around COVID was extremely high not only around our patients but our colleagues and our families.

3. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia.

One of the challenges as a long COVID sufferer was not knowing that I was at risk of getting long COVID. I understood theoretically that it may happen but I never thought it would be me. The literature suggested it was those who had severe illness that would get long COVID. It was in patients who were in ICU for long periods of time and had lost muscle mass and organ function. It did not occur to me that it could affect someone young, healthy and fit in the prime of their life. I simply did not have time to have long COVID. When I was diagnosed, I scoured the literature to understand what was happening to my body. As a physician, it is the only way I know how to make sense of illness, to

understand how it happens from a biological perspective. Sometimes I reflect that was the reason I became a doctor in the first place. No matter how much I read, I could see how researchers were scrambling and grasping at straws. Publication after publication repeated the same information. It was clear that it was a multisystem disease. It was clear that there was evidence that there was a preponderance in women. There was evidence that it was similar to myalgic encephalitis or chronic fatigue syndrome. Nobody quite understood the risk factors other than general socioeconomic determinants of health and potentially a background of severe COVID and comorbidities. The causes seemed unclear. There was the possibility of virus replicating in sanctuary reservoirs in the body. There was the potential that it was an autoimmune abnormality related to the virus and possibly a microthrombotic constellation of complications. As for the management, the literature was sparse. It was, for lack of a better term, educated guesses of how to address this multiorgan dysfunction. As a doctor who has now experienced long COVID, it felt like researchers were not only grasping at straws but publishing every idea that came into their minds, sometimes publishing the same idea or the same data just in different ways and different prose. At the end of the day, there was no known effective therapy and there was no way to successfully manage a patient so that they would recover faster, if at all.

There was a focus on the systems or organs that were affected, "If the patient has myocarditis, treat as per myocarditis; if they have inflammatory lung disease, treat the lung disease; if there are gastrointestinal symptoms, manage those symptoms; if there is fatigue, use various exercise strategies." None of these were evidence based. It was extremely difficult for me to accept that there was no evidence. The data on the incidence of long COVID ranged greatly, from 4% to 30% in some publications. I could not find compelling evidence to believe either of those figures. The reason I am a sceptic of all the current research and the numbers that are expressed in the literature is the simple fact that this is an extremely challenging disease to enumerate. I make this observation as a researcher with lived experience. In the first instance when I felt unwell, I did not recognise I had long COVID. There was no language for me to explain that this was long COVID. Most of the discourse in the public domain pointed to a severe illness that would be so debilitating and so nebulous that I did not even think what I was experiencing was long COVID. The fact that I was fainting all the time and had no control of my blood pressure did not occur to me to be related to COVID even as a physician and a researcher in COVID. I can imagine for non-clinicians it would be very difficult to articulate the symptoms that persist after COVID, so the pickup rate for this problem is going to be extremely low.

The other challenge is the lack of knowledge amongst clinicians around post-COVID symptoms and complications. I presented to a general practitioner who was very kind and when I explained to her that I felt extremely lightheaded and breathless, she listened to my chest and she said, "your chest is clear." she listened to my heart and said, "your heart sounds sound normal." She checked my blood pressure and said, "It is very low but you look okay!". She sent me to get investigations including an ECG to check my heart given I was so breathless. It did not occur to her to say this could be long COVID, and also it did not occur to her that it was probably unsafe for me to walk out of her clinic. My abnormal blood pressure did not trigger a red flag or an alarm. I was always trained that if a patient has low blood pressure and is lightheaded that requires intervention because essentially the patient could lose consciousness. Unfortunately, this experience was replicated over and over as I expressed my symptoms very clearly in a very technical and professional manner but was always met with scepticism, "you look okay," "your colour looks good: (I am a black woman), "you will probably get better soon." At no point were my expression of seriously debilitating symptoms ever met with the level of concern I would expect from clinicians working in the pandemic with a good understanding of the effects of COVID and potential long COVID. It became clear to me that those caring for me knew less about COVID and long COVID than I did. Sometimes as I lay in my hospital bed for weeks on end I reflected that denial is a way of protecting themselves. How does someone work with patients every day knowing that they are at risk of exposure to a disease that has a risk of creating such severe

disability for them while they are in the prime of their lives. I also realised that clinicians do not have time to talk to each other. My cardiologist thought my heart problem was not the cause of my breathing problems. My respiratory physician did not think my lungs were the cause of my high heart rate. My early morning coughing was thought to be related to my asthma and not necessarily related to any gastrointestinal side effects. My headache was related to possibly sinusitis and not to any of the other symptoms I had. It took six months before I met a clinician who looked at me and said, "your autonomic nervous system has been damaged by COVID. It has manifested with a labile heart rate, dysfunctional breathing, dysfunctional gut movement and probably neurological complications with headaches and cognitive impairment". That was too long to wait for but such a relief to hear. I am tearful just thinking about that moment when I was not seen as a constellation of organs not working but a person experiencing an illness that had various manifestations.

I began to research the risk factors and how I may have fit the pattern for long COVID. All I could find was it affected women disproportionately, especially women in their prime between the ages of 40 and 60, and that potentially my ethnic background had a role to play in my risks. I believe that researching long COVID begins with a good understanding of the biases that exist in our current healthcare paradigms. The current systems are not fit for purpose. We talk about patient-centred care, but during my outpatient treatment, I didn't feel centred in the discussions about my care or about my condition. People would always talk about me when I was not there, so I could never correct any misconceptions or incorrect information, which occurred repeatedly. It was incredibly challenging to feel so unheard and have to repeatedly correct my history to my clinicians. It certainly did not feel like they understood what was happening to me and therefore could make informed decisions about my care in my absence. Despite all the negative experiences I have had, I can categorically say I am proud to be a physician and part of a community of human beings that wake up every morning in the service of others. Every doctor and every nurse was trying their best. They offered care to the best of their abilities and under significant time, resource and personal pressures. My experiences are not a reflection of their skill and care but the systems under which they are operating.

One of the areas I think is in much need of research funding is co-designing models of care with long COVID patients. Even in the absence of known treatments, it is clear that the model of care that we are accustomed to in clinical medicine, even in multidisciplinary teams, is not effective. I wanted to be in the room with all the people who were going to look after me or had something to offer towards my recovery. I wanted to tell my story one time and have them all hear it and all tell me what they thought at the same time. I wanted them all to agree and be on the same page at the same time so I did not receive contradictory information from one clinician one day and then a different opinion the next day from within the same team. I wanted to be able to direct my care as the central team member in the multidisciplinary team. Our current systems do not allow for this and research into more appropriate models for long COVID need to be made. Another area is the use of telehealth, which was extremely helpful to me when I was unable to get out of bed, get into the car, find parking and walk to an entrance of a clinic. Some days I was bed bound and being able to turn on my computer and speak to a clinician was extremely helpful. We need to be able to understand how we can utilise digital health methods for long COVID care. Appointment management systems that are linked to the hospital systems would be a real help so that the burden of recalling appointments is solved electronically. Understanding the practical challenges facing patients with this level of disability is key to supporting them. I recall for my first COVID clinic appointment the front desk staff informed me that I could call and have someone meet me at the carpark with a wheelchair if I needed it. I was struck by how moving that gesture was. It was as if someone understood what I was going through for the first time without me saying a word. It is these little things that make us feel seen, heard and valued.

4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader

community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;

I think the broader health of our community will never be the same again. I do not think that we will ever be able to offer the high-quality care that we used to offer in Australia. Our primary healthcare sector has been decimated. I now wait six to eight weeks to be able to see a GP in my area. My GP colleagues tell me they are burnt out and cannot sustain the high levels of demand, the costs incurred to maintain their businesses and also the devaluing of their services. I think hospital systems are so overwhelmed by the denial of the existence of COVID in the community and the impact it has on individual patients with COVID infections but on the resources that are redirected towards COVID and take away from the care of patients that would normally expect a high level of attention and resource utilisation for serious conditions that require emergency or life-saving interventions. Our human resources and our physical resources that were at capacity prior to the COVID pandemic have been stretched and eroded in ways that are invisible to our community, healthcare leaders and politicians. No one in the healthcare sector is willing to speak up and say, "We can't do this anymore." We are stretched beyond our capacity and the people who suffer at the end of it all will be the patients presenting at our doors. We have been asked to discharge patients so that we can make room for the queues of patients in the emergency departments. When we discharge these patients, we know that this is under less than ideal circumstances. We know that some patients discharged with COVID maybe going home of vulnerable family members. We can no longer hold on to patients in hospital to protect the family members at home. The pressure of an ill family member and the carer requirements that come with that are extraordinary and invisible to the community but are borne by families and mostly women. My husband is a stay-at-home father. When I got long-COVID, he became not only my carer but the carer of my three children. The physical and psychological pressure of this has taken its toll. I am privileged to have access to sick leave and workers compensation payments to support my recovery. This was not easy to achieve, given I was completely incapacitated by COVID. It took many months to access those entitlements. I am very aware that I am privileged to be in this position and that many Australians do not have the luxury of self-isolation, access to sick leave and entitlements that can support their recovery. For all those who live in overcrowded homes where it means that they are at risk of repeated infections with COVID, my heart breaks. For all those who have no access to stable income and support financially to recover, my heart breaks.

I have not even mentioned groups that face greater disparities in health outcomes due to either intersectional identities or social determinants of health. My patients who are in rural regional Australia who may suffer with long COVID and cannot dream of accessing a long COVID clinic are never going to have the validation and support I did to make me understand that despite the lack of efficacious therapy that what I was going through was real and that it meant that I had to stop working and look after myself until my body healed. I think about women who bear the brunt of the carer responsibilities for their parents and their children who will not have the luxury of being able to stop and prioritise their own wellbeing and care. I certainly found this extremely challenging. I think about those with language barriers who cannot even express their symptoms or articulate what may be happening to them for it to be diagnosed as long COVID and for them to be heard, validated and supported. I think about all the racial bias that occurs and the fat phobia that we demonstrate in the healthcare system so that women who are in larger bodies are often told to "exercise so that they can regain their fitness". While I was extremely fit, I do live in a larger body and was in fact told many times that it was due to my weight. I recall that when I was first admitted into hospital I was weighed three times within the first two days but my respiratory rate was only recorded once, when I requested it.



I am not alone in experiencing long COVID amongst my colleagues. Many of my medical colleagues have been perplexed by the fault lines in medicine that we did not recognise before. We only saw them so very clearly in a singular shared experience when we got long COVID and could see our profession from the inside. There is an over exaggeration of the risks of people with existing health conditions in terms of the risks of long COVID. The term "existing health conditions" does not capture the diversity of those conditions. Some may have simple skin conditions, some may have mild blood pressure problems, but neither increases your risk of long COVID nor does it increase your risk of severe COVID. However, it is often seen as an excuse for why some patients may have severe complications from COVID. It is not expected that someone with a mild skin condition or a mild blood pressure problem will have long COVID. There is no evidence to support that. Patients with disability have existing physical disabilities or neurological disabilities that may make it challenging them to acquire more levels of disability and this is certainly a good reason to ensure that these patients are protected as much as possible with vaccination and antiviral access. One of the ironies of my situation is that when I got COVID the second time I was eligible for antivirals not because I had experienced a hospitalisation with my first COVID infection, which in my opinion is a risk factor for long COVID and for complications from a second infection of COVID, but because I had a BMI of 30. A BMI of 30 is considered obese in white populations but not in black populations, which is what my racial background is. I think a lack of understanding of those at greater risk is one of the challenges in Australia. For instance in the evidence produced by the COVID-19 National Clinical Evidence Taskforce, racial background and ethnicity was never identified as a risk factor in Australian guidelines. This, however, was well recognised in data from other countries. In PBAC recommendations, although Aboriginal and Torres Strait Islander status was considered a risk factor, other ethnicities who also had a higher risk of mortality from COVID were never included. It also means that these under-recognised at-risk groups are likely to bear a disproportionate burden of the impacts of long COVID. I am pleased that I have the opportunity to offer my expertise in intersectionality in medicine and have raised this issue with the COVID-19 National Clinical Evidence Taskforce and now advise them on this issue.

5. The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and

Repeated infections have been shown in numerous publications to increase the risk of long COVID. Certainly with the impact of waning immunity and various vaccination compliance records amongst Australians, it is clear that many Australians will experience repeated COVID infections. While the risk of long COVID increases with each new acquired COVID infection, the long-term implications are very difficult to establish for any individual patient. It is clear, however, that the health system will have to accommodate the many post-COVID complications reported in the literature, including an increased risk of type 1 diabetes in children, lung, heart and neurological disorders. For those who did not seek medical attention for non-COVID conditions during COVID for fear of acquiring COVID or due to lockdowns there are implications. We have seen an increase in presentations with later-stage cancers that would have been picked up either in screening or or delayed care. However, an added concern is the ability to access healthcare has also dramatically reduced because of the reduction in the healthcare workforce either due to the transient furloughs with every wave, staff leaving the healthcare professions and a significant reduction in services in hospitals that are overwhelmed and unable to sustain funding with the previous funding models that incentivised activity-based funding.

We have minimal expertise and specialist clinics for patients experiencing post-COVID complications particularly in children. This level of coordinated care is very challenging to build on a national scale without dedicated resources and upfront investment in these services. A lack of a coordinated

approach will undoubtedly lead to inequitable health care outcomes. We are facing a significant crisis in healthcare workers as demonstrated in other countries around the world. The rates of burnout, career dissatisfaction and illness related to COVID have also affected the healthcare workforce which will undoubtedly have a long-term impact on the healthcare services we are able to provide the community. Australia's excellent healthcare system is based on a highly skilled healthcare workforce with tremendous knowledge and skill that is being systematically eroded with no clear urgent national contingencies to mitigate this. The impact of long COVID in terms of the levels of disability and immune suppression and risk of recurrent infections on ongoing compounding health conditions will mean we will have a high proportion in our population with excessive comorbidities and disabilities that will undoubtedly impact our economic stability, productivity and health.

6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

Having had the experience of long COVID, I can categorically say that I do not want to have any more COVID infections. I know with every infection my risk of COVID complications will increase. My disability and symptoms will recur and potentially last longer, although I am not sure anyone knows what repeated infections will mean longer term beyond the first one or two years of long COVID. I believe that the best practice to address this risk is to prevent the spread of COVID. I believe the best approach to preventing the risk of long covid is preventing acquiring any further infections. I am concerned that the public health messaging and public discourse around prevention is suboptimal and will not mitigate this risk. The messaging around personal responsibility is challenging because I am unable to take personal responsibility for other people's actions putting the risk of my children acquiring COVID and bringing it home to me extremely high. I was disappointed that during the pandemic I had to explain to people that fitted masks were better than surgical masks because there was so much confusion around the need for fit testing with P2/N95 masks. I believe that public health education campaigns need to focus on the value of masking, ventilation and an acknowledgement that COVID is an airborne virus and therefore ventilation is extremely important. I would like to see an investment in improvement of ventilation of indoor spaces. I think CO2 monitors in schools and HEPA filtration devices or assessments of indoor spaces particularly in public health and public education settings would be vital. I am heartened to see the private sector taking note of this and engaging in protective measures of their staff. I think that it is important to educate about the value of minimising recurrent infections with COVID to avoid long COVID given the significant potential for disability in each individual. I believe that as we have transitioned to an internationally open society, we will need to curtail the spread of COVID so that its impacts are also not felt at home. I would like to see more messaging around the need to protect our families and our communities so that we can continue with our quality of life outdoors, our livelihood and professions as well as a healthy family life, all of which are the cornerstones of Australian society.