

OzSAGE submission for the Inquiry into Long COVID and Repeated COVID Infections – Parliament of Australia

Key points

OzSAGE members have been patients and many are treating health professionals themselves. They have concerns for the impact of long COVID and post-acute sequelae on their home, community and work life, the difficulties accessing care and antiviral medication, the confusing maze and wait for review from multiple specialists, the lack of clarity for their diagnosis, cause of their symptoms and the uncertainty and conflicting information on appropriate treatment. One of our member patients related, *“the frustration is accessing care and then accessing people who are knowledgeable around long COVID and then coordinating care. One of the biggest problems is this brain fog issue. Someone has to coordinate multiple doctors’ appointments from various specialties, none of whom talk to each other. It’s really hard to keep track of all of that.”*

1. The precise incidence of long COVID has yet to be determined, but a growing body of scientific evidence indicates that, internationally, at a minimum 4% of vaccinated people who have a breakthrough infection will experience symptoms lasting for three months or longer. More credible estimates, repeated in several studies, are [around 15%](#), with high estimates over 30%. [An Australian survey](#) estimated 29%. The incidence of long COVID is higher in unvaccinated people, and reinfection increases the risk. There is no reason to think Australia will be exceptional.

2. Vaccination can reduce the risk of a person developing long COVID and other serious post-acute sequelae of COVID-19. The extent of protection remains uncertain, with estimates ranging from 15 to 41%, indicating less than half of cases of long COVID are prevented through vaccination. A vaccine-only pandemic strategy is insufficient to protect Australians from long COVID and repeat SARS-CoV-2 infections, particularly when, without action, high numbers of infections will continue to occur.

3. In addition to the risk of developing long COVID, people infected with SARS-CoV-2 are at significantly higher risk of serious cardiovascular and metabolic complications, including heart attack, stroke, diabetes, and kidney disease, as well as damage to the nervous and immune systems. There is credible evidence that the risk of experiencing these outcomes increases with repeat infections. Infection during pregnancy may have adverse outcomes for both mother and baby,

4. Children are at risk of developing long COVID. The US Centres for Disease Control (CDC) has also reported that children and adolescents can experience serious post-acute sequelae including myocarditis, cardiomyopathy, kidney failure, diabetes, and pulmonary embolism and other thrombotic events. A Danish study showed the highest risk was in children 0-3 years compared to older children, a compelling reason to vaccinate younger children.

5. There is clear and compelling evidence from around the world that SARS-CoV-2 spreads readily in schools. Children are at high risk of infection and reinfection if

mitigation measures such as improved ventilation and air cleaning technologies are not present in the school environment, as recommended by The Lancet COVID-19 Commission Task Force on Safe School, Safe Work, and Safe Travel, Whitehouse Summit on Improving Indoor Air Quality. Australia's National Covid-19 Evidence Taskforce does not currently cover ventilation - a gap that we recommend should be filled.

6. SARS-CoV-2 will continue to circulate into the foreseeable future. Australia will experience ongoing waves of COVID-19 due to the winding back of strong preventive and isolation measures, waning vaccine efficacy, suboptimal booster rates and immune evasion. High levels of infections and reinfections will lead to impacts on workforce, reduced life expectancy and diminished quality of life due to long COVID and post-COVID health problems.

7. The symptoms of long COVID - which can include profound fatigue, shortness of breath, and cognitive problems - can be incapacitating. The symptoms could have cardiac, respiratory, immunological or neurocognitive aetiology, but no clear screening, testing and referral protocols exist. There is a need for guidelines on screening, testing and referral. We need better imaging techniques, and increased access to imaging, oxygen delivery services, surge capacity and maintaining respiratory physician and allied personnel, and rehabilitation services including services for patients who cannot manage at home. Treatment guidelines are needed, with early data suggesting antivirals reduce the risk of long COVID.

8. Long COVID is a heterogeneous problem affecting many or some organ systems requiring a holistic perspective on diagnosis, treatment and prevention, not a one-size-fits-all approach. However, patients require a clear treatment pathway. People report being sent to multiple specialists within long COVID clinics which can be confusing, particularly when contradictory advice is sometimes given. Accessing and coordinating care can be difficult when patients are acutely unwell. Some patients report being discharged without a diagnosis or specific treatment.

9. Australia should collect and publish data on long COVID prevalence and incidence. Given conflicting definitions of long COVID, it is difficult to know how many people are affected. There are now International Classification of Diseases (ICD) diagnosis codes for post-COVID conditions. There is a need for information specific to Australia's demographic profile. Collection of local data in a systematic way at the primary care level should be encouraged.

10. Health care workers, including GPs and emergency physicians, need education and decision support tools to better recognize, diagnose and manage long COVID and post-acute COVID-19 sequelae.

11. In the absence of urgent preventive action, long COVID and repeat SARS-CoV-2 infections will result in enormous health, social, economic costs for Australia without urgent preventive action. The Brookings Institution recently estimated that four million Americans are unable to participate in the workforce due to long COVID. Similar impacts can be expected in Australia. The full impact of long COVID is yet to manifest in Australia because the population was largely protected from infection in 2020 and 2021.

12. Clean indoor air is essential to mitigate repeat SARS-CoV-2 infections and resultant long COVID. Peer countries are moving to set targets for unfiltered indoor CO₂ levels (as a proxy for ventilation) in public spaces, such as schools, restaurants, and workplaces. For example, Belgium has recently passed legislation that requires all public places to monitor their indoor air quality and install a CO₂ monitor that is visible to the public. In New Zealand, all schools have been supplied with a CO₂ monitor and air purifiers are used when ventilation is insufficient. Australia should follow by mandating and championing indoor air quality standards and other clean indoor air technologies. More cost effective is investment in safe indoor air and other mitigations.

13. Australia should also ensure that ongoing, updated vaccine boosters are offered to people of all ages, including children, at appropriate intervals based on evidence for protection against adverse outcomes due to COVID-19 infection, not limited to severe disease and death. People for whom vaccination is contraindicated should be supported with other mitigation measures.

14. Reinfection with SARS-CoV-2 is common and it is likely that the majority of Australians will be infected repeatedly throughout their lifetime (possibly two to three times per year) unless mitigation measures are put in place to limit the spread of COVID-19. These measures should include: improved ventilation in public buildings, better testing regimens, mask mandates in high-risk environments (such as healthcare and public transport) and during times of rising incidence, the provision of adequate sick leave for all employees, and a requirement for people with COVID-19 to isolate so that they do not infect others. Close contacts should test and mask.

15. There is evidence to suggest that early use of anti-viral treatment may reduce the risk of people developing long COVID. Hence wider availability of subsidised antivirals may reduce the burden of Long COVID. It is important that access to subsidised antivirals is broadened, including to young adults, who may suffer the greatest loss of quality of life because of their longer expected lifespan. The cost of anti-viral treatments which prevent around a quarter of post-COVID sequelae, if used in timely manner, can be over a \$1200 per person.

Long COVID definition and prevalence

The World Health Organisation (WHO) has [defined post COVID-19 condition](#) (more commonly known as long COVID) as a condition that emerges within three months after infection with SARS-CoV-2, resulting in symptoms lasting at least two months, which cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, and cognitive dysfunction, which generally have an impact on a person's everyday functioning. Symptoms may be persistent or fluctuate over time.

There are other definitions including that of UK National Institute for Health and Care Excellence (NICE). NICE defines acute COVID-19 as signs and symptoms present for up to four weeks after SARS-CoV-2 infection; ongoing symptomatic COVID-19 as signs and symptoms of COVID-19 from four to 12 weeks; and a post-COVID-19 syndrome as signs and symptoms that develop after an infection consistent with COVID-19 that continue for at least 12 weeks and are not explained by an alternative diagnosis. In addition to these clinical case definitions, NICE notes that the term "long COVID" is commonly used to describe signs and symptoms that continue or develop after acute COVID-19, and includes both ongoing symptomatic COVID-19 (4-12 weeks) and post-COVID-19 syndrome (12 weeks or more). Codes for "post COVID-19 condition" have also been defined in the [International Classification of Diseases](#) (ICD). In ICD-10, the code is U09, while in ICD-11 it is RA02.

It is important to note that the incidence of long COVID depends on a number of factors, including the particular variant of SARS-CoV-2 that a person was infected with, the severity of the initial infection, the person's age and sex, the presence of any pre-existing health issues, and whether they were vaccinated. The varying incidence of long COVID in different studies reflects differing definitions, measurement methods, variants involved, vaccination history in populations included, and reporting.

[A systematic review](#) and meta-analysis of 33 studies involving 15,244 hospitalized and 9,011 non-hospitalized patients found post-COVID-19 symptoms in more than 60% of patients infected by SARS-CoV-2. [Recent data from Canada](#) shows that close to 15% of people who had tested positive for COVID-19 or suspected that they had been infected reported symptoms at least three months following initial infection. More women (18%) reported long-term symptoms than men (11.6%) but there were no significant differences by age group. People who experienced severe COVID symptoms at time of infection were [more likely to report longer-term symptoms](#).

The UK's Office for National Statistics (ONS) has reported that the incidence of long COVID (12 weeks) after infection with the delta variant was about 9% in double-vaccinated individuals and [5% in triple-vaccinated individuals](#). [After infection](#) with the Omicron BA.1 or BA.2 variants, the incidence of long COVID (12 weeks) in triple-vaccinated people is about 4%. Incidence is substantially higher in people who were hospitalised for COVID-19. Children can also get long COVID, with the risk highest in [children 0-4 years](#).

The variant too can affect incidence – in one study there was a [4.5% risk of long COVID](#) following Omicron compared to 11% after Delta. Even mild COVID can result in long COVID, with one study finding [diffuse swelling of the heart](#) in people who had

long COVID after initial mild infection. Well conducted studies in the US estimate the risk to be around 15%. A meta-analysis found [that 80% had post-acute symptoms](#).

In regard to Australian data, one [Australian study related 5% affected](#) with symptoms three months later, whilst another reported [a 29% prevalence](#) of long COVID at four weeks. During the first wave of COVID-19 in New South Wales, [4% of infected people had not recovered after three](#) months. Women, older people, and those with pre-existing health problems took longer to recover.

[By August 2022](#), it was estimated that at least 52% of Australians had had COVID-19. Of these, 11% have had COVID-19 twice and 5% have had it three times or more times. Almost one-third of Australian adults (29%) who had COVID-19 had symptoms that lasted for at least four weeks, and it has been estimated that 4.7% of Australian adults have had or currently have post-COVID syndrome (symptoms lasting for three months or more). A more recent study suggests that at [least 65% of Australians](#) have had COVID-19, but did not report how many were affected with long COVID.

Long COVID is defined by symptoms rather than pathology, but likely reflects heterogeneous pathophysiology, as COVID-19 can affect almost any organ system including the lungs, heart, brain and immune system. Long COVID is a [complex multisystem disease](#) for which diagnostic tests and triage are not well established. Although the incidence of long COVID is higher in people who were initially hospitalised with COVID-19, the severity of long COVID is not always related to the severity of the initial infection. People who experienced only a mild illness initially may subsequently develop severe long COVID. Symptoms can include fatigue, breathlessness, persistent cough, depression, headaches, mood swings, memory loss, other neurocognitive deficits, musculoskeletal inflammation, pain, muscle weakness, gastrointestinal upset, skin rashes, and immune dysregulation.

People who have had COVID-19 (including those with a mild initial illness) are at increased risk of [heart attack, stroke, diabetes, kidney disease](#), and other [serious complications](#). Vaccination is even less effective at preventing these outcomes. It has been reported that receiving 2-doses of either the Pfizer or Moderna COVID-19 vaccine (or the single-dose Johnson & Johnson COVID-19 vaccine) is only associated with a [15% reduction in the risk of experiencing](#) these severe post-acute complications of COVID-19. Concerningly, research indicates that the risk of experiencing these outcomes [increases with reinfection](#). [Over double the risk of deaths and hospitalizations](#) have been found with repeat infections.

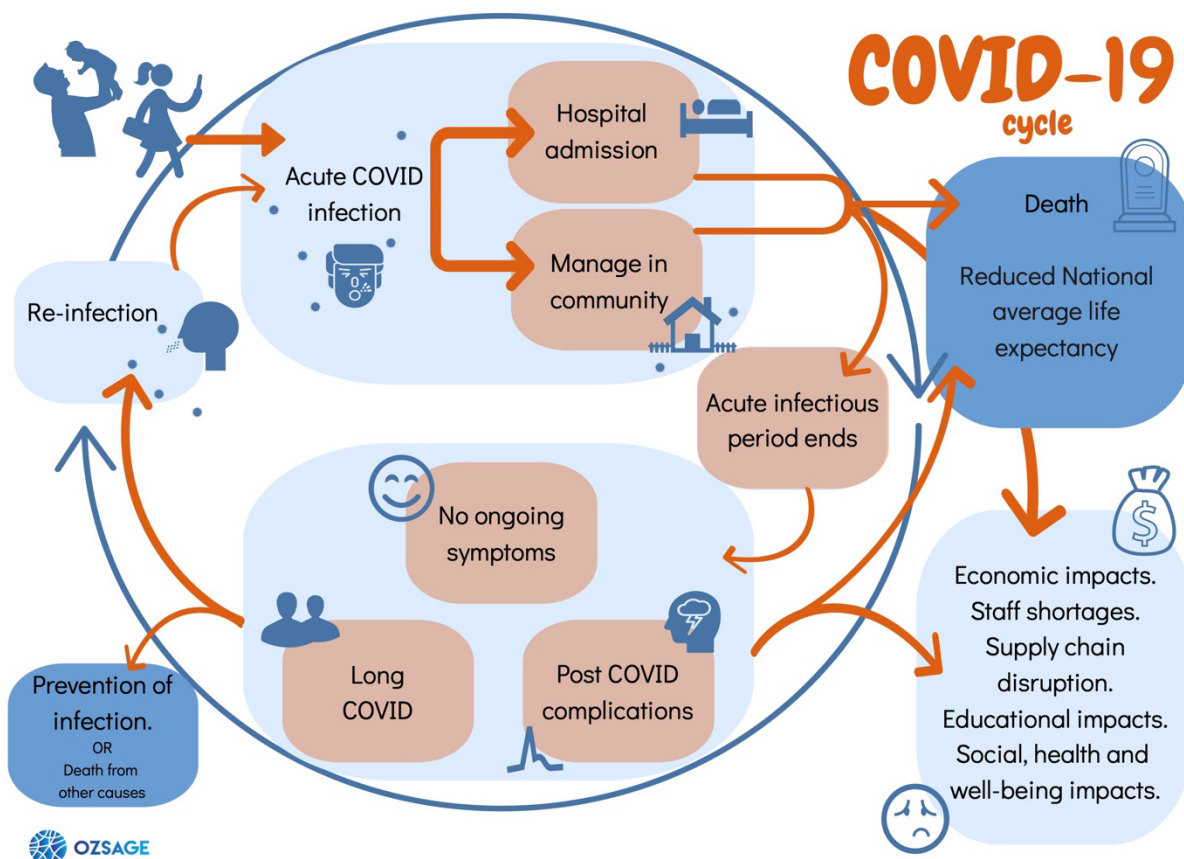
A [recent analysis](#) by the CDC of the medical records of over three million children and adolescents found that those who had COVID-19 were at increased risk of myocarditis and cardiomyopathy, pulmonary embolism and other thrombotic events, kidney failure, and diabetes.

Infection with SARS-CoV-2 confers only limited immunity, particularly in the case of the omicron variant and other new highly immune-evasive variants. Reinfection with SARS-CoV-2 is common and it is likely that the majority of Australians will be infected repeatedly throughout their lifetime unless measures, such as improved ventilation, are put in place to limit the spread of COVID-19, such as improved ventilation.

Australia is relying on a vaccine-only strategy for COVID-19, but as noted above, vaccination does not fully protect against long COVID. Available [vaccines lower the risk of hospitalization and death](#), but do not protect well against infection, especially if boosters have not been received. Omicron infection confers [low protection against reinfection](#), and reinfection is increasingly common with more immune evasive new variants. Rates of vaccination are [sub-optimal for the third dose and in children](#). Vaccination is not currently recommended for children under five years unless they are immunocompromised.

The world is likely to experience further, ongoing waves of COVID-19 for years, with both [good and bad years ahead](#). As the Omicron variant has shown us, even "milder" variants can lead to enormous number of deaths, hospitalisations, and long COVID. Any variant that displaces the Omicron variant must have a transmission advantage over it, which could occur through either greater immune evasion and/or increased intrinsic transmissibility. Thus, we can expect very large numbers of Australians to experience repeated infections (reinfections) over the years ahead. Even if only a small proportion of these infections leads to long COVID, the number of affected people could be very large in absolute terms. In the United Kingdom, [3.5% of the entire population](#) is already affected by long COVID.

There is still much that is unknown about the epidemiology and pathophysiology of long COVID and the impact of multiple infections and emerging variants. Even if the true incidence of long COVID is at the lower range of estimates (2% compared to 30%), the problem is very large when considered in terms of population health and likely burden of the health system and economy. Protecting Australians from reinfection during future waves of COVID-19 requires a two-pronged approach: access to updated coronavirus vaccines (boosters) on a regular basis, accessible testing, non-pharmaceutical interventions such as masks and public health measures to deliver clean indoor air. This is part of a [Vaccines-Plus](#) strategy. While a [significant outlay](#) in health spending to cope with long COVID is planned, this will not be adequate to deal with the demand for health services. Prevention of the spread of disease and efforts to flatten the curve with multi-layered protections is imperative, as [OzSAGE outlined in our advice](#) about preventing Long COVID in June 2022.



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

There are significant and distressing social and economic impacts of long COVID. Patient experiences in countries similar to Australia, such as [Scotland](#), show that the effects of long COVID go well beyond just individual health implications. Long COVID also impacts quality of life which affects the patient's work, social and family life, mobility and activities of daily living. People with long COVID have reported the effects of social isolation and feelings of distress, including shame, guilt and stigma related to continuing lack of ability to participate fully in social life, work or education. These individual impacts are then passed to not just the health system but also workplaces, resulting in labour shortages, support required from social services, disrupted education and dysfunction in the broader community in general. People with long COVID can experience financial stress and workplace management can be unhappy with absences, loss of effectiveness and have concerns for safety.

Worldwide, people experiencing long COVID symptoms have had to fight to have their illnesses and disability recognised by [medical experts](#). There are no specified diagnostic or clinical triage pathways to help GPs and other health providers to navigate the care of long COVID patients. Long COVID clinics and individual providers may prescribe unproven therapies and graded exercise, without adequate diagnostic work up. Some groups at economic disadvantage or with disability have effectively had no access to diagnosis or treatment. Others report denial or minimisation of their symptoms by providers despite failure to test for cardiac, vascular, respiratory, neurocognitive or immunological [pathology](#). Patients and their families have had to [band together](#) and advocate. People with long COVID do not necessarily recognize their symptoms and sometimes suffer in silence. Public health campaigns about long COVID and post COVID-19 conditions are needed.

The very definition of long COVID emerged from peer support networks of people who had begun to share their experiences on social media in the hope of finding support and help from others in their [situation](#). There are several Australian-based long COVID support groups on Facebook, including "Australia long COVID community" with 2.8 thousand members, demonstrating how important such peer support has been for people. Patient-led evidence has been crucial in generating details about how the condition is manifested, often led by healthcare practitioners who themselves have been [affected](#) by long COVID. The desperation that people have experienced in not being listened to or acknowledged by healthcare services has unfortunately sometimes resulted in them seeking untested and potentially dangerous cures and remedies that have been [publicised](#) online.

An OzSAGE member described to us, *"The frustration is accessing care and then accessing people who are knowledgeable around long COVID and then coordinating care. One of the biggest problem is this brain fog issue. Someone has to coordinate multiple you know doctors appointments from various specialties, none of whom talk to each other it's really hard to keep track of all of that. I honestly forgot most of my appointments or a lot of my appointments. I got the dates wrong, the times wrong, just simple things like that. The care is very fragmented and I got conflicting advice even from within the same long COVID clinic, so clinicians are not well informed around long COVID. There isn't a standard evidence based pool of information that they all*

work off. There is frustrations around access and gaining evidence based advice or advice that is useful and coordinating care.”

Multisystem damage to organs and immune effects cause the symptoms of long COVID, which result in functional, physiological and physical impairment. These range from impaired respiratory function, heart failure, arrhythmias, postural orthostatic tachycardia syndrome (POTS), thromboembolic disease, cognitive impairment and dementia to immunological syndromes. Children have also been shown to experience [effects on brain function](#), [lung](#) damage and [dysfunction](#), and [type 1 diabetes](#) (at around twice the rate of that following other viruses). Symptoms have been shown in some to be [prolonged greater than two months](#) with particular risk for ages zero to three years.

Some symptoms differentially affect [females](#) and [other population groups](#). Symptoms can be subtle leading affected individual to ignore them or avoid seeking medical attention for them of fear of being dismissed. However, -the underlying pathology can be serious. People may also give up on seeking care after their complaints are disregarded, or may be deterred by the costs involved or difficulties accessing medical review.

There is a subgroup of people who are unable to be vaccinated with current vaccines, leaving them with higher risk of long COVID.

Patients with long COVID experiencing repeat infection often want access to antiviral medication to prevent potential further exacerbation of their condition, but may not be offered this by medical providers despite any disability. Patients may face significant costs if not in the limited subgroup currently eligible for subsidised antiviral medication. Antiviral therapies are not available to those who have had prior severe COVID-19 infection, despite evidence that SARS-CoV-2 [can persist in the body long after acute infection](#).

Monoclonal antibodies and some anti-viral medications have lost/are losing effectiveness against more recent variants and subtypes of virus. This means that people with immunosuppression and other illnesses, or who could not be fully vaccinated are at increased risk of serious health outcomes.

Australia is now experiencing a high number of excess deaths. The excess death rate noted by [actuaries](#) is largely due to COVID-19 and its post-acute complications, including cardiovascular disease. The later complicating conditions are creating additional pressure on wait lists for review, investigation and treatment. The Ministry of Health in Singapore recently released a report on excess deaths which found that the gap between the official number of deaths from COVID-19 and the estimated excess deaths could be explained by a recent SARS-CoV-2 infection. There were no excess deaths among people who did not recently have [COVID-19](#).

The public health system is not able to meet all care needs for long COVID and patients can face payment of specialist gap fees. Clear pathways for work claims and workplace changes to protect people from reinfection are needed along with access to the National Disability Insurance Scheme (NDIS).

<https://doi.org/10.1038/s41467-022-33415-5>

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

Australia is yet to see the full impact of mass infections, including multiple reinfections, and therefore the experience overseas of the effects on health systems is relevant for our future. Long COVID is not just a long tail to an acute infection, it's a chronic condition that lasts a very long time. There is no scientific reason to think that people in Australia will be exceptional to the sequelae of this virus.

We do not have local data so we do not know for sure how common Long Covid is in Australia. It is difficult to truly know how many people in Australia are suffering from long COVID until we have that data. GPs do not currently have a diagnostic code/consistent diagnostic code for long COVID and without a diagnostic code it is more difficult to be able to assess the extent of the scale of long COVID in Australia. For example, in NSW Health, long COVID is not an available diagnosis on Power Chart, however, there is an ICD code.

Australia is a very diverse community. This diversity means we are unlikely to experience impacts like any other country, so our ability to collect local data for our own population is vital. We need to be looking at data for what GPs are experiencing.

Many cases are presenting to emergency but some people are being sent home without a diagnosis. People are attending the GPs and being sent home with label of 'chronic fatigue' but there may be no cause able to be attributed to chest pain where ECG and other testing is normal. For example one OzSAGE health care provider relates, *"We are at an early stage of diagnostic awareness. There is the word finding difficulty amongst many people you talk to who have had COVID. If you make an effort to notice it, you will see a lot of people have it. They say, 'since COVID I can't think through my emails. I can't find words. I have to look at my email more closely'. There is a spectrum of disability, a range of complications and implications for individuals, including being bed bound. Symptoms tend to be minimised or under recognised."*

GPs, emergency physicians, and other health workers need education to better recognise long COVID and post-COVID conditions. Another OzSAGE healthcare provider says, *"Initially in the pandemic the illness was proclaimed by some specialists and institutions to be mild for children, yet with time serious outcomes for children have become clear in the research. There best be an education campaign of the health professionals on these serious outcomes, as the initial public messaging on purported "mildness" was so strong. We need to act in precautionary manner and be alert to early cardiac, neurological, diabetes disease for example in our future generations.*

A national approach for children with long COVID is needed. There is lack of access to paediatric expertise and co-ordinated care in long COVID. There are examples of patients having to undergo referrals internationally and seeing multiple specialists, and even more than one of the same specialty, and being prescribed multiple medications. Immunologists, cardiologists, rehabilitation physicians, neurologists are all examples of specialists that patients have had to source themselves. Some patients may have to travel from remote or regional areas to access care, at significant cost. Specialists who have paediatric expertise are a much smaller pool than for adult population and may have already been overloaded with diseases from prior to the pandemic. Specialised paediatric long COVID clinics are needed and systems standardised where possible.

A group at particular risk of prolonged and/or repeated infections are transplant patients and those on haemodialysis. They are already at heightened risk for infections and often are frail. Repeated and prolonged infections have resulted in increased episodes of care, hospitalisation and in many cases, ICU admissions, risk of nosocomial transmission, and not uncommonly, graft loss with its own consequences.

Clearance (of PCR positivity) is usually required before patients are released back into the community. OzSAGE healthcare worker points out, "Prolonged hospital stay, isolation and separation from family are a worry". In many cohorts, survivor patients are experiencing their third or even fourth infections.

Treating physicians and occupational medicine physicians are carrying increasing load of patients referred for repeated infections and long COVID. There is increasing pressure on clinic bookings as individual needs are complex to assess. Many small businesses are not used to fitness for work situations which require due and fair process. Understanding of work tasking, any safety critical or business process critical aspects, and flexible working arrangements is helpful. For some individuals, in a wave of community transmission and with increasing resistance by the virus to treatments, work from home may be the only practical safe health recommendation. However, many jobs are not suited to work from home. This creates pressure on insurers, assessing income protection and total and permanent disablement, with the inevitable extra paperwork and time for the physicians involved.

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

There is evidence that SARS-CoV-2 [can persist in the body](#) after the initial infection and can cause a range of complications in the lungs, heart, blood vessels, brain and [immune](#) system. People who have had COVID-19 are at increased risk of cerebrovascular events, ischaemic heart disease (IHD) events, and any cardiovascular event. In a study of US veterans, the absolute risk [observed per 1,000 COVID-19 cases](#) was: for non-hospitalised cases: 2.8 cerebrovascular events, 1.8 IHD events, and 26.2 events of any kind. For hospitalised cases it was: 19.9 cerebrovascular events, 29.8 IHD events, and 160.6 events of any kind, and for COVID-19 cases that required ICU treatment there were 31.1 cerebrovascular events,

50.3 IHD events, and 311.5 events of any kind. The excess burden for [diabetes diagnoses per 1,000 COVID-19 cases](#) was: non-hospitalised: 8.3 diabetes diagnoses, hospitalised: 56.9 diabetes diagnoses, ICU: 89.1 diabetes diagnoses. Other complications include metabolic, rheumatological, intestinal, and dermatological. Damage to organ systems has been found even in people with mild infection. Six months after infection, people with break through infection have a 1.75 times higher risk of death and a 1.5 times higher risk of post-acute sequelae.

In the study of US veterans, vaccination was shown to reduce the risk of long term complications by only 15%. From a chronic burden of disease perspective, the main areas of concern are fatigue, chest pain and pain [cardiovascular](#) and [respiratory](#) disease, [neurological disorders](#) (which may include Parkinson's disease and dementia), diabetes, and [immunological](#) conditions.

Because the SARS-CoV-2 virus damages multiple organ systems, including the brain, the resulting long COVID conditions are numerous, complex and still evolving. Adequate government funding is needed for research, prevention, and treatment. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID is still emerging. We need a national cohesive approach to data and research because each state and research group are collecting small data sets that are not aligned or co-ordinated. More research is needed to document the patient experience of long COVID. Co-design with patient input and studies developed with health worker long COVID patients could provide valuable information. Nonetheless, there is still a significant amount of research being published on long COVID. Much of this points to systemic causes such as ongoing inflammation, micro blood clots, reactivation of latent viruses including Epstein-Barr virus and varicella zoster virus, and the damage caused to organs by the original infection.

As there are no established diagnostic criteria for long COVID, and its underlying causes are still being established, treatment is limited to supportive care and symptom control. Many are now seeing similarities between long COVID and other post-viral conditions such as myalgic encephalomyelitis/chronic fatigue syndrome. The list of viruses that cause post-viral conditions is long and includes Ebola, the 2003-2004 SARS virus, and Epstein-Barr to name a few.

While people with certain risk factors such as high blood pressure, diabetes, obesity or other chronic conditions are at increased risk of COVID-19, there is currently no clear link between these conditions and long COVID. Long COVID can present in anyone who has had COVID-19, including those who only had mild symptoms initially.

Education of doctors on the [full range of support](#) that they can provide to their patient's will be helpful. In addition to diagnosis and treatment and involving other health providers, the doctor can direct patients to educational resources, watch for red flags, and provide sickness certification and graduated work plans. Workplace recommendations need to be included in care pathways.

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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

The illness from long COVID and repeat SARS-CoV-2 infections causes severe disruption to the smooth running of society extending out from the individual to their families, friends, workplaces and communities and overall with impact on national economic health and security.

Health

In the coming years, long COVID will place a substantial burden on Australia's health system in the coming years. In [a large study from Scotland](#), 6% of long COVID patients had no recovery and 42% had only partial recovery at 18 months, although this study was limited by a low response rate. Nonetheless, it demonstrates that at least in absolute terms, recovery from long COVID may take a long time for a significant number of people. Over time, as more people become infected and reinfected, the cumulative burden of long COVID will increase.

The increased demand on the health system will be compounded by health workforce shortages. There is already a widely recognized shortage of GPs. Long COVID cuts into their workforce numbers and yet the complex patient need is increased. Previous projections of the impact of COVID-19 on the hospital system will underestimate the true need.

The impacts of long COVID are exacerbated for those with less access to health care, such as older Australians, regional rural and remote Australians, First Nations people, people with disabilities and those from lower socioeconomic groups.

Whilst [older people](#) are more likely to experience post-acute complications, youth and children are vulnerable. The [Covid-19 Schools infection Survey England: Long Covid and Mental Health reported in March 2022 that 2%](#) of primary school pupils and 5% of secondary school pupils had experienced long COVID. [Children's health conditions are complicated by repeat infection](#) with COVID-19. Waves of disease adversely affect [mental health](#). The long-term generational impacts of COVID-19 and may be significant. Children and young people have the most infections and therefore could ultimately end up with greatest burden of disability - more so than the current aged population. We need to protect children and young people to secure Australia's future health, social, and economic prosperity.

Social

[Secondary impacts of Long COVID](#) include damages to the entire family unit, especially if children are caring for a sick family member or cannot have their needs met due to illness in adult family members. Single parent families would be more severely impacted by long COVID in the parent.

In older people, the illness can trigger the movement from independent living to being supported or needing institutional care.

Carers of persons with underlying health conditions face increased demands when their loved one is unwell, that stretches care for the rest of the family. People relying on in-home care services often find themselves subject to staff shortages that may leave them without access to required care. Data from the Optimise Study, a longitudinal cohort study in Victoria measuring the impacts of COVID-19, reported that 302 (61%) of participants reported they had a family member or friend who had experienced long-CoVid with 128 (42%) of the 302 reporting providing support to family members or friend/s with long COVID.

Important milestones may be missed to protect loved ones from illness.

Key volunteers in the community may also be affected by acute and chronic illness and volunteering has become less feasible as a lifestyle choice during the pandemic. The community hubs that support well-being have dwindled in capacity to provide services. -

Patients with long COVID may face depression and marginalisation due to low health provider awareness of the condition and lack of available diagnostic or treatment pathways.

Economic

Australian Bureau of Statistic data shows an [increase in the number of people working fewer hours](#) due to continued disruption from the Omicron variant and influenza between April and May 2022. The number of people working fewer hours due to their own illness in May 2022 (780,500 people) was the highest level recorded during the pandemic. In addition to acute illness disrupting the workforce, longer term effects are already being seen due to long COVID, with most evidence coming from countries that experienced large waves of COVID-19 earlier than Australia. It has been observed that workers taking days off for COVID health reasons [are more likely to be out of work](#) in the future.

US Census data show [a 13% increase in cognitive disability \(having trouble concentrating, remembering or making decisions\) in April/May 2022 average compared with January/February 2020 average](#). [Around 2.0 million people in the UK \(3.1% of the population\)](#) were experiencing self-reported long COVID as of 1 May 2022, and around 398,000 (20%) reported that their ability to perform day-to-day activities had been “limited a lot”. The US Department of Health and Human Services has recognised [long COVID as a disability](#) under the Americans with Disabilities Act (ADA). In the UK, levels of disability following infection are affecting the workforce. [A quarter of employers](#) reported that long COVID is a major cause of workplace absence.

An [Australian study](#) shows that “a significant net health benefit may be attained by adaptive NPIs formed by partial social distancing measures, coupled with moderate levels of the society’s willingness to pay for health gains (health losses averted).”

Problems with cognition, sudden cardiac or neurologic events have implications for [safety critical](#) and business process-critical tasking. For example, in roles such as commercial pilots and vehicle drivers, surgeons, police or key critical organizational management including our defence forces, catastrophic outcomes can occur due to direct and indirect consequences of COVID-19.

It is likely that future claims for income support through the disability support pension and unemployment benefits will rise. The significant proportion of individuals experiencing symptoms for the foreseeable future as a consequence of contracting COVID-19, will impact resourcing for Workers’ Compensation claims. Insurers affected include those funded privately, but large numbers of staff, particularly those working for government including in healthcare facilities, are covered under insurance funded by public treasuries. There are therefore serious considerations for state Treasuries in their insurer exposures.

Removing the legal obligation to isolate increases the spread of COVID-19, resulting in less safe workplaces. Infectious disease contributes to ongoing workforce loss and incapacity. There are examples of large companies, such as in mining and healthcare, having already searched overseas for workers and not found adequate replacement supply of workforce. Protecting the workforce with layers of mitigations is critical to economic well-being and national security.

According to the [Brookings Institution](#) long COVID in the US will result in lost wages equal to almost 1% of the US GDP. In Australia, that equates to over \$24 billion based on the GDP predictions.

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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

Without a [Vaccines-Plus](#) strategy including safe indoor air, masks, testing and tracing, and increased access to anti-virals, Australia is likely to see a large increase in the prevalence of chronic illness and disability related to COVID-19. This will place considerable pressure on our already stretched health, rehabilitation and disability services and supports. Primary care, paramedics, hospitals, and allied services are already over-stretched. Commonwealth state hospital funding will need to change, and the 6.5% cap will need to be lifted.

The [health system is already chronically over-burdened](#) by COVID-19, and there are concerns about the [costs of the NDIS](#) due to higher demand than the original modelling by the [Productivity Commission](#) suggested. To be [eligible for the NDIS](#) someone needs to be less than 65 years old at entry to the Scheme and have a permanent disability that substantially reduces their functional capacity or ability to undertake activities in one of the following areas: communication, self-care, learning, mobilising, and self-management. It is clear that long COVID can affect functioning across all of these areas. People with disability who do not meet these criteria are meant to receive services and supports through other systems (referred to as Tier 2) across all levels of government. However, there is widespread acknowledgement that these services have not been available as states and territories and the Commonwealth have [directed funding to the NDIS](#). This means that people with fluctuating disabilities, including psychosocial disability, have often missed out on supports. This has sometimes resulted in a deterioration in their functional capacity and potentially increased their risk of needing NDIS funding in future.

Long COVID results in additional upward pressure on the NDIS through the deterioration in functioning of people who are already on the NDIS and through new entrants to the scheme who develop significant, permanent disability due to long COVID requiring individual packages for equipment, therapy, personal care and other supports. Many people with long COVID will not be eligible for NDIS, at least initially. However, these people will still require support from rehabilitation, health and non-NDIS funded disability services. A substantial burden of chronic disease will likely impact the health system in the coming years. Prevention of long COVID and repeated SARS-CoV-2 infections and investment in these services will be critical to improve or prevent deterioration and future reliance on the NDIS.

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

The COVID-19 pandemic is not over. Assertions that COVID-19 cannot be treated as an exceptional disease are not helpful in the face of a disease that has clearly caused exceptional levels of death, hospitalisation, and disability. There are several key areas that governments must address to reduce the impact of long COVID and repeat SARS-CoV-2 infections in Australia.

Prevention of SARS-CoV-2 infection is essential [to reduce the long-term burden of disease](#) and disability from COVID-19. There is a need for strong messaging from public health leaders and politicians which acknowledges the increasing incidence of long COVID, and that the best way to prevent long Covid it is to reduce the spread of COVID-19 in the community. Dealing with [misinformation](#) is important to address, given the proliferation of unverified and often incorrect information online. Renewed efforts to raise the rates of 3rd and 4th dose boosters (especially bivalent), and to increase vaccination rates in children are imperative. A Vaccines-Plus strategy includes safe indoor [air](#), masks, testing and tracing, which will all reduce transmission. The combined effects of these mitigations can substantially reduce the disease burden of COVID-19 and long COVID. The [nuances of testing](#) and ongoing free supply of rapid antigen tests (RATs) is also important. [Inequalities in testing](#) compound disease spread in some communities. Anti-viral medications appear to [reduce post-COVID sequelae](#) by around a quarter only, and can cost over \$1000, so prevention is far preferable.

Treatment initiatives should include broader, affordable and equitable access to antivirals to decrease viral load and hasten recovery. Non-evidence based (and potentially dangerous) treatments should not be provided to long COVID patients and serious cardiac or respiratory conditions need to be excluded. A treatment pathway that includes referral to relevant specialists such as respiratory physicians, cardiologists, immunologists or neurologists should be developed.

Modelling is urgently needed to assess the likely impact of long COVID on the job capacity of Australian workers, the health system, the NDIS and other disability services, and the likely demands on income support due to disability caused by long COVID. This should test best and worst-case estimates of long-term disease and disability to inform planning for the future.

Raising awareness and providing education about long COVID and the spectrum of post-acute complications of COVID-19 for patients and health care providers is important. Employers should also be made aware of the potential for increasing numbers of employees with long COVID so that they can plan for workforce issues.

Clinical pathways and clinical decision support tools for GPs should be established for assessment, investigations and specialist referral. This includes protocols on specific diagnostics for abnormalities not detected by routine tests (e.g. pulmonary, microclots, myocarditis). It should be noted that routine tests such as a chest x-ray may be normal, but that specialised diagnostic testing is required for some conditions,

including magnetic resonance imaging (MRI) scans and other investigations. These need to be clearly mapped out for health providers.

Education is needed for employers and organisations on pathways for medical fitness for work review and extended sick leave for staff. Occupational physicians, and other doctors with occupational interest (involving occupational therapists and neuropsychologists if needed), can clarify if an individual who complains of symptoms or is making significant errors, is capable of safe work or identify what supports are needed to maintain their role safely. The providers can also help clarify treatment plans and the prognosis and support for return from extended sick leave if needed.

Infrastructure to manage increased burden of chronic illness including specialised long COVID clinics, and health system planning for the increased burden of chronic cardiac, respiratory and other complications is needed. Specialised clinics must be accessible to disadvantaged groups. This could be achieved through outreach programs in existing health networks, upskilling regional health practitioners, and ongoing support for telehealth MBS item numbers.

Commonwealth and state and territory governments need to plan for the potential increased demand for disability services including the NDIS in coming years. Investments should then be directed to supporting people who are disabled by long COVID to receive the necessary services and support through the health system, rehabilitation, tier 2 disability supports, and the NDIS if they experience significant and permanent disablement.

Support for people who are unable to work or have reduced work capacity due to long COVID is needed. Consideration should be given to expansion of Job Access Disability support with workplace accommodations including [promoting flexible working conditions](#), rehabilitation services, incentives for employers to accommodate workers disabled by COVID-19 (such as subsidisation of work from home equipment, and supernumerary work placement), and income support for people with reduced work capacity due to long COVID.

National standards for clean indoor air are needed. Peer countries are beginning to set targets for CO₂ levels in indoor spaces as a proxy measure for good ventilation. For example, Belgium will require all public places to monitor their indoor air quality and install a CO₂ monitor that is visible to the public. In New Zealand, all schools have been supplied with a CO₂ monitor and air purifiers are used when ventilation is insufficient. Australia should follow by mandating and championing indoor air quality standards and other clean indoor air technologies. Governments could consider a rebate scheme to support investment in ventilation infrastructure, such as Victoria's Small Business Ventilation Program (Ventilation Rebate). Governments should also urgently [improve ventilation infrastructure](#) in Australia's schools, because there is clear and compelling evidence from across the world that schools play an important role in the spread of SARS-CoV-2. The [Whitehouse summit](#) on improving indoor air quality also provides helpful guidance. It is time to [decrease the spread of COVID-19](#) in poorly ventilated indoor spaces.

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