

Submission to House of Representatives Standing Committee for Health, Aged Care and Sport Inquiry into Long COVID and repeated COVID infections

Key facts

- The prevalence rate of Long COVID in unvaccinated patients could realistically be as high as 40 per cent. The best available evidence shows vaccines only cut this risk by 15 per cent. There could be as many as 3.5 million Australians suffering or who have suffered Long COVID.
 - The widely quoted UK Office of National Statistics (ONS) estimate of a 13.7 per cent prevalence rate is an outlier. The ONS underestimates the prevalence rate since it includes persons with suspected COVID infections.
- Long COVID is a mass disabling event. COVID-19 is more than forty times more likely to severely disable a person than polio.
- Long COVID is having a major economic impact. It has already reduced the labour participation rate by 1.8 per cent in the US, 1.3 per cent in the UK and up to 1 per cent in Australia. This could shave 1 per cent off GDP in the US and up to 1.8 per cent in Australia.
- Around half of Long COVID patients have ME/CFS. Their condition may be permanent and severely disabling.
- ME/CFS has a worse quality of life rating than late-stage HIV/AIDS or lung cancer. Treatments are needed as a matter of urgency. Despite the need, the Government only spends 42c per ME/CFS patient a year on research.

Key Recommendations

- **Recommendation 1**: The ABS should be funded to conduct an ongoing survey on the prevalence, severity and duration of Long COVID as well as its economic and social impacts.
- **Recommendation 2**: Leverage existing ME/CFS research to speed up Long COVID research. Direct Long COVID research towards treatments and management.
- **Recommendation 3**: Increase funding for research into treatments for ME/CFS and other post-viral syndromes to prepare for the next pandemic and to treat current patients. Any research into GET should not be conducted by conflicted or vested interests.
- **Recommendation 4**: The RACGP guidelines for ME/CFS should be updated in line with the NICE guidelines to state that Graded Exercise Therapy should not be used to treat ME/CFS. Pacing should be recommended instead.

- **Recommendation 5**: Stronger guidance should be provided to doctors that there are serious risks in using Graded Exercise Therapy to treat forms of Long COVID that exhibit PEM.
- **Recommendation 6**: Legislate to remove barriers to entry for cash-poor companies whose Long COVID treatments have been approved in the EU or US. Alternatively, the TGA should provide practical guidance on how bedbound or housebound long haulers are able to access overseas-approved medications through the Personal Import Scheme.
- **Recommendation 7**: Release guidance on how ME/CFS and Long COVID patients can access social security. This should be binding on social security agencies and be able to be applied retrospectively during administrative review.
- **Recommendation 8**: Release guidance on disability protections and employer accommodations for Long COVID and ME/CFS patients. The Australian Public Service should act as a best practice model.

Introduction

Thank you for undertaking this important inquiry into Long COVID. I am an experienced public policy analyst with qualifications in law, economics and finance who has severe myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a post-viral illness similar to Long COVID that follows other serious illnesses like glandular fever. Unlike many others with ME/CFS or Long COVID, I only experience periodic brain fog and have been able to slowly write this submission. I suspect you may face difficulty getting many submissions from those with Long COVID as their brain fog makes it difficult to write long submissions.

Because of my personal experience with ME/CFS, I have long been concerned about the economic and social impact of Long COVID which I quantify in this submission and its appendix. I also speak with many Long COVID patients online through chat groups and have gathered much anecdotal evidence.

This submission reflects my personal views and analysis and does not reflect those of my employer.

Long COVID is more common than often reported

Studies show a wide range of prevalence estimates of Long COVID as outlined in Table 1 below. Table 1 only includes studies whose cohorts included non-hospitalised patients.

The frequently cited prevalence rate of 13.7 per cent estimated by the United Kingdom Office of National Statistics (ONS) is an outlier which relies on self-reported COVID infection status. This

means that part of the studied population may not have been infected by COVID-19 but another viral illness such as influenza which has a lower incidence of post-viral syndromes. As outlined in [Table 1](#), there are higher quality studies which find a higher prevalence rate or around 30 per cent. **A meta-review of fifty studies found a global estimated pooled prevalence of 43 per cent,**¹ which is significantly higher than the ONS estimate.

Studies generally agree that vaccination reduces the risk of Long COVID. However, the reduction may be far less than the often quoted halving of risk. A recent meta-review finds that **vaccination only reduces the risk of catching Long COVID by 19 per cent.**²

Table 1: Studies estimating the prevalence of Long COVID

Authors	Hospitalised patients only?	Confirmed COVID cases only?	Control group?	Estimated prevalence
Liu et al ³	No	Yes	No	5% after 12 weeks
Office of National Statistics ⁴	No	No	No	13.7% after 12 weeks
Tenforde et al ⁵	No, outpatients only	Yes	No	35% after 2-3 weeks
Taquet et al ⁶	No	Yes	Yes	32.7% after median of 24 weeks

¹ Chen Chen, Spencer R. Hauptert, Lauren Zimmermann, Xu Shi, Lars G. Fritsche, Bhramar Mukherjee, Global Prevalence of Post-Coronavirus Disease 2019 (COVID-19) Condition or Long COVID: A Meta-Analysis and Systematic Review, *The Journal of Infectious Diseases*, 2022.

² Gao, P.; Liu, J.; Liu, M. Effect of COVID-19 Vaccines on Reducing the Risk of Long COVID in the Real World: A Systematic Review and Meta-Analysis. *Int. J. Environ. Res. Public Health* 2022, 19, 12422.

³ Liu B, Jayasundara D, Pye V, et al. Whole of population-based cohort study of recovery time from COVID-19 in New South Wales Australia. *Lancet Reg Health West Pac* 2021;12:100193

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021>

⁵ Tenforde MW, Kim SS, Lindsell CJ, et al. Symptom Duration and Risk Factors for Delayed Return to Usual Health Among Outpatients with COVID-19 in a Multistate Health Care Systems Network — United States, March–June 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:993-998.

⁶ Taquet M, Dercon Q, Luciano S, Geddes JR, Husain M, Harrison PJ (2021) Incidence, co-occurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19. *PLoS Med* 18(9): e1003773.

Blomberg et al ⁷	No	Yes	Yes	61% after 6 months
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We need to know how many Australians have Long COVID

We do not know how many Australians have Long COVID. The Australian Bureau of Statistics (ABS) and the various health agencies do not survey Long COVID prevalence in Australia. The rate of Long COVID can vary greatly from country to country. Around 14 per cent of all Americans have Long COVID⁸ while 3 per cent of the entire UK population have Long COVID.⁹ Are we more like the US or UK? Without data, we can only estimate based on available statistics.

Australia has had 10.1 million cases of COVID-19 as of 9 September 2022.¹⁰ Assuming that the two meta reviews cited above are correct, that means **there are up to 3.5 million Australians who are suffering or have suffered Long COVID** of varying severity and duration.

Long COVID has a grabbag of causes - some may never recover

There are no well-designed studies on the duration of Long COVID or the recovery rate. The CDC observes that Long COVID studies tend to report a lower prevalence rate the longer their observation period following acute infection. A Minneapolis Fed survey found half of long haulers recovered from Long COVID.¹¹

The recovery rate, however, seems to stall after a few months. The ONS found there are 892,000 Britons with Long COVID who caught COVID-19 at least a year previously and 429,000 who caught it at least two years previously, a sizable portion of the 2 million Britons with Long COVID.¹²

The recovery rate may be explained by the fact that Long COVID is a collective term for a wide range of symptoms. Some cases of Long COVID may, for instance, be caused by organ damage and will heal in those first few months. **About half of Long COVID cases meet the**

⁷ Blomberg, B., Mohn, K.Gl., Brokstad, K.A. et al. Long COVID in a prospective cohort of home-isolated patients. Nat Med 27, 1607–1613 (2021).

⁸ www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm

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www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19latestinsights/infections

¹⁰ www.health.gov.au/resources/publications/coronavirus-covid-19-at-a-glance-9-september-2022

¹¹ <https://www.minneapolisfed.org/research/institute-working-papers/long-haulers-and-labor-market-outcomes>

¹²

www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1september2022

diagnostic criteria for ME/CFS and may never recover.¹³ ME/CFS has a 5 per cent recovery rate after six months.¹⁴

COVID-19 does not disable most people who catch it, nor do all Long COVID patients become severely disabled. Something similar can be said of polio. In fact, only 0.1 to 0.5 per cent of polio sufferers suffer paralytic poliomyelitis. By comparison, drawing together the statistic compiled above, 4.3 per cent of COVID-19 patients will become severely disabled by Long COVID. In other words, **COVID-19 is around forty times more likely to disable you than polio.**

Long COVID has significant labour force implications

Estimates of how many long haulers are able to work vary. The Minneapolis Federal Reserve found 25.9 per cent of long haulers had to reduce or stop work.¹⁵ On average, these long haulers reduced their work week by ten hours or about 25 per cent of a 40 hour week.

Long COVID is an economic disaster

The Brookings Institute estimates that between 2 to 4 million people, around 1.8 per cent of the US civilian labour force, have so far been disabled by Long COVID. Brookings estimates this is equivalent to US\$168 billion p.a. in lost income or 1 per cent of GDP.¹⁶

In a similar vein, the Bank of England has noted that the UK participation rate has fallen by 1.3 per cent since the pandemic with most of this caused by long term sickness, particularly Long COVID.¹⁷

This submission, using the conservative methodology set out in Appendix A, calculates there are around 240,000 Australians who are no longer working full time solely as a result of Long COVID. By comparison, only 29,000 Australians have HIV of any severity.

This is equivalent to a drop of 1.0% in the participation rate, A\$11.0 billion in lost wages or 1.8 per cent of GDP. This drop in our participation rate is being masked by other factors. Unlike the US and UK, we closed our borders to international workers who have yet to return. This may be

¹³ Kedor, C., Freitag, H., Meyer-Arndt, L. et al. A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity. *Nat Commun* 13, 5104 (2022)

¹⁴ Cairns, R.; Hotopf, M. (January 2005). "A systematic review describing the prognosis of chronic fatigue syndrome". *Occupational Medicine (Oxford, England)*. 55 (1): 20–31.

¹⁵ <https://www.minneapolisfed.org/research/institute-working-papers/long-haulers-and-labor-market-outcomes> See also [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00299-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext) and <https://www.tuc.org.uk/sites/default/files/2021-06/Formatted%20version%20of%20Long%20Covid%20report%20-%20v1.3.pdf>

¹⁶ www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/

¹⁷ www.bankofengland.co.uk/speech/2022/may/michael-saunders-speech-at-the-resolution-foundation-event

causing unexpected tightness in our labour market which is hiding the mass disabling event that occurred on our shores. This could weigh upon Australia's productivity rate as our remaining workers must support these newly disabled Australians through our social security system. The loss of so many workers will also worsen the inflation crisis that Australia is currently facing.

We need a Long COVID damage report from the ABS

Ultimately, no one knows how many Australians have Long COVID and how many have been disabled by it. This submission has relied upon international data or studies because no hard data exists in Australia.

The number of Australians with Long COVID matters. We need to know what percent of our labour force is no longer able to work - potentially permanently - due to Long COVID. We need to know whether our social security and health care systems are being swamped by a tide of Long COVID that our top bureaucrats are blind to because of a lack of data. We ought not rely on complicated calculations with many assumptions when data should be readily available.

The Australian Bureau of Statistics (ABS) should be funded to conduct an ongoing survey on the prevalence, severity and duration of Long COVID. The survey should also ask about Long COVID recovery rates. It should survey the labour force impacts of Long COVID including asking about whether long haulers have reduced their hours or ceased to work. It should survey applications, approvals and rejections for social security as a result of Long COVID. This would provide insight into the damage done to our economy and social fabric by Long COVID.

<p><u>Recommendation 1</u>: The ABS should be funded to conduct an ongoing survey on the prevalence, severity and duration of Long COVID as well as its economic and social impacts.</p>

Long COVID is similar to ME/CFS and can learn from ME/CFS research

Like Long COVID, ME/CFS is an umbrella term for post-viral fatigue that has no other observable cause. One can think of it as being Long Flu or Long Glandular Fever, for instance. Sufferers of both conditions share many symptoms, in particular post-exertional malaise (PEM), orthostatic intolerance, brain fog and sleep disturbances.¹⁸

¹⁸ Wong TL, Weitzer DJ. Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)-A Systemic Review and Comparison of Clinical Presentation and Symptomatology. Medicina (Kaunas). 2021 Apr 26;57(5):418.

It is likely that Long COVID covers a number of different ailments. Some patients may be suffering from organ damage. Another sub-type of Long COVID may be similar to ME/CFS. About half of Long COVID cases meet the diagnostic criteria for ME/CFS.¹⁹

Significant research dollars have been ploughed into Long COVID research, much of it replicating findings that have already been demonstrated for ME/CFS. For example, Australian researchers have identified the same deficiency exists with calcium channels in the brains of both ME/CFS and Long COVID patients.²⁰

Research dollars could be better directed moving past the basics of the illness and directed towards treatments. Patients are suffering badly and can't wait for science to catch up when an existing body of knowledge is there waiting to be tapped.

Recommendation 2: Leverage existing ME/CFS research to speed up Long COVID research. Direct Long COVID research towards treatments and management.

More funding for ME/CFS and Long COVID research

Despite being a relatively common illness (around 0.4 to 1 per cent of Australians have ME/CFS) relatively little Australian funding goes towards ME/CFS research. **The Federal Government spends less than \$100,000 a year on ME/CFS research, equivalent to 42c per Australian ME/CFS patient** a year.²¹ This is a global problem, with ME/CFS found to be the most underfunded illness relative to disease burden.²²

As a result of this historic underfunding, there are currently no scientifically validated treatments for ME/CFS or Long COVID, leaving 2.2 million Australians to suffer a potentially debilitating disease without any adequate treatment. The next pandemic will also leave a long trail of post-viral syndromes. If we begin our research now, we might avert the next disaster.

Patient advocates have observed that post-pandemic, governments around the world have funded research into GET as a Long COVID treatment.²³ These pose the risk of significantly exacerbating the condition of Long COVID patients. These trials are often run by conflicted interests or those with a history of arguing, without evidence, that ME/CFS is a psychological disorder. Limited research funds should not be used on such risky and biased studies.

¹⁹ Kedor, C., Freitag, H., Meyer-Arndt, L. et al. A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity. *Nat Commun* 13, 5104 (2022).

²⁰ www.abc.net.au/news/2022-03-18/long-covid-and-chronic-fatigue-links/100916990

²¹ <https://treasury.gov.au/sites/default/files/2019-03/360985-Emerge-Australia.pdf>

²² Dimmock, E. M. et al., Estimating the Disease Burden of ME/CFS in the United States and its relation to research funding, *Journal of Medicine and Therapeutics*, DePaul University Chicago, USA, Vol 1 pp 1–7, 2016.

²³ e.g.

https://twitter.com/exceedhergrasp1/status/1532394645941936131?t=SHIkGR5_hINL8uNqe_15MA&s=19

Recommendation 3: Increase funding for research into treatments for ME/CFS and other post-viral syndromes to prepare for the next pandemic and to treat current patients. Any research into GET should not be conducted by conflicted or vested interests.

The RACGP guidelines for Long COVID and ME/CFS should be aligned

Historically, graded exercise therapy (GET) has been recommended as a treatment for ME/CFS and some are recommending it for Long COVID. GET involves the patient gradually increasing the exercise they do over a period of time. The primary study on which promoters of GET rely has been discredited.²⁴ It is based on the theory that ME/CFS is a psychological condition despite abundant evidence that it is biophysical in nature.

GET is risky for ME/CFS patients as they have exertional intolerance. ME/CFS patients have been found to have reduced oxygen consumption during exercise tests and cannot increase their oxygen consumption.²⁵ This is different to other known conditions such as cystic fibrosis and other lung diseases.

GET can worsen the condition of ME/CFS patients for months, years or permanently.²⁶

This is also likely to be true for the half of Long COVID patients who meet the diagnostic criteria for ME/CFS.

Patient groups advocate pacing instead of GET. Pacing involves patients managing their energy usage so they do not exacerbate their symptoms.

The UK's National Institute for Health and Clinical Excellence (**NICE**) has reviewed the **evidence supporting GET and found that it "was deemed to be of low or very low quality."** The new NICE guidelines for ME/CFS recommend pacing.²⁷ In the US, the CDC no longer recommends GET and recommends pacing.²⁸

²⁴ Vink, Mark; Vink-Niese, Alexandra (October 8, 2018). "Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review". *Health Psychology Open*. 5 (2).

²⁵ Keller, B.A., Pryor, J.L. & Giloteaux, L. Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO₂peak indicates functional impairment. *J Transl Med* 12, 104 (2014).

²⁶ Geraghty, K., Hann, M. & Kurtev, S. (2019). Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys. *Journal of Health Psychology* 24(10):1318-33.

²⁷ www.nice.org.uk/guidance/ng206

²⁸ www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.html

Australia has yet to change its guidelines for ME/CFS, which have not been updated since 2015. The RACGP guidance for ME/CFS continues to support GET.²⁹

By contrast, the RACGP guidelines for Long COVID recognise the risks of exercise. They "[r]ecommend that patients pace and be selective when prioritising daily activities [and] [r]ecommend caution with return to exercise (reduce if there is any increase in symptoms)."³⁰

Similarly, the latest version of the World Health Organisation's guidelines, *Clinical Management of COVID-19*, distinguishes between forms of Long COVID that do and do not exhibit PEM (although they adopt the equivalent terminology of post-exertional symptom exacerbation).³¹ This makes sense as Long COVID is an umbrella term. Gentle exercise is likely to be helpful to forms of Long COVID that are not similar in nature to ME/CFS. However, exercise can worsen the condition of those with ME/CFS-like Long COVID.

This leads to a disparity in treatment between patients with ME/CFS and those with Long COVID who otherwise meet the ME/CFS diagnostic criteria.

Recommendation 4: The RACGP guidelines for ME/CFS should be updated in line with the NICE guidelines to state that Graded Exercise Therapy should not be used to treat ME/CFS. Pacing should be recommended instead.

Despite the RACGP and WHO guidance, the major Australian Long COVID clinics appear to use graded exercise therapy to treat cases of Long COVID.³²

Recommendation 5: Stronger guidance should be provided that there are serious risks in using Graded Exercise Therapy to treat forms of Long COVID that exhibit PEM.

Legislate a pathway for Long COVID treatments

Some companies have begun researching Long COVID treatments with clinical trials under way or about to begin for RSLV-132, BC 007, Ampligen and other medicines. Unfortunately, the **companies behind these treatments are small and likely cannot afford to jump through the regulatory hurdles for every country around the world.** They are likely to seek approval in the US and EU first and only apply to smaller markets like Australia once they recoup their initial investments.

²⁹ www.racgp.org.au/clinical-resources/clinical-guidelines/handi/handi-interventions/exercise/graded-exercise-therapy-chronic-fatigue-syndrome

³⁰ www.racgp.org.au/clinical-resources/covid-19-resources/clinical-care/caring-for-patients-with-post-covid-19-conditions/the-most-common-scenario-non-specific-multisystem

³¹ www.who.int/publications/i/item/WHO-2019-nCoV-Clinical-2022.2

³² www.theguardian.com/australia-news/2022/jul/09/long-covid-what-we-know-about-it-and-how-best-to-treat-it

This means that **Long COVID treatments could be denied to Australian patients for years while American and European patients get early and safe access**. The high cost of seeking Therapeutic Goods Administration (TGA) approval in Australia is a large barrier to such small start ups. These costs take the form of statutory fees as well as legal costs associated with the application process.

One solution is for a HECS-style loan program covering both application fees and other costs associated with filing an application for TGA approval, similar to that previously recommended by this committee in its inquiry into approval processes for new drugs. It is important to extend this recommendation to cover non-statutory costs of application as these can also be significant for small, cash-poor start-up companies.

Alternatively, provisional TGA approval could be automatically granted to Long COVID treatments that have received approval in the US or EU without the need for a separate TGA application. Once available, doctors should be able to prescribe these Long COVID medications to ME/CFS patients on an off label basis.

If the Government is not willing to legislate, they should not prevent disabled Australians from accessing such medicines. The TGA allows for overseas-approved medicines to be imported through the Personal Import scheme.³³ It is not, however, clear how a patient might procure an intravenously-administered medicine like BC 007 or Ampligen through such a scheme and guidance could assist.

Recommendation 6: Legislate to remove barriers to entry for cash-poor companies whose Long COVID treatments have been approved in the EU or US. Alternatively, the TGA should provide practical guidance on how bedbound or housebound long haulers are able to access overseas-approved medications through the Personal Import Scheme.

Clearer access to social security is required for Long COVID and ME/CFS patients

Anecdotally, **many ME/CFS patients struggle to access Jobseeker, the Disability Support Pension (DSP) and the National Disability Insurance Scheme (NDIS)**. Many are unaware, as I was, that you could be eligible for Jobseeker if you had a medical certificate stating you are unable to work.

Those with moderate or severe ME/CFS and Long COVID should be eligible for the DSP, but face bureaucratic hurdles in practice. Persons are eligible if they meet certain non-medical rules, their condition will last more than 2 years, their condition is fully diagnosed, treated and stabilised, have an impairment rating of >20 points and cannot work more than 15 hours/week.

³³ www.tga.gov.au/publication/personal-import-scheme

Because individual doctors have differing views on whether ME/CFS is a permanent condition, some are told their condition will not last more than two years. This is despite evidence of a recovery rate of 5 per cent. The hurdles are even greater for those with Long COVID for which no prior evidence exists as to its longevity. Despite a lack of scientifically validated treatments for ME/CFS, applicants are often told they have not tried all available treatments. This often pushes patients to try GET, which risks further disabling them.

Similar disputes about the permanence of ME/CFS act as a barrier towards accessing the NDIS.³⁴ Assessment guidelines for NDIA assessors should be developed in collaboration with clinicians with expertise in management of ME/CFS and the ME/CFS community.

The US Government has issued guidance on how Long COVID patients are able to access certain rights, including for healthcare purposes.³⁵ The Commonwealth Government should release similar guidance, making it retrospective so that administrative review processes are able to follow the guidance in assessing claims that have been wrongfully denied.

Recommendation 7: Release guidance on how ME/CFS and Long COVID patients can access social security. This should be binding on social security agencies and be able to be applied retrospectively during administrative review.

Employer accommodations are needed for Long COVID and ME/CFS patients

Because those with ME/CFS and some forms of Long COVID cannot tolerate physical or mental exertion, those who can continue to work may need accommodations to do so.

The Government, through the Fair Work Ombudsman and the Australian Human Rights Commission, should release guidance stating that persons with Long COVID and ME/CFS may have a disability providing them legal protection, including under the Fair Work Act. They should outline the accommodations that employers could provide.

The Australian Public Service, with its 150,000 staff, should act as a best practice model in terms of offering Long COVID and ME/CFS-affected staff accommodations to work if they can.

Recommendation 8: Release guidance on disability protections and employer accommodations for Long COVID and ME/CFS patients. The Australian Public Service should act as a best practice model.

³⁴ www.emerge.org.au/faqs/can-people-with-mecfs-get-support-from-the-ndis

³⁵ www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html

Appendix A - Methodology for estimating economic impact of Long COVID in Australia

This submission makes the assumptions set out in Table 2 and follows the methodology used by the Brookings Institute for estimating the impact of Long COVID on the American economy.³⁶ This submission used the most conservative assumptions available, including, where available, figures identified through meta reviews rather than relying on individual studies.

Table 2: Assumptions and calculations for quantifying the economic damage of Long COVID

<u>Variable</u>	<u>Assumption</u>	<u>Source/Comment</u>
How many Australians caught COVID-19?	10.1 million	Commonwealth Department of Health as at 9 September.
Long COVID prevalence (pre-vaccination)	43%	Meta review: Chen Chen, Spencer R. Hauptert, Lauren Zimmermann, Xu Shi, Lars G. Fritsche, Bhramar Mukherjee, Global Prevalence of Post-Coronavirus Disease 2019 (COVID-19) Condition or Long COVID: A Meta-Analysis and Systematic Review, <i>The Journal of Infectious Diseases</i> , 2022.
How much does vaccination decrease Long COVID risk?	19%	Meta review: Gao, P.; Liu, J.; Liu, M. Effect of COVID-19 Vaccines on Reducing the Risk of Long COVID in the Real World: A Systematic Review and Meta-Analysis. <i>Int. J. Environ. Res. Public Health</i> 2022, 19, 12422.
How many Australians were vaccinated when they caught COVID-19?	96%	A conservative assumption that ignores the reality that the unvaccinated are more likely to catch COVID-19. www.health.gov.au/initiatives-and-programs/covid-19-vaccines/numbers-statistics
How many Australians have/had Long COVID?	3.5 million	Calculated using the above assumptions
What proportion of long haulers recover?	50%	The Minneapolis Fed survey contains the only recovery statistic identified. https://www.minneapolisfed.org/research/institute-working-papers/long-haulers-and-labor-market-outcome
How many Australians have	1.8 million	Calculated using the above assumptions

³⁶ www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/

ongoing Long COVID?		
How many long haulers can no longer work full time?	26%	<p>A conservative assumption from the Minneapolis Fed survey. (https://www.minneapolisfed.org/research/institute-working-papers/long-haulers-and-labor-market-outcome) </p> <p>By comparison, the UK Trade Union Commission estimates 36% can no longer work full time (https://www.tuc.org.uk/sites/default/files/2021-06/Formatted%20version%20of%20Long%20Covid%20report%20-%20v1.3.pdf) . A Lancet study found 67% cannot work full time (https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext) .</p>
What proportion of these people were employed before catching COVID-19?	64%	The Australian employment to population ratio captures the proportion of Australians over 15 who are employed (ABS Labour Force Survey, Aug 2022).
What proportion of long haulers are adults?	82%	For simplicity, this submission assumes adults and children are equally likely to catch Long COVID (despite evidence children are less likely to catch it). The adult to child (under 15 years old) ratio is calculated from ABS Cat. 31010.002.
How many Australian long hauler adults stopped working or reduced hours?	240,000	Calculated using the above assumptions
What proportion of these can work part time?	44%	<p>Calculated using the Trade Union Commission study which showed 20% of long haulers cannot work at all and 16% must work reduced hours (https://www.tuc.org.uk/sites/default/files/2021-06/Formatted%20version%20of%20Long%20Covid%20report%20-%20v1.3.pdf) </p>
By what proportion of their hours did part-time long haulers reduce?	25%	<p>The Minneapolis Fed study found that, on average, they reduced their hours by 10 hours a week; using that number and a 40-hour work week, we can assume that these workers reduced their hours by 25%.</p> <p> (https://www.minneapolisfed.org/research/institute-working-papers/long-haulers-and-labor-market-outcome) </p>

How many full time equivalent workers have been lost to Long COVID?	213,600	Calculated using the above assumptions
What is the impact on the participation rate?	-1.0%	Calculated using the above as a fraction of Australia's 21.1 million working age population
What is the economic damage as calculated by lost wages?	\$11.0 billion	Calculated assuming long haulers have the same median personal income as other Australians (\$51,389).
What is the economic damage as a proportion of GDP?	1.8%	Calculated using Australia's GDP of \$614b