Estimating the Current Scale and Impact of Long COVID in Australia

SUMMARY | 11 NOVEMBER 2022

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11th November 2022

Introduction
Over the last twelve months, more than 10 million Australians have reported a test-confirmed infection with COVID-19, while sero-surveillance indicates that at least 65% of adults and 64% of children may actually have been infected by the end of August 2022 (equivalent to 16.8 million people). As the number of infections has grown, so has recognition of and concern over the risks of “Long COVID” or Post-Acute Coronavirus Syndrome – the complex set of long-lasting symptoms and conditions which have been reported by millions of people around the world following acute illness with COVID-19. Yet Australia still has no surveillance system for Long COVID, and information on likely numbers of Long COVID cases in this country remains fragmentary and highly limited.

We have therefore undertaken new modelling analysis to estimate the likely scale of Long COVID given the evolution of infections in Australia up until September 2022. As we concluded our modelling exercise in October, an important study was published by the ANU’s Centre for Social Research and Methods which provides one estimate of Long COVID prevalence in August 2022. We have used this study to triangulate against our modelled estimates.

We have used the World Health Organization’s definition of Long COVID:

“Post COVID-19 condition, also known as Long COVID, occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19. Symptoms last for at least 2 months and cannot be explained by an alternative diagnosis.

Common symptoms include fatigue, shortness of breath and cognitive dysfunction, as well as others that generally have an impact on everyday functioning. Symptoms may appear following initial recovery from an acute COVID-19 episode, or persist from the initial SARS-CoV-2 infection.”

The Scale of Long COVID – International and Australian Evidence
A growing number of countries now collect systematic data on the prevalence of Long COVID in their populations. In June 2022, 7.5% of American adults reported currently experiencing Long COVID symptoms, while 14.2% of adults said they had “ever experienced” Long COVID since the pandemic began. In August 2022, 1.8 million people in the United Kingdom reported current Long COVID symptoms (2.7% of the population), as did 1.4 million Canadian adults. However, there remains considerable uncertainty over the proportion of people who will actually develop Long COVID following a COVID-19 infection; recent estimates range from 43% of people showing Long COVID symptoms after 28 days to as few as 3.7% at three months. Rates of recovery and the proportion of people who may still experience Long COVID over longer timeframes also remain uncertain – although international evidence increasingly suggests that some people remain ill more than two years after their initial infection. What is clearer is the relatively consistent finding that 20-25% of
people with Long COVID report significant negative impacts on their ability to conduct their daily activities. Meanwhile, British data suggests that 5-10% of people with Long COVID may be effectively unable to work; yet US data suggests that over 20% might be forced to stop working.

There is less data available on Long COVID in Australia, and in particular there is no regular official surveillance of Long COVID, in contrast to other peer countries. However, the ANU found that, in August 2022, 4.7% of adult Australians (or 9.7% of adults who reported having had a COVID-19 infection) said that they “...have had or currently have post-COVID-19 syndrome (symptoms that lasted 3 months or more)”. This is equivalent to 1.07 million Australian adults. They also found that – similar to other countries – 21.6% of them reported that their Long COVID symptoms reduced their ability to carry out day-to-day activities “a lot”.

The Model

We developed a stock and flow model that estimates the likely number of Long COVID cases resulting from the actual numbers of COVID-19 infections reported across Australia between 1st January 2021 and 4th September 2022. This provides accurate predictions of Long COVID cases until 4th December 2022. We used three different estimates of prevalence (the proportion of COVID infections that will result in Long COVID three months later), and tracked recovery over time to 52 weeks post-infection, and also used evidence from a recent systematic analysis to adjust estimates for the impacts of vaccination. In our main report, we provide both national results and outputs for each State and Territory, based on their specific experience of COVID infections.

Headline Results

Our different models and scenarios indicate that at least 160,000 Australians will likely be experiencing Long COVID symptoms by 4th December 2022; for over 35,000 of these people, their symptoms will cause significant limitations to their activities. Yet the actual number could be significantly higher than this, potentially as high as several hundreds of thousands (Table S1).

<table>
<thead>
<tr>
<th>Model:</th>
<th>Long COVID cases – any severity</th>
<th>Long COVID cases with activity “limited a lot”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td>189,627</td>
<td>64,474</td>
</tr>
<tr>
<td>Model 2</td>
<td>160,645</td>
<td>35,312</td>
</tr>
<tr>
<td>Model 3</td>
<td>1,278,764</td>
<td>196,797</td>
</tr>
</tbody>
</table>

Table S1: Predicted Long COVID cases, week commencing 4th December 2022

Once the results of the ANU survey became available, we checked our model against their estimates. This involved adjusting their estimate of people who had “ever had” Long COVID to only those with “current symptoms”, based on ratios seen overseas. This adjusted estimate (“ANU Current”) is shown against our model outputs for mid-August in figure S1 below.

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Given the results of our models and the ANU data, the true number of people with Long COVID of any severity in early December will almost certainly exceed the outputs of Model 1 (>189,000 people), yet not be as high as those of Model 3 (1.27 million people). We can therefore be relatively confident that several hundred thousand people across Australia will be experiencing Long COVID symptoms in December 2022. Based on our adjusted “current symptoms” estimate from the ANU survey, we suggest that over 500,000 people might still be experiencing current Long COVID symptoms of any severity in early December 2022 – of whom more than 110,000 might have symptoms that limit their activities “a lot”.

Our model also allows us to estimate the potential number of people might be unable to work due to Long COVID (albeit within quite wide ranges, from 5% to 25% of people with Long COVID. While we largely discount Model 3 as being unrealistically high, the other models still suggest that, in all likelihood, tens of thousands of Australians may be unable to work because of Long COVID in coming months.

<table>
<thead>
<tr>
<th>Model</th>
<th>Any Long COVID</th>
<th>% Unable to Work</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Cases</td>
<td>5%</td>
</tr>
<tr>
<td>Model 1</td>
<td>189,627</td>
<td>9,481</td>
</tr>
<tr>
<td>Model 2</td>
<td>160,645</td>
<td>8,032</td>
</tr>
<tr>
<td>ANU Current est.</td>
<td>~ 540,000</td>
<td>~ 27,000</td>
</tr>
<tr>
<td>Model 3</td>
<td>1,278,764</td>
<td>63,938</td>
</tr>
</tbody>
</table>

Table S2: Potential numbers of people unable to work due to Long COVID, 4th December 2022
Discussion

Our results suggest that, by early December 2022, several hundred thousand Australians will most likely still have Long COVID symptoms; given the ANU survey findings, this number could easily be over half a million. Several tens of thousands, and perhaps more than 100,000 of these people will still be experiencing symptoms that limit their daily activities a lot, with likely impacts on their ability to work and with potential for long term disability. These Long COVID cases are the product of COVID infections that occurred before early September; our estimates do not include any Long COVID cases that will arise from new COVID infections after this point in time.

With no definitive treatment yet available – and worrying overseas data indicating that a proportion of people with Long COVID might realistically expect to experience it for several years – the prospect of tens of thousands of Australians experiencing long-term illness and disability from this condition seems more likely than not. Yet continuing lack of data and the resulting uncertainty seem to have combined with an apparent lack of urgency to prevent the development of a concerted and integrated health policy response to Long COVID and Post-Acute Coronavirus Syndrome.

Today, Australia is not where it could or should have been in its response to Long COVID and Post-COVID conditions. The Australian healthcare system is currently feeling the effects of many grave stressors, some springing directly from COVID-19, others the result of long-term trends and tensions coming to a head as COVID exposed unsustainable systems and practices. Mounting an appropriate response to Long COVID is especially challenging because it comes on top of these existing pressures; yet it also cannot be ignored simply because it is inconvenient. Calibrating an appropriate, cost-effective response to Long COVID that meets the needs of patients while recognising the realities of scarce resources and competing priorities must start with an urgent effort to remedy the increasingly unacceptable deficits in this country’s understanding of the condition.
Recommendations

Based on the results of our modelling, we make the following recommendations for action by the Australian Government in five key areas (see full report for more details):

**Surveillance, Data and Monitoring**

2. Direct and fund the Australian Bureau of Statistics and the Australian Institute of Health & Welfare jointly to establish a nationwide, monthly population survey of Long COVID prevalence (drawing directly from ONS experience).
3. Direct and fund the Australian Bureau of Statistics to increase the frequency and sensitivity of key labour market collections to allow more timely and frequent monitoring of health impacts, including specific questions on Long COVID.
4. Use the AIHW’s COVID-19 linked data registry to focus on post-COVID mortality, severe illness and healthcare utilisation to better understand the burden and impacts of more severe post-COVID sequelae.

**Healthcare Delivery Requirements and Models**

5. Reinstate and resource a focal point for ongoing evidence assessment and updating of guidelines on optimal clinical management of Long COVID and post-COVID sequelae.
6. Use Long COVID as a natural experiment to create regional pooled funding models, to mobilise and deploy both public and private healthcare provider resources.

**Employment, Disability and Social Protection Systems**

7. Review policies on employer obligations for sick leave (short and longer-term) and accommodations to ensure adequate support for employees with Long COVID; leverage innovative and equitable new solutions to protect workers and families from poverty in the face of any long-term illness.
8. Develop clear policies with respect to Long COVID and access to National Disability Insurance Scheme, Centrelink disability and welfare benefits, superannuation etc.
9. Review the treatment of COVID-19 and Long COVID by insurers (especially life insurance) to ensure that consumers are not unfairly disadvantaged.

**COVID-19 Control Measures and Policy Settings**

10. Model likely burdens from Long COVID and other post-COVID sequelae and use this modelling to inform decision-making on COVID-19 control measures.
11. Recognise explicitly in all policies, statements and communications that further growth in Long COVID can still be minimised through effective control and prevention of COVID-19.
12. Ensure that the potential burden of post-acute sequelae is explicitly factored into future pandemic preparedness and resilience planning.

**Research and Development**

13. Develop a National Long COVID Research Mission to mobilise and coordinate government, university / research and private sector resources through directed, mission-focused research and development.