Estimating the likely scale of Long COVID as Australia re-opens

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Introduction

As the COVID-19 pandemic unfolded around the world during 2020\(^1\), it began to become clear that some patients who had survived infection with SARS-CoV-2 were not recovering as rapidly as others.\(^2,3\) As the months passed, the existence of such COVID ‘long-haulers’ was increasingly recognised and studied around the world,\(^4\) even as the health systems of many countries struggled with high numbers of deaths and acutely ill patients. There has been extensive debate over the correct terminology and precise definitions of what has come colloquially to be known as ‘Long COVID’.\(^2\) However, there has been a broad acceptance that significant numbers of patients have experienced a longer-term, multi-system disease, well after their initial acute infection would have typically been expected to resolve.\(^2,3,5\) Long COVID symptoms frequently include combinations of ongoing, severe fatigue; respiratory problems; neurological issues (including sleep problems); muscle and joint pain and weakness; mental health problems, including depression and anxiety; and a wide range of other symptoms which vary in intensity but can persist for months in some patients.\(^2\) There have been arguments over what this syndrome should be called (e.g. Long COVID, post-COVID-19 syndrome, post COVID-19 condition); and suggestions by some that ‘Long COVID’ may be broadly psychosomatic in nature or is ‘associated more with the belief in having experienced COVID-19’\(^6,7,\) claims which have been strongly refuted both by people living with the condition and researchers.\(^2,8\) What is not in question is that, in countries which have suffered severe COVID-19 pandemics to date, large numbers of patients have been coming forward requiring care and support for debilitating, ongoing post-COVID illness; so much so that the English Health Secretary, Sajid Javid, recently expressed his alarm at the scale of the Long COVID problem facing the National Health Service in that nation.\(^9\)

In May 2021, we authored an Issues Brief\(^2\), published by the Deeble Institute for Health Policy Research, which considered how the Australian healthcare system needed to prepare to face the challenge of the longer-term sequelae of COVID-19. In the Issues Brief, we reviewed the evidence on the long-term clinical sequelae of COVID-19 and available evidence on the prevalence of Long COVID, before discussing appropriate, value-based health system responses.
At that time, we estimated that there may have been a few thousand (between 2,800 and 5,400) people who might have experienced Long COVID following the various Australian outbreaks in the first year of the pandemic.2

Since May, a number of factors have changed significantly, which may well have consequences for the impact of Long COVID in Australia. Immense progress has been made in vaccinating the population; yet significant outbreaks have occurred (and continue) in New South Wales (NSW), Victoria and, to a lesser extent, the Australian Capital Territory (ACT)10; and these South Eastern states have all commenced substantially along the path to re-opening as envisaged in the National Plan.11 The Doherty Institute modelling11, which was used to underpin the National re-opening plan, envisaged several scenarios in which large numbers of new COVID-19 cases eventuate, even with high levels of vaccination. Meanwhile, the most recent outbreaks in NSW and Victoria have already generated close to 140,000 new COVID-19 cases.12, 13 Even as death and hospitalisation rates have declined rapidly (compared with 2020) due to immunisation and improved treatment options, absolute numbers of COVID-19 cases in recent and coming months will be several times larger than those seen last year. These levels of infections will, in turn, almost certainly generate significantly larger numbers of Long COVID cases than have previously been seen in Australia. This briefing paper, therefore, provides updated estimates of likely numbers of Long COVID cases due both to the current outbreaks and the evolution of infections envisaged by the Doherty modelling of re-opening options.

Methods

The number of Long COVID cases was estimated by multiplying the number of COVID-19 survivors by the probability or proportion of cases obtained from the studies conducted in NSW14 and the United Kingdom (UK).15

COVID-19 survivors

The potential future number of COVID-19 cases modelled for this study was obtained from the results published in the Doherty Modelling Interim report to the National Cabinet as of 17 September 2021; the Doherty modelling sought to estimate possible COVID-19 case numbers over a 180-day period, for different scenarios following international reopening.11
The actual COVID-19 cases observed in the recent outbreaks in NSW (period of 16 June 2021 to 30 October 2021) and Victoria (period of 01 August 2021 to 30 October 2021) were obtained from the publicly available data sources.\textsuperscript{12, 13, 16} The number of deaths were not included in the analysis, on the assumption that patients who died due to COVID-19 would not experience Long COVID symptoms. The number of symptomatic infections occurring in vaccinated and unvaccinated individuals were directly estimated in Doherty’s interim report\textsuperscript{11}. Actual numbers of fully vaccinated COVID-19 infections from locally acquired cases were reported in NSW’s epidemiological report, which noted 5,014 cases and 71 deaths in fully vaccinated persons.\textsuperscript{13} COVID-19 reporting in Victoria is not as comprehensive as with the NSW, presenting only the total number of COVID-19 cases without disaggregating by vaccination status.\textsuperscript{12} For this reason, we assumed that 7\% of the total cases in Victoria occurred in fully vaccinated individuals similar to the rates generated from the NSW epidemiological report.\textsuperscript{13} Table 1 shows the number of cases used in this analysis.

Table 1 COVID-19 Survivors

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Doherty Modelling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 2C (Vacc)</td>
<td>2C= 70% vacc (high seeding: 1,000-4,500 cases per day), Low PHSM + Partial TTIQ</td>
<td>39,560</td>
</tr>
<tr>
<td>Scenario 2C (Unvacc)</td>
<td></td>
<td>205,315</td>
</tr>
<tr>
<td>Scenario 2D (Vacc)</td>
<td>2D= 70% vacc (high seeding: 1,000-4,500 cases per day), Med/Low PHSM + Partial TTIQ</td>
<td>24,041</td>
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<tr>
<td>Scenario 2D (Unvacc)</td>
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<td>131,810</td>
</tr>
<tr>
<td>Scenario 3B (Vacc)</td>
<td>3B= 80% and Med seeding (300-1000 cases per day) baseline PHSMs and partial TTIQ</td>
<td>147,707</td>
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<tr>
<td>Scenario 3B (Unvacc)</td>
<td></td>
<td>760,248</td>
</tr>
<tr>
<td>Scenario 3C (Vacc)</td>
<td>3C=80% and High seeding (1,000-4,500 cases per day) baseline PHSMs and partial TTIQ</td>
<td>162,025</td>
</tr>
<tr>
<td>Scenario 3C (Unvacc)</td>
<td></td>
<td>799,410</td>
</tr>
</tbody>
</table>

2021 Outbreak in Australia – Actual Cases

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW (Vacc)</td>
<td>Outbreak from 16 June 2021 to 30 October 2021</td>
<td>4,943</td>
</tr>
<tr>
<td>NSW (Unvacc)</td>
<td>30 October 2021</td>
<td>64,220</td>
</tr>
<tr>
<td>VIC (Vacc)</td>
<td>Outbreak from 01 August 2021 to 30 October 2021</td>
<td>4,825</td>
</tr>
<tr>
<td>VIC (Unvacc)</td>
<td></td>
<td>62,685</td>
</tr>
</tbody>
</table>

Note: Vacc= Vaccinated, Unvacc= Unvaccinated, NSW= New South Wales, VIC= Victoria, PHSM=public health and social measures, TTIQ=test, trace, isolate, quarantine
Doherty modelling scenarios are explained in full elsewhere. In brief, partial test, trace, isolate, quarantine (TTIQ) is the ‘the observed reduction in transmission (43%) resulting from test-trace-isolate-quarantine responses at the height of the Victorian ‘second wave’ when case numbers were in the hundreds per day and the system was under strain resulting in delays.’

Under ‘baseline’ public health and social measures (PHSM), Australians are not enforced to stay at home but there are some low-density requirements and social distancing (1.5 sqm rule) measures. Under ‘low’ PHSM, there are some capacity limitations and restrictions on recreational, retail and workplace, but there are no ‘stay at home’ orders. Under ‘medium’ PHSM, Australians are mandated to stay at home except for work (but are encouraged to work from home when possible), study and activities that are considered essential.

**Probability of developing Long COVID**

The Long COVID probabilities were obtained from studies conducted in NSW and by the Office of the National Statistics in the UK. A recent population-based cohort study in NSW following 94% (n=2,904/3,096) of the confirmed cases between April and July 2020 found that 20% of the COVID-19 survivors still experienced symptoms within a month and around 5% at three months. Meanwhile, in the UK, the COVID infection survey was conducted following 21,622 participants who tested positive from swab tests. The study noted Long COVID prevalence of 22.1% and 9.8% at five and 12 weeks respectively and was later updated to 21.0% at five weeks and 13.7% at 12 weeks.

Since the duration of Long COVID is still unknown, we have decided to extend the data up to two years with the assumption that patients will no longer experience Long COVID symptoms at two years. We extrapolated the data points using a fitted decay function similar to the method used by a study that quantified the long-term impact of Long COVID in the UK. The decay function constant and the rate of decay are noted in table 2, and these were derived from the UK COVID infection survey data and NSW population-based study.

According to a recent UK study, patients who are fully vaccinated (yet who still suffer a breakthrough SARS-CoV-2 infection) appear less likely to experience Long COVID, reporting an odds ratio of 0.51 (95% CI 0.32–0.82; p=0.0060).
To properly account for the effect of vaccines on Long COVID itself in this analysis, we converted the odds ratio to relative risk (RR= 0.54) [20] and directly applied this estimate to vaccinated individuals. Conversion to rates and probabilities were applied in this analysis.\textsuperscript{21}

<table>
<thead>
<tr>
<th>Source</th>
<th>Constant</th>
<th>Power term</th>
<th>Extrapolated data at 52 weeks</th>
<th>Extrapolated data at 104 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>CIS data points</td>
<td>0.3111</td>
<td>-0.061</td>
<td>1.30%</td>
<td>0.1%</td>
</tr>
<tr>
<td>NSW Data points</td>
<td>0.5629</td>
<td>-0.172</td>
<td>0.01%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>

\textit{Note: Figures noted here are baseline data}

Results

Figures 1, 2 and 3 present the potential Long COVID caseload arising from i) the modelled Doherty Scenarios for 180 days following national reopening and ii) the recent outbreaks in Victoria and NSW (until 30 October 2021).

Depending on the scenarios used within the original Doherty Institute model, there appears to be potential for large numbers (at least initially) of Long COVID cases, as shown in Figures 1 and 2 below. However, total numbers of Long COVID cases decline quite rapidly over time. Crucially, it is now no longer clear that the COVID-19 cases anticipated by the Doherty model will eventuate at the scale suggested in their original estimates.

Under Scenario 2C, 70\% of Australians are fully vaccinated. There are high seeding infection rates and, therefore, a partial effect of ‘test, trace, isolate, quarantine’ (TTIQ) responses were assumed. While maintaining a low level of public health and social measures (PHSM), Doherty model results noted 244,875 COVID-19 infections resulting in our Long COVID estimates of 60,000 (using ONS data points) or 77,000 (using NSW data points) cases. A lower number of COVID-19 survivors who would experience prolonged symptoms was estimated for Scenario 2D. This is when other factors remain the same as Scenario 2C, but a medium/low PHSM are to be maintained (Figure 1).
In this scenario, around 38,000 (using ONS data points) or 49,000 (using NSW data points) Long COVID cases were calculated from the 155,851 Doherty modelled COVID-19 cases. More than 200,000 (ONS) or >280,000 Long COVID cases were calculated under Scenarios 3B and 3C with over 900,000 to 960,000 modelled COVID-19 symptomatic infection (Figure 2). Scenarios 3B (medium seeding infection rate) and 3C (high seeding infection rate) present cases when PHSMs were relaxed to baseline and Australians are 80% fully vaccinated.

**Figure 1 Potential Long COVID cases for scenarios 2C and 2D**

![Graph showing potential Long COVID cases](image)

**Notes:** Solid lines presents the results using the ONS data points and Dashed lines presents the results using the NSW datapoints, results noted here excludes the impact of permanent disability and post-intensive care syndrome.
By contrast, Figure 3 presents estimates of likely Long COVID cases numbers given the actual COVID-19 case numbers reported in NSW and Victoria over recent months. There were 67,803 COVID-19 cases and 293 COVID-19 related deaths in the recent Victorian COVID-19 outbreak in the period 01 August 2021 to 30 October 2021. Our model suggests this would generate between 16,962 initial Long COVID cases (using ONS data points) and 22,019 (using NSW data points) in Victoria. Meanwhile, the total COVID-19 cases in NSW from 16 June 2021 to 30 October 2021 were 69,681 of which 69,418 were locally acquired. There were 518 COVID-19 related deaths overall with 516 from local sources. Our model suggests that the NSW outbreak may so far have given rise to between 17,377 Long COVID cases (using ONS data points) and 22,559 initial Long COVID cases using NSW data points (Figure 3).

The number of COVID-19 survivors exhibiting prolonged symptoms decreases over time as shown in all figures. A faster decline can be observed when NSW Long COVID data points and extrapolation were used; the NSW data suggest that a larger number of COVID-19 survivors may initially experience post-acute syndrome, but the number of Long COVID cases will then decline more rapidly.
Using ONS Long COVID data points and extrapolation generates a lower number of initial Long COVID cases, but this number of Long COVID cases decreases more gradually over time.

**Figure 3 Potential COVID cases from the recent Victorian and NSW COVID-19 Outbreak**

Notes: Solid lines presents the results using the ONS data points and Dashed lines presents the results using the NSW datapoints, results noted here excludes the impact of permanent disability and post-intensive care syndrome.

**Limitations**

Our model is subject to a number of limitations. First, in using outputs of the Doherty model as the basis for our estimated case numbers, our modelling unavoidably incorporates any limitations inherent to the Doherty model. If the scenarios generated by the Doherty modelling prove to have been overestimates, then so too will our estimates of Long COVID cases. Second, the total number of fully vaccinated individuals both for NSW and Victorian outbreaks were not available at the time of this writing. Therefore, we have applied the estimate for fully vaccinated COVID-19 related infections coming from NSW locally acquired infections to both states. Third, it is possible that our source estimates for expected rates of Long COVID cases may not fully reflect precise circumstances of the Delta variant in a population rapidly approaching high levels of vaccination coverage. For simplicity, we have presented total numbers of likely Long COVID cases within a two-year time frame.
In reality, new Long COVID cases will emerge (with an appropriate lag) in parallel with the actual distribution of new COVID-19 cases over time; thus peak numbers of Long COVID cases will, at any given point in time, be somewhat lower than the cumulative curves shown above.

The nature of current re-opening strategies in both NSW and Victoria mean that their current outbreaks will blend into those associated with re-opening in the Doherty model in a way that cannot be clearly distinguished.

Our modelling as presented here only includes Long COVID; it is important also to remember that a significant proportion of those severely ill COVID-19 cases who have required ventilation are likely to develop Post-Intensive Care Syndrome (PICS) and require long-term rehabilitation and care even after they have been discharged from hospital. The clinical needs of PICS survivors are significantly different from those of people living with Long COVID.

Implications for Health Services

Our results provide Australian health system policy makers and planners with an initial sense of the likely magnitude of Long COVID caseload over coming months. In practice, it is highly unlikely that everyone experiencing Long COVID would require specific service provision in the first few weeks of their post-acute phase – during which large numbers of patients will experience recovery from Long COVID. However, those still experiencing Long COVID after three or more months are much more likely to seek care. Health systems in NSW and Victoria should, therefore, each anticipate several thousand cases of longer duration Long COVID who are likely to come forward for care in increasing numbers from now onwards, as a direct consequence of their ongoing outbreaks. Over coming months, if the Doherty modelling of new COVID-19 cases under the national re-opening plan holds, Australia might expect some tens of thousands of >3 month duration Long COVID cases nationwide. Current evidence strongly suggests that these numbers will diminish over time as individual cases recover; but our modelling suggests that we might still reasonably expect thousands of people to be experiencing Long COVID some one year after their initial infection.
As Australia moves towards full ‘re-opening’ within and between states and territories, and with the resumption of international travel, it is important to state that effective primary prevention remains crucial to mitigate the longer-term health consequences of COVID-19. Vaccination not only reduces transmission and protects against severe illness; it seems likely that it also reduces the probability of fully-vaccinated individuals developing Long COVID, if they do subsequently become infected with SARS-CoV-2. Other Public Health and Social Distancing measures need to remain within the arsenal of public health decision makers; and more information on the potential burden of Long COVID needs to be fed into future decision-making on public health responses to COVID-19, along with considerations of mortality and hospital system workload.

In our earlier Issues Brief\(^2\), we called for Australian policy makers to prepare for Long COVID, and to seize the opportunity Long COVID offers to trial and implement new approaches to better integrating and coordinating care for people with chronic conditions. It is not clear that much progress has been made in this regard in the months since the Brief was published. However, as a new wave of Long COVID cases is almost certainly already forming, the following preparations are now even more urgently needed:

- State and territory health departments and health service leaders must recognise that Long COVID requires an effective response in primary health care and cannot be adequately managed by relying exclusively by specialised Long COVID clinics in tertiary health care centres. Demand is gravely outstripping the capacity of such specialist clinics to cope in many countries.

- General practitioners require access to high quality, up-to-date clinical guidelines and pathways for Long COVID care. A national centre of excellence for post-COVID care needs to be established rapidly to ensure high quality, standardised care information is available nationwide.

- State and territory system managers need to act now to establish care coordination centres which can mobilise access to care across general practice, allied health, and medical specialists in both public and private sectors.
Disclaimer

We used publicly available results and outputs from the Doherty Institute modelling exercise as the basis for our analysis. The Doherty Institute team was not involved in our work on Long COVID, and we were not involved in the original work of the Doherty Institute. Our use of the Doherty modelling, therefore, does not in any way imply endorsement of our analysis by the Doherty Institute.

References


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