

## Supplementary A to Submission 309: Additional findings from our Long COVID Survey

### Background

These results are additional findings from the survey run in October 2022 to inform our written submission (309). Details about the survey can be found in our initial submission.

A total 607 people participated in this survey with a rough response rate of 21%.

### Results

#### Vaccination pre-Long COVID

The following table shows the number of vaccines respondents had before developing Long COVID. We note that those infected in Alpha and Delta waves did not have access to vaccines. Almost half of respondents have had 3 doses of vaccines prior to Long COVID.

*Table 1. Number of vaccines before Long COVID*

# of vaccines	N	%
0	74	12.19
1	17	2.80
2	159	26.19
3	292	48.11
4	65	10.71
<i>Total</i>	607	100.00

#### Current Long COVID symptoms

We reported previously about the proportions of people with specific Long COVID symptoms.

A current symptom is defined as reporting either 'mild', 'moderate' or 'severe' for a specific symptom. If the person reported they did not have the symptom or it had resolved, this was not included in the current symptoms count.

Among all respondents, the average number of current Long COVID symptoms was 21.9. The median was 22 (SD= 6.6).

#### Current symptoms by gender

We then examined whether there were differences in the number of current symptoms by gender. The median number of symptoms among females was 23.0 and for males, it was 20.0. The average number of symptoms was 19.6 for males and 22.2 for females. These differences were statistically significant.

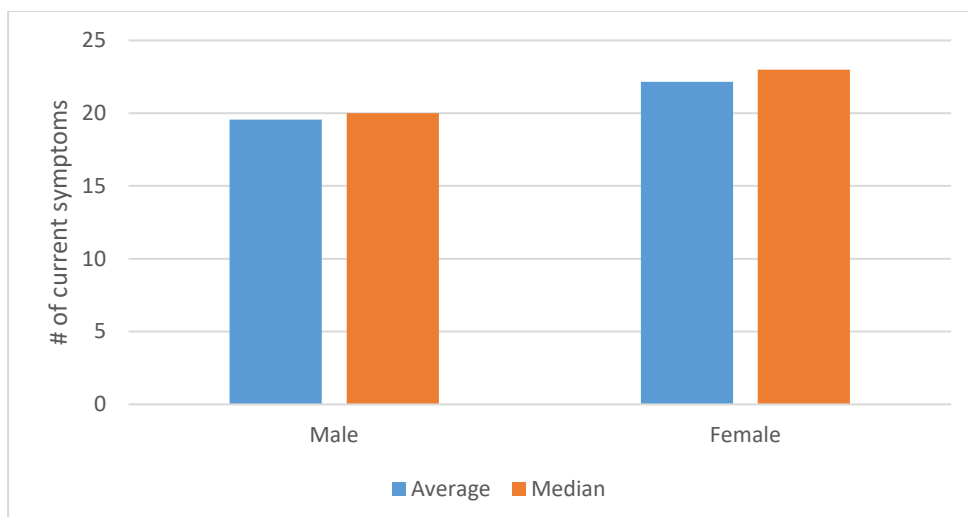


Figure 1. Current Long COVID symptoms by gender

### Current symptoms by age

We aggregated age into 5 categories due to smaller sample sizes in the youngest and oldest age groups. Compared to the 30-39 years old group, those 60 or older and those under 30 reported significantly fewer number of symptoms.

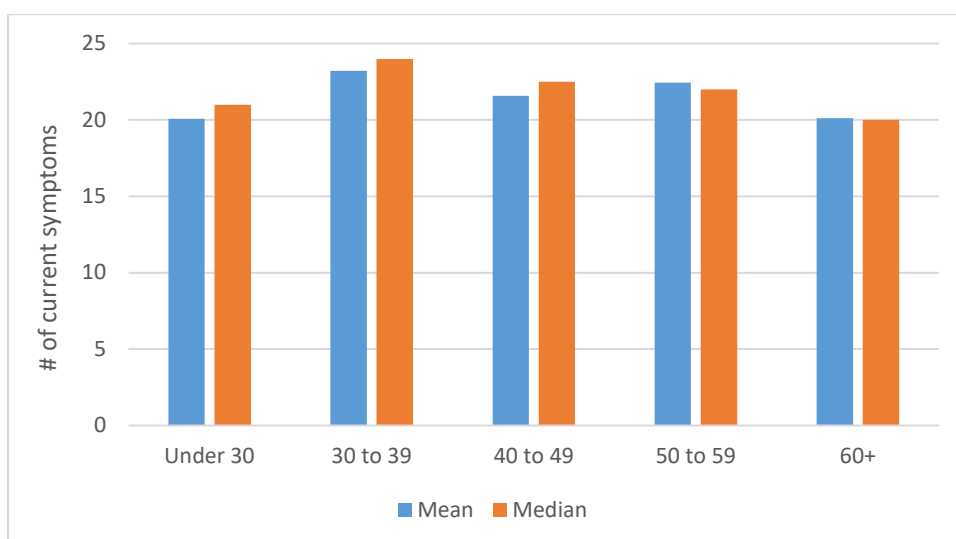


Figure 2. Current Long COVID symptoms by age

### Current symptoms by number of vaccines before developing Long COVID

Those who had no vaccine or had a single dose of COVID vaccine had a higher number of current symptoms compared to those with 2 or more doses of vaccine. The effect of the number of vaccines on current symptoms was statistically significant.

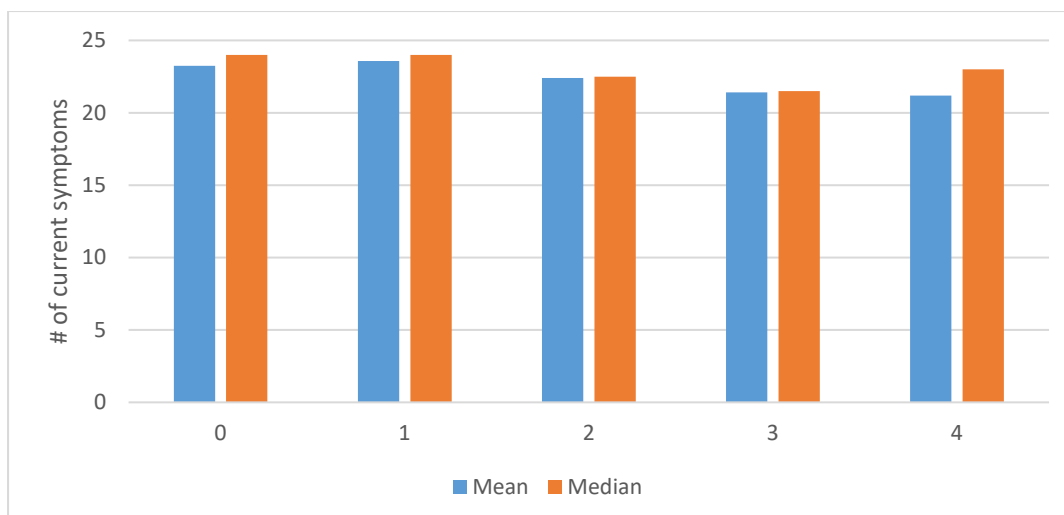


Figure 3. Current Long COVID symptoms by vaccines prior to Long COVID

### Current symptoms by COVID wave of first infection

About 90% of respondents in our survey had their first COVID infection with the Omicron variant. Those who were first infected with Omicron reported significantly fewer current symptoms compared to those infected in earlier waves.

### Severe Long COVID symptoms

We previously reported on the proportion of people who said their specific Long COVID symptoms were severe. Here we created a count of severe symptoms for further analysis.

Overall, respondents reported on average 12 of their symptoms were severe (median= 10).

### Severe symptoms by gender

Compared to males, females reported a higher number of severe Long COVID symptoms.

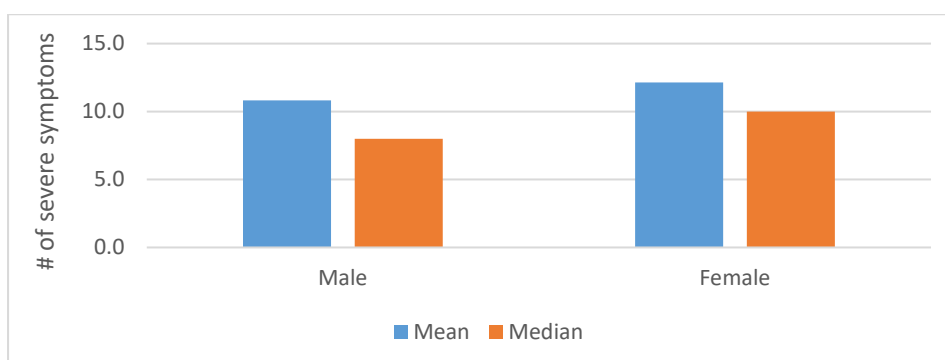


Figure 4. Severe Long COVID symptoms by gender

### Severe symptoms by age

The findings here are similar to what we observed for current symptoms (any severity). Those 60 and over reported fewer severe symptoms compared to those aged 30 to 39 years old.

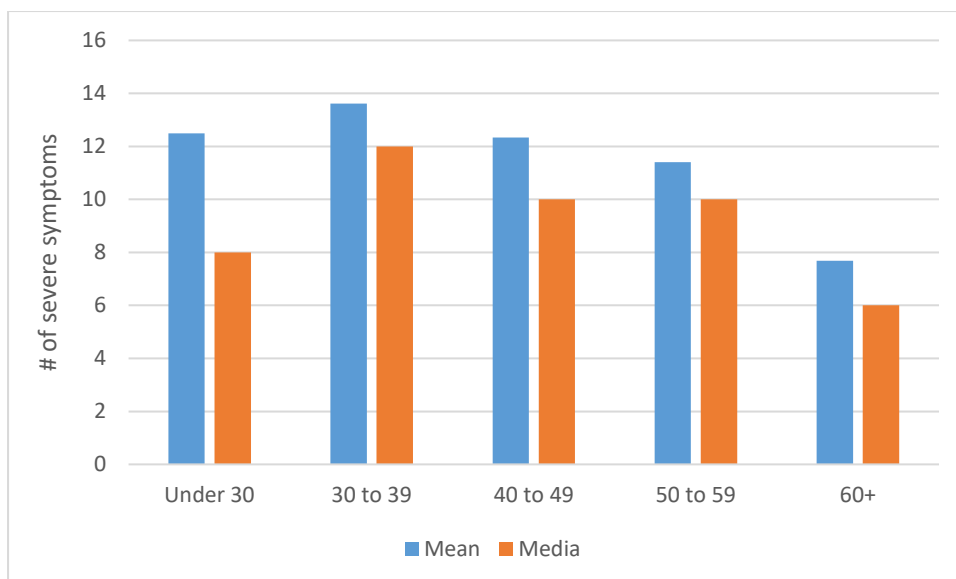


Figure 5. Severe Long COVID symptoms by age

#### Severe symptoms by number of vaccines before developing Long COVID

Those who had four doses of a COVID vaccine prior to their infection reported a smaller number of severe Long COVID symptoms. However, the overall difference in the number of severe symptoms by vaccine doses was not statistically significant.

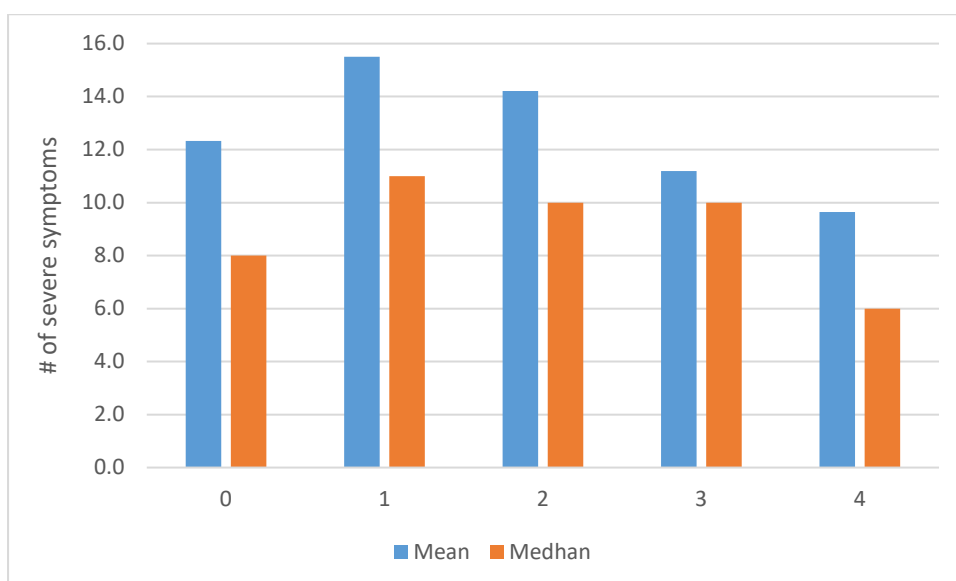


Figure 6. Severe Long COVID symptoms by doses of vaccines prior to Long COVID

#### Severe symptoms by COVID wave of first infection

Similar to the findings in the literature, we found that those whose first infection was Omicron reported fewer severe symptoms than those in earlier waves. The median number of severe symptoms reported by those first infected with Omicron was 10 compared to 12 among those first infected with earlier COVID waves.

### Impact of Long COVID symptoms on diagnosis and care

The symptoms themselves act as a barrier to diagnosis and treatment due to their impact on long haulers. Respondents reported fatigue/PEM severely impacted their efforts to get better. Concentration, working memory and breathlessness also impaired respondent's ability to get a diagnosis and treatment.

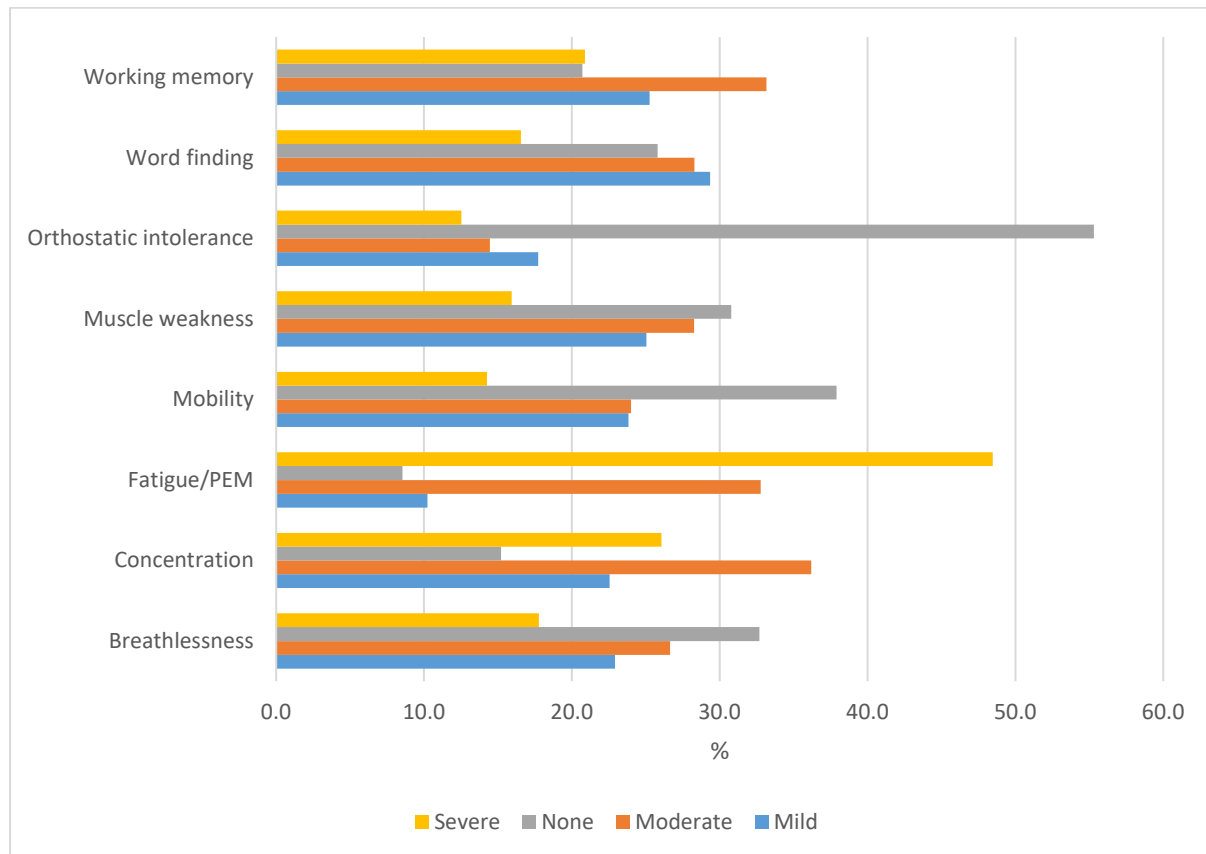


Figure 7. Impact of Long COVID symptoms on diagnosis and treatment of Long COVID

### Which symptoms were more likely to be resolved?

Here we examined the proportion of specific Long COVID symptoms that were reported as 'resolved' at the time of the survey. This may indicate which Long COVID symptoms could expect improvement over time.

Diarrhoea, fainting, chest pain, nausea/vomiting and skin rashes were most likely to be reported as resolved (ranging from 11.1% resolved to 6.9% resolved).

If we examined the top six symptoms reported as severe, below are the proportions of people who indicated that these symptoms have resolved:

- Fatigue/PEM (3.6% resolved); this symptom was experienced by 98% of respondents
- Concentration issues (1.7% resolved); this symptom experienced by 97% of respondents
- Sleep (3.8 % resolved); this symptom experienced by 90% of respondents
- Information processing (2.6% resolved); this symptom experienced by 93% of respondents
- Working memory (2.2% resolved); this symptom experienced by 94% of respondents
- Dysautonomia (4.0% resolved); this symptom experienced by 61% of respondents

This suggests that severe symptoms are more likely to persist in patients compared to other symptoms.

### Discontinued treatments

Our submission provided information on treatments trialled by respondents. Here we examined which treatments were reported as discontinued. This could be an indicator of effectiveness (or lack of) as respondents were experiencing an average of 20 Long COVID symptoms at the time of the survey. We note some drugs and therapies are meant to be used for short periods so we are not comparing like for like here.

Treatments that were most likely to be discontinued were Hyperbaric Oxygen Therapy (82%), antibiotics (76%), Cardiac medication -other (74%), corticosteroids (67%) and aspirin (64%). Treatments that were least likely to be discontinued (i.e. respondents were persisting with these treatments) were pacing (5% discontinued), oral vitamins (9%), speech therapy (11%), low dose naltrexone (12%) and psychological therapy (15%).

### Limitations

The findings presented here are self-reported. Further information about the limitations of our survey are described in our submission. As with our initial findings, we have not independently QA'd these results due to a lack of resources and time.

One of the limitations we raised in our submission was that we were not able to ask about participants' health status prior to long COVID. We also realised that we did not have any information on perceived effectiveness of treatments in our survey.

Therefore, we ran a min-survey with Long COVID Australia Facebook group members at the beginning of February. The survey was only opened for a few days and we also had limited time to draft the survey. Nonetheless, we present findings from our mini-survey in **Supplementary B** to our submission.