



**Health Issues Centre**  
Consumer voices for better healthcare



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“See us, hear us, believe us.”

“You only see us on our best days. You don’t see us when we are curled up in pain on the couch unable to move.”

## Acknowledgements

### With thanks

We acknowledge the funding support provided by the Victorian Department of Health and the Lord Mayor's Charitable Foundation that enabled this work.

We acknowledge and thank our partners in this work, Long COVID Support Australia and Long COVID Australia.

Most of all, we would like to thank every person who completed this survey, as it is the experiences of those who have lived, and continue to live, with Long COVID whose voices we need to hear in order to shape treatment, care, supports and research to best meet their needs.

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Health Issues Centre acknowledges the Traditional Custodians of the unceded lands on which this work was conducted. We honour and pay our respects to Elders past and present. We are committed to shaping a health system that supports self-determination.

Health Issues Centre also acknowledges lived and living experience of ill health, harm and recovery. We honour the courageous and important contribution of those who draw on their experiences to transform our health system.

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## Terms and abbreviations used in this report

### Definitions:

**COVID-19** – an infectious disease caused by the SARS-CoV-2 virus.<sup>i</sup>

**Lived and living experience** – people who identify as having a personal experience of Long COVID or a family member and/or carer who have experience in supporting a person living with Long COVID. A carer might be from a person’s chosen family, rather than the family of origin. Lived experience is inclusive of people who have recovered from Long COVID.

**Long COVID** – defined as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation.<sup>ii</sup>

**Post exertional malaise** – defined as the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

### Abbreviations:

CFS	Chronic fatigue syndrome
COVID-19	Coronavirus disease, variant 19
GP	General practitioner
HIC	Health Issues Centre
ME	Myalgic encephalomyelitis
MS	Multiple sclerosis
NDIS	National Disability Insurance Scheme
OT	Occupational therapist
PBS	Pharmaceutical Benefits Scheme
PD	Professional development
PEM	Post-exertional malaise
POTS	Postural orthostatic tachycardia syndrome
RTW	Return to work
SARS	Severe acute respiratory syndrome

## Executive summary

Health Issues Centre partnered with members of Long COVID Support Australia and Long COVID Australia to develop a survey to hear from those with lived and living experiences of Long COVID. The survey was open for two weeks and explored:

- Health status pre- and post-COVID infection
- Experiences of health services
- Impacts of Long COVID on work and study
- Wellbeing impacts of Long COVID on daily life
- Areas for future research, public awareness and education priorities.

The high-level findings are summarised in the infographic on the next page followed by a series of recommendations arising from this work.

*“It’s debilitating, terrifying and the stress induced by the ‘not knowing’ is awful. Life changing and grief inducing – so much loss to deal with – loss of life, loss of physical abilities, loss of strength (mental and physical), loss of job and ability to work full time, loss of independence and ability to care for myself with simple food tasks, loss of social interactions and friendships/support... Loss of understanding – the lack of understanding about how debilitating this illness is, is horrible. ‘It’s all in your head’ and ‘you need to choose to get better’ are the hardest and most hurtful things – NOBODY chooses to live like this. The cost on society is massive.”*

*“The symptoms are potentially life long. It is depressing, lonely, overwhelming and quick – nothing can prepare for the changes to health. I’m 27 and am wondering if my reproductive health has been so highly affected by Long COVID whether I can have kids – have I been robbed? I’m experiencing memory loss, it’s terrifying. I have breathing issues, I can’t walk more than 5 metres without issues. How will my older body react to this? Will I live to know my older self? It’s awful these things have to cross my mind, my entire life has changed.”*

## Who we heard from



TOTAL

**534**

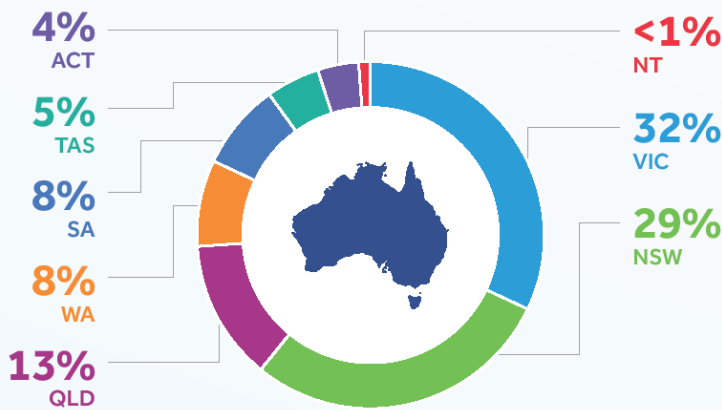
respondents  
across Australia



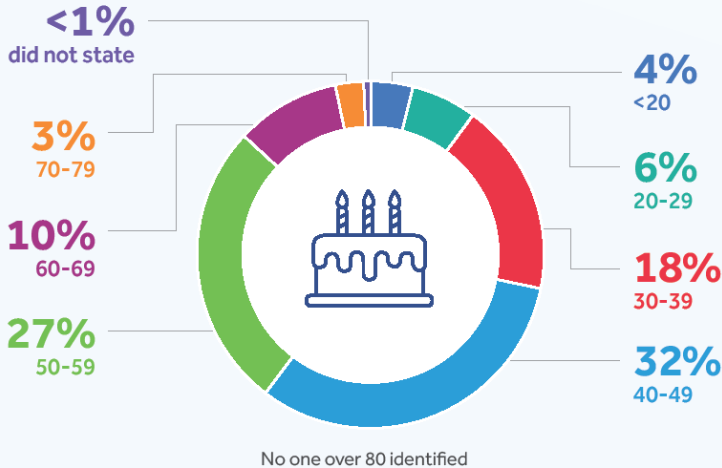
GENDER IDENTIFICATION

**86%** Women  
**12%** Men  
**1%** Non-binary  
**1%** prefer not to state

## WHERE



## AGES



## HEALTH CONDITION PRIOR TO COVID 19 INFECTION



**54%**  
had a pre-existing  
health condition

**46%**  
did not have a pre-existing  
health condition

## Negative impacts of Long COVID on...



**97%**

work



**85%**

study



**54%**

experiences of stigma  
or discrimination

Other impacts included reduced capacity to function in day to day life, social isolation, financial difficulties, mental ill health, complex symptom presentations and lack of recognition.

*Invisible illness doesn't mean no illness  
or that it's a state of mind*

## What do people with Long COVID want from the health sector?



**Recognition** - to be seen  
and heard



**Prevention** - continue to  
promote and practice COVID  
safety measures in health and  
community settings



**Greater understanding and  
treatment of this complex  
condition** - training and  
education, understanding the  
biology, investigating symptom  
and curative treatments, training  
and education on this condition



**Better diagnostics for Long  
COVID** and recording of  
COVID-19 infection rates



**Collaborative care practices**



**Honour and involve living  
and lived experience** - people  
with Long COVID can and  
want to contribute and partner  
in research, education and  
awareness across the health  
sector and community.



**Learn from overseas** and build  
on that research and practice

*Getting the message out there so people  
are not made to feel like a fraud*

## **Recommended areas for focus arising from this work:**

### **Recognition**

People with Long COVID need to be seen, heard and believed. That stigma and invalidation only serves to potentiate the many crippling impacts of this condition for many people.

### **Understanding and education**

That there needs to be greater understanding amongst health professionals of Long COVID, its complexity, treatment options and support and care needs of those who are affected. This requires consistent, evidence-informed training and education for health professionals on Long COVID including to understand the biology of Long COVID, its symptom profile and multiple body systems that can be impacted, as well as the significant links to postural orthostatic tachycardia syndrome (POTS) and myalgic encephalomyelitis (ME/CFS).

### **Community awareness**

That greater community awareness of Long COVID is needed so that those affected are supported and that the health system, workplaces, educational institutions and government supports can be enabled to support people to live as well as they possibly can with the many potential impacts of this condition.

### **Prevention and monitoring**

Understanding the wide-reaching implications of Long COVID on individuals and society and that COVID safety measures in health and community settings should continue be promoted and practised. That tracking COVID infection numbers in the community can contribute to people making mindful choices as to their personal safety.

### **Diagnosis and data capture**

That a valid diagnostic tool is needed to support greater, more consistent and earlier diagnosis of Long COVID. That the tracking and reporting of Long COVID cases is an important measure to understanding the scale and potential impact of Long COVID and contribute to health professional and community knowledge and awareness.

### **Multidisciplinary collaborative care**

That evidence-based models of care are created that reflect the multi-system nature of Long COVID and the significant impacts on health, wellbeing and functioning. That coordinated, multidisciplinary approaches to the active management of physical and psychosocial needs are essential to effectively supporting those with Long COVID to function in the community and in their daily lives.

### **A collaborative approach to research is essential**

That research is urgently needed that doesn't duplicate what we already know but works to find effective treatments and a cure. Honour and involve lived and living experience

### **The way forward needs to have people with lived and living experience at the centre and partners**

People with Long COVID are instrumental in identifying Long COVID and have a depth of understanding that is useful in the research and treatment of the condition. People with Long COVID can and want to partner in research, education and awareness-raising.



# 1. Background

In 2022 the Commonwealth Government undertook an inquiry into *Long COVID and Repeated COVID Infections* and, in early 2023, published the report *Sick and tired: Casting a long shadow*.<sup>iii</sup> The inquiry and report highlighted many of the challenges experienced by people living with Long COVID, and identified gaps in knowledge and reporting of Long COVID across the health sector.

At a similar time, Health Issues Centre (HIC) received funding from the Victorian Department of Health and the Lord Mayor's Charitable Foundation to develop a Long COVID online peer support community. The HIC's Long COVID support website (a Wix online forum) was launched in September 2022 and membership grew over the coming year to 251 members. Articles and research were routinely reviewed and shared by HIC with the forum members and peer exchange was moderated over the course of that year.

In recognition of the rapidly changing landscape and the overlap of this work with the Australian Long COVID Facebook group, HIC explored the establishment of a partnership to grow this work, its reach and impact. In March 2023, the HIC Project Team was expanded to include the involvement of convenors of Long COVID Support Australia and also of the emerging new not-for-profit organisation, Long COVID Australia. The focus of the project shifted to supporting the establishment of Long COVID Australia through the codesign and implementation of a survey to further explore the experience and profile of Long COVID in Australia and identify strategic priorities from people with lived and living experience. This work has also involved:

- planning for and migration of the HIC online forum to Long COVID Support Australia to support the growth and sustainability of the platform and place it in the hands of people with lived and living experience;
- support for the engagement and participation of people with living experience of Long COVID in the Victorian Department of Health Long COVID conference in September 2023. This included the:
  - provision of advice to the organising committee informed by living experience advisors to make the event safe (physically and psychologically) for people to attend the event;
  - submission and presentation of seven posters (one presenting the preliminary findings of this survey and six from Project Team members with living experience of Long COVID);
  - presentation of a powerful account of the impact of Long COVID presented by a Project Team member, Miquette Abercrombie in opening the conference session about the health economics of Long COVID.

This report summarises the findings from the codesigned Long COVID survey which was completed by 534 people.

## 2. Methodology

### Engagement approach

The Project Team considered the best way to engage with people with lived and living experience of Long COVID. It was determined that due to varying states of ill health a survey would be the best option as it would:

- allow respondents to take the survey in their own time
- not require lengthy written submissions (unless wanted)
- not require participation at the same time via online or in person consultations.

To further aid participation in the survey, the following features were incorporated:

- All questions were optional to give respondents the choice to decide what they wanted to or were able to share.
- Respondents could close and return to the survey at a later date, with their data intact.
- Tracking mechanisms were applied to help respondents see how much was left of the survey to complete.

### Survey development

The Project Team developed a survey that explored a mix of open- and close-ended questions to accommodate varying abilities. The survey guided participants through a series of questions about their own experiences as well as capturing their reflections on changes they would like to see in the support and management of Long COVID for individuals and the community and their views on research priorities.

The survey explored the following six areas:

- Health status pre- and post-COVID infection
- Experiences of health services
- Impacts of Long COVID on daily life
- Areas for future research, public awareness and education priorities
- Demographics of participants.

A copy of the survey can be viewed as Attachment 1 accompanying this report.

### Survey promotion and monitoring engagement

The survey was open from 14<sup>th</sup> to 30<sup>th</sup> June 2023. A short run was identified as important to not fatigue or stress the community. Further, the short time frame was seen as a motivator to energise and prompt those who wanted to respond to do so.

The survey was primarily promoted through Long COVID Support Australia, HIC's Long COVID online forum membership and HIC's social media and Consumers Connect newsletter.

The project team regularly monitored survey completion rates and the locations of respondents to adapt messaging and target further engagement.

### **Data collection**

Survey data was collected on the Qualtrics platform due to its data security and ease of use. The survey data was analysed through a combination of NVivo and Qualtrics platforms.

### **Data analysis**

A thematic analysis was applied to the qualitative data and assisted in understanding how people think and feel about Long COVID. Each key theme is described with the use of direct quotes for illustrative purposes. Quantitative data was analysed using simple descriptive statistics.

### 3. Results – The profile of survey participants

A total of 534 surveys were submitted.<sup>1</sup> The profile of participants is further described below and 7% (n= 33) of respondents indicated that someone assisted them to complete the survey.

#### 3.1. Age

Survey participants reflected a range of ages with at least ten in every aged group up to 79 years (Figure 1). There were no participants who were 80 years or older. The highest response rate by age were those who identified as 45–49 years old (18%, n=86), closely followed by those who identified as 50–54 years old (15%, n=75). For the survey responses for young people, these were often completed by parents and carers on their behalf.

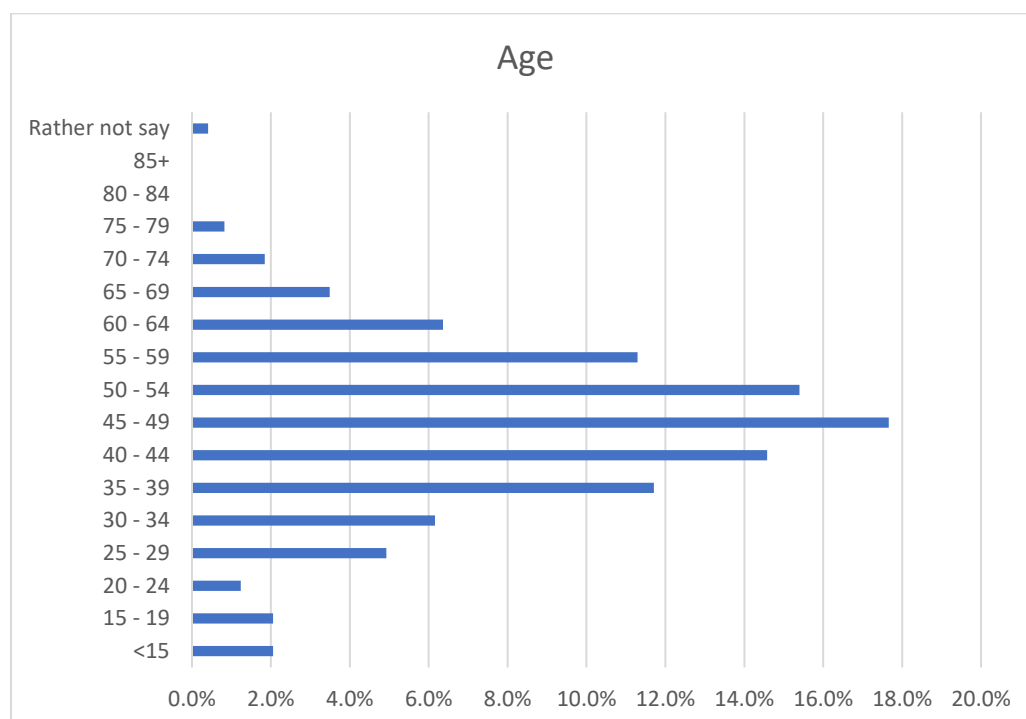


Figure 1: Age of survey respondents

#### 3.2. Gender

Significantly more women than any other gender participated in the survey (Table 1). This high representation from women aligns with research which indicates that women are more susceptible to Long COVID.<sup>iv</sup>

<sup>1</sup> Note that all questions were optional, whilst some had branching applied meaning that not every question was answered by 534 respondents. To qualify for inclusion in the data analysis, respondents needed to reach the end of the survey and select 'submit' to their responses. Some final comments made by respondents indicated some fatigue in completing the survey.

Gender	Total	%
Female	415	85.7%
Male	57	11.8%
Non-binary	7	1.4%
Prefer not to state	4	0.8%
Other	1	0.2%
<b>TOTAL</b>	<b>484</b>	<b>100%</b>

Table 1: Gender breakdown of survey respondents

### 3.3. Cultural identity

Approximately 4% (n=17) of respondents identified as Aboriginal and Torres Strait Islander out of a total of 482 responses, and 9% (n=45) as speaking a language other than English at home out of a total of 483 responses.

### 3.4. Location

People from all states and territories participated in the survey, with 32% (n=149) coming from Victoria and 29% (n=135) from New South Wales, reflecting these as the most populous states in Australia (Figure 2).

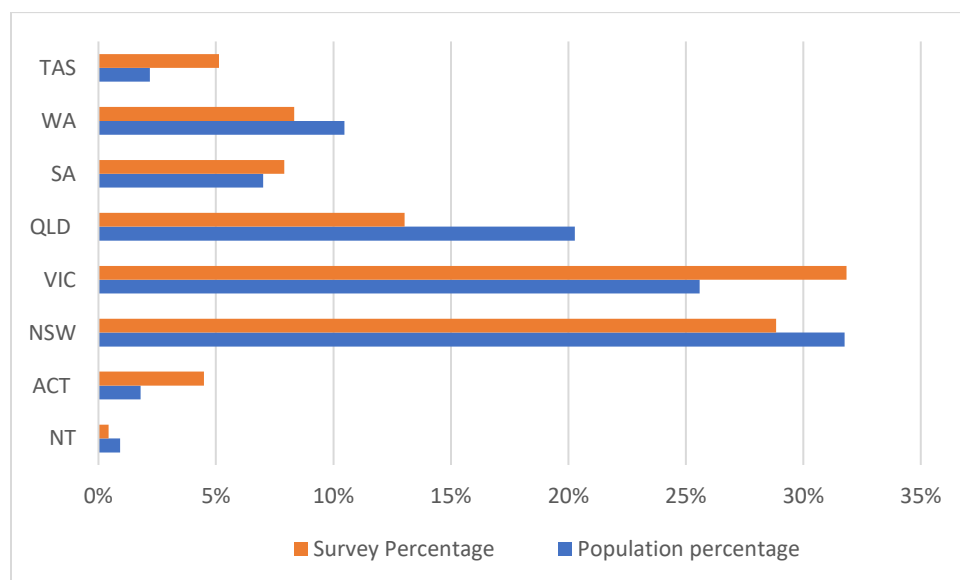


Figure 2: State and territory distribution of survey respondents compared to total percentage of the Australian population based on the 2021 Census

Most respondents (61%) lived in major cities, followed by 22% from inner regional and 13% from outer regional areas (Table 2).

Region	Total	%
Major cities	287	61%
Inner regional	103	22%
Outer regional	62	13%
Remote	9	2%
Very remote	5	1%
Unable to classify	6	1%
<b>TOTAL</b>	<b>472</b>	<b>100%</b>

Table 2: Survey respondents by geographic remoteness classifications

### 3.5. Duration of Long COVID

Almost half of respondents (45%, n=237) reported that they had been experiencing Long COVID for 12–18 months, followed by 19% for 9–12 months (Figure 3). Note that 6% (n=30) of respondents have been living with Long COVID for more than 24 months.

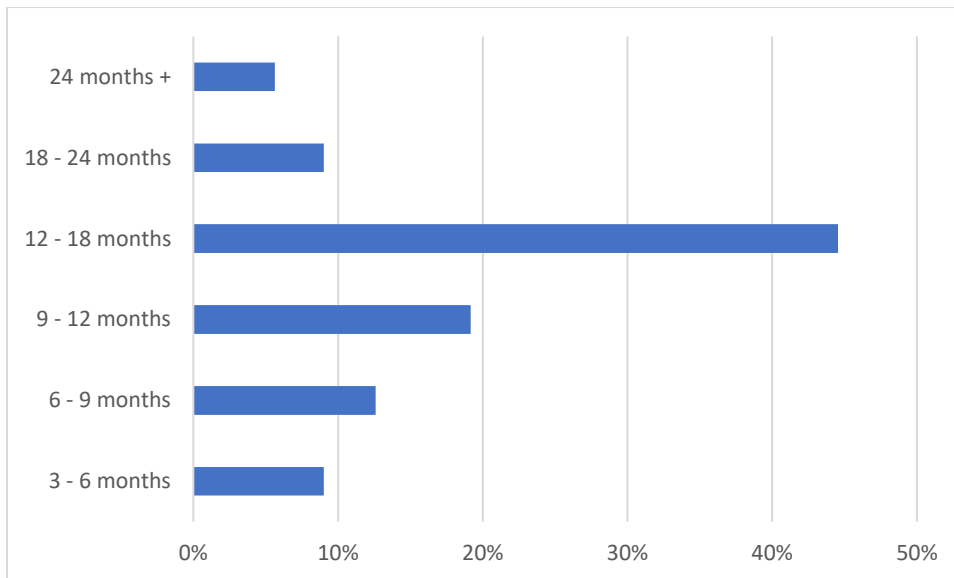


Figure 3: Length of time living with Long COVID

## 4. Results – Health status pre- and post-COVID infection

### 4.1. Current health status in relation to Long COVID

Survey participants were asked two questions about their current health status in relation to Long COVID. The first provided a series of statements with respondents selecting the one that best describes their current status compared to when they started their Long COVID journey (Table 3). Only 2% noted that they have recovered from Long COVID with a further 6% noting that they had previously recovered but their Long COVID had relapsed.

	Total	%
I have recovered from Long COVID	13	2%
My health has improved	213	40%
My health remains the same	112	21%
My health has worsened	125	24%
I had recovered but my Long COVID has relapsed	33	6%
I am not sure	35	7%
<b>TOTAL</b>	<b>531</b>	<b>100%</b>

Table 3: Current health status in relation to Long COVID

The second question asked people to describe their current health status in relation to Long COVID with responses coded and themed and shown in Table 4. The majority (88%) of respondents responded that they are living with Long COVID, whilst 6% reported having recently recovered from Long COVID. Twenty-three respondents (5%) reported that they are both living with and caring for someone with Long COVID.

	Total	%
I am living with Long COVID	430	88%
I have recently recovered from Long COVID	27	6%
I am both living with Long COVID and caring for someone who is also living with Long COVID	23	5%
I am caring for someone with Long COVID	7	1%
<b>TOTAL</b>	<b>487</b>	<b>100%</b>

Table 4: How respondents identified their connection to Long COVID

The key themes in participants' descriptions of their health status are further illustrated below:

- Many described feeling ill, low or poorly (n=128):

*“Awful. I don’t do so many of the things I used to enjoy and if I do something I need the next few days at home to recover.”*

*“Very poor. Some days I am bed bound. I couldn’t work for 4–5 months as I was constantly fatigued/dizzy/heart racing. Just standing up would make me faint. I barely go out or exercise*

*and have put on weight and now have high cholesterol. I feel like I've aged 10 years since contracting COVID in April 2022."*

*"Much the same as three years ago."*

- Others described declining health with severe effects and negative impacts on most or all areas of life (n=76):

*"Diabolical. I am a shadow of my former self. I used to be very active in the community, with my family, in my job and hobbies. I am a super independent go-getter person who after multiple attempts to push through this (having never heard of Long COVID at the time), only got worse and worse and I now depend on others for basics. I live with crippling 24/7 fatigue, severe PEM if I try to do a little more and have found that after severe PEM I never return to my level before that event. This is terrifying. I have to miss out on living life, I've hardly seen friends as even if they visit me and I am lying down, social interaction is too exhausting. I am a social person and love people, so this has a huge impact on my mental health. I try every treatment I hear of and research as much as I can to find answers. It's not a life."*

*"Noticeably worsened – I fatigue extremely easily and am easily out of breath. It makes it difficult to manage day-to-day activities, including managing the symptoms of my pre-existing conditions."*

*"Long COVID has caused cognitive and mobility issues similar to chronic fatigue and MS. I now work from home and part-time. I'm considering taking months off to reduce the impact on my nervous system to try to heal faster."*

*"I feel at seven months I'm getting worse unfortunately. I'm feeling a lot worse physically with escalating symptoms, and I feel that the health industry don't care and treat you like a mental health person that it's all in your head. It's a very depressing and isolating time."*

- Some reported improvement in symptoms and/or overall health (n=102). It was noted repeatedly that the road to improvement and recovery was slow and incremental:

*"Improving over time but still is impacting ability to work, socialise or complete small tasks."*

*"Going ok, but not 100%. My breathing is ok, but suffer from fatigue every couple of weeks and have leg pain continually when I am active."*

*"Improving but having episodic crashes (PEM). Overall, it is a frustrating and isolating process."*

- Improvements were not always linear and the fear and experience of reinfection was devastating:

*"You don't want to go out into the community even if you are feeling a little better, because I have been told that I should not get COVID again if I can avoid it as it will be very bad for me. I am constantly scared that I may get reinfected and what it could do to me if I did."*



*“Finally made some improvements since April this year, but got reinfected just two weeks ago and back to square one :(.”*

- A small group described how they had fully recovered.

*“I would say, a year on, I have now recovered. It took 10 months for all symptoms to go. They were extremely debilitating for 5 months and then it took another 5 months to slowly improve.”*

#### 4.2. Pre-existing conditions prior to COVID-19 infection

Prior to their infection with COVID-19, just over half of respondents (54%, n=288) indicated that they had pre-existing health conditions, whilst 46% (n=246) did not. Respondents described their pre-existing health conditions, which were coded and grouped into a series of categories as shown in Table 5. The top five pre-existing health conditions reported were respectively: neurological, asthma, cardiovascular, thyroid and reproductive in nature.

Health condition	Total	% <sup>2</sup>
Neurological (includes migraines, autism, brain injury, epilepsy, anxiety, ADHD)	87	32%
Asthma	74	27%
Cardiovascular (includes hypertension, Raynaud’s, cholesterol)	48	18%
Thyroid (includes hypothyroidism, thyroiditis or no thyroid)	30	11%
Reproductive (includes endometriosis & PCOS)	21	8%
Autoimmune and immune-related disorders	20	7%
Gastrointestinal conditions	20	7%
Musculoskeletal (includes osteoporosis)	19	7%
Arthritis	17	6%
Diabetes	17	6%
Fibromyalgia	17	6%
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)	14	5%
Respiratory (other than asthma)	12	4%
Allergies (including hay fever)	11	4%
Coeliac	8	3%

Table 5: The top 15 health conditions reported by respondents as pre-existing their COVID-19 infection

#### 4.3. Level of physical activity prior to COVID-19 infection

Over half of the respondents 53% (n=280) reported being moderately active pre COVID-19 infection, 44% (n=235) reported being highly active and only 3% (n=17) reported not being active. Of those who were not active, this was primarily noted as being due to pre-existing health conditions.

<sup>2</sup> Note percentages will not total 100% as some respondents reported more than one pre-existing health condition.

#### 4.4. Diagnosis of Long COVID

The majority (82%, n=436) of respondents have a formal diagnosis of Long COVID. For most respondents, the diagnosis was made by a GP, followed by a specialist and Long COVID clinic respectively (Table 6).

Diagnosis location	Total	%
Diagnosis via GP	222	51%
Diagnosis via specialist (includes cardiologist, neurologist, respiratory and immunologist)	86	20%
Diagnosis via Long COVID clinic	56	13%
In process of receiving a diagnosis	9	2%
Diagnosed whilst in hospital	8	2%
Diagnosed by integrative GP	6	1%
Referred to Long COVID clinic by GP	5	1%
Specialised clinics (includes clinics not explicitly focused on Long COVID e.g. Austin Health Recovery Program)	5	1%

Table 6: Top 8 places where respondents received their Long COVID diagnosis

#### 4.5. Long COVID symptoms

A series of questions were asked to understand the breadth of health symptoms experienced across the different body systems. Tables 7–11 show the detailed results with the following noted in summary:

- 96% of respondents noted nervous system issues with brain fog, followed by anxiety the most common
- 88% noted cardiovascular system issues with heart palpitations, followed by chest pain the most common
- 79% noted respiratory system issues with shortness of breath, followed by persistent cough most common
- 83% noted gastrointestinal issues with nausea, followed by low appetite the most common
- 43% noted reproductive system issues with the severity and number of premenstrual symptoms, followed by irregular menstruation the most commonly reported symptom.

In addition to the body systems above, respondents identified pain such as muscle weakness, general fatigue, dizziness and sleep disturbances as further symptoms they experience.

Overall, brain fog (91%), heart palpitations (73%), shortness of breath (73%), anxiety (67%) and memory loss (66%) were the top five specific symptoms experienced across all health systems.

Nervous system issues	Total	%
Brain fog	481	91%
Anxiety	355	67%
Memory loss/amnesia	351	66%
Depression	285	54%
None of the above	21	4%

Table 7: Nervous system issues experienced by respondents

<b>Cardiovascular system issues</b>	<b>Total</b>	<b>%</b>
Heart palpitations	388	73%
Chest pain	295	56%
High blood pressure	185	35%
Low blood pressure	172	33%
None of the above	62	12%

*Table 8: Cardiovascular system issues experienced by respondents*

<b>Respiratory system issues</b>	<b>Total</b>	<b>%</b>
Shortness of breath	387	73%
Persistent cough	159	30%
None of the above	112	21%

*Table 9: Respiratory system issues experienced by respondents*

<b>Gastrointestinal related issues</b>	<b>Total</b>	<b>%</b>
Nausea	299	56%
Diarrhoea	261	49%
Low appetite	231	44%
Abdominal pain	230	43%
Constipation	212	40%
None of the above	88	17%

*Table 10: Gastrointestinal related issues experienced by respondents*

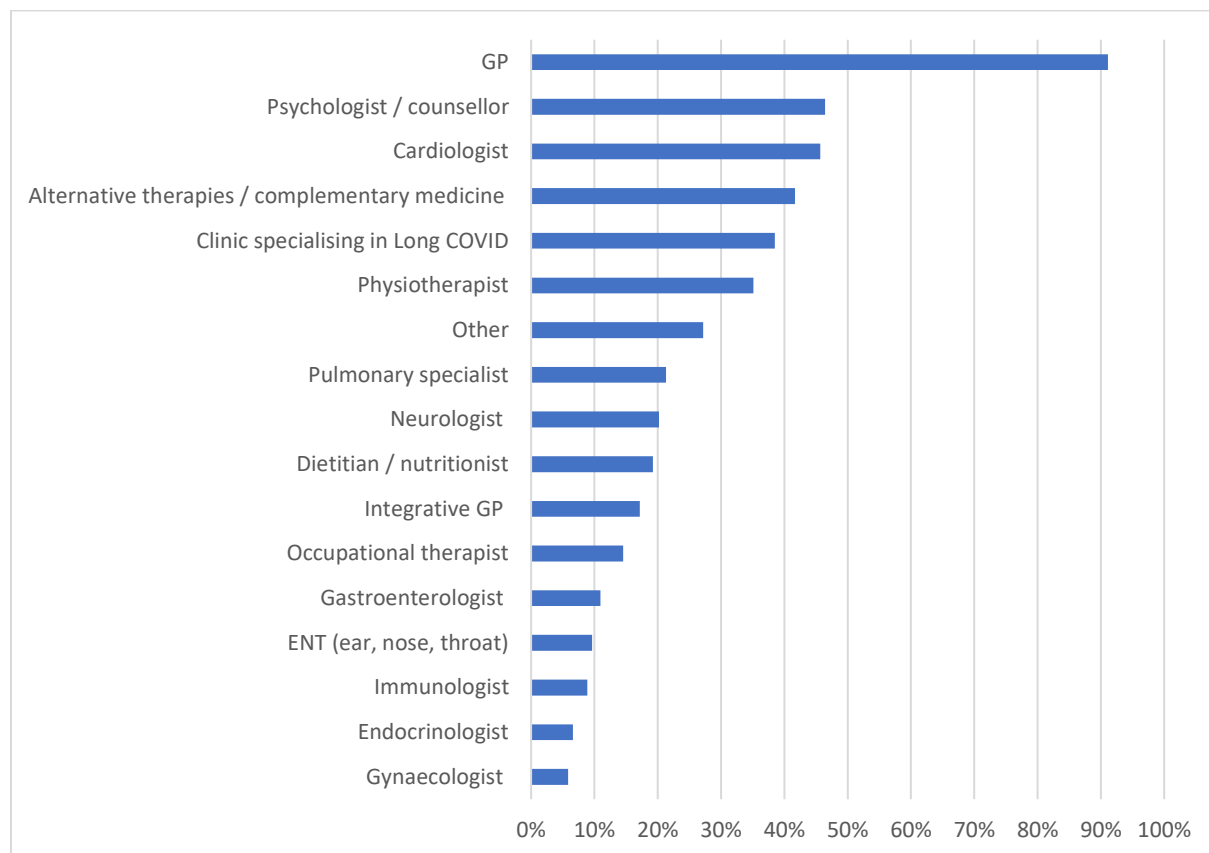
<b>Reproductive related issues</b>	<b>Total</b>	<b>%</b>
Increase severity and number of premenstrual symptoms	129	24%
Irregular menstruation	106	20%
Painful menstruation	85	16%
Erectile dysfunction	14	3%
None of the above	303	57%

*Table 11: Reproductive related issues experienced by respondents*

## 5. Results – Experiences of health service

### 5.1. Accessing healthcare for Long COVID

Respondents were asked where they sought healthcare assistance to support their recovery from Long COVID. The top five responses were GP (91%), followed by cardiologists (46%), psychologist/counsellor (46%), complementary or alternative medicine (42%, predominantly acupuncturist and naturopath), and clinics specialising in Long COVID (38%). Figure 4 outlines the range of services and/or health professional support that respondents have accessed.



*Figure 4: Parts of the healthcare system accessed by respondents to provide Long COVID support*

As noted above, GPs play a critical role in the management and support of Long COVID, often being the first port of call. Table 12 shows rated experiences with GPs in relation to acknowledging, providing information, support, resources and referrals:

- Most respondents (70%) noted that their GP acknowledged their condition.
- Only 35% of respondents noted that their GP provided them with Long COVID information and support when it was needed and 29% noted being directed towards helpful resources.

These findings echo the challenges expressed by people with Long COVID around being heard and seen and supported. They also highlight the challenges in the health system regarding the emergence and recognition of Long COVID and the availability of information and support, as well as knowledge and capabilities in the health system.

Statement	n	Weighted average	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My GP has acknowledged my Long COVID condition	450	3.92	9%	7%	14%	23%	47%
My GP has provided me with Long COVID information and support when needed	427	2.95	18%	19%	27%	20%	15%
My GP has directed me towards helpful resources such as medical specialists	460	2.58	34%	18%	19%	14%	15%

Table 12: Ratings of support provided by GPs in relation to Long COVID

## 5.2. COVID-19 vaccination

Most (90%) of the respondents noted having had one or more vaccinations prior to developing Long COVID (61% had three or more vaccinations). Of the 10% who had not been vaccinated prior to developing Long COVID, some noted in their open-ended responses that vaccinations were not available at the time.

When asked how many vaccinations they have had in total, 97% of respondents indicated they had received one or more vaccinations (78% reporting three or more) indicating that many people continued to access vaccinations after developing Long COVID.

Figure 5 shows the number of vaccinations prior to developing Long COVID (in blue) and the total number of vaccinations (in orange) that respondents reported they had at the time of completing the survey.

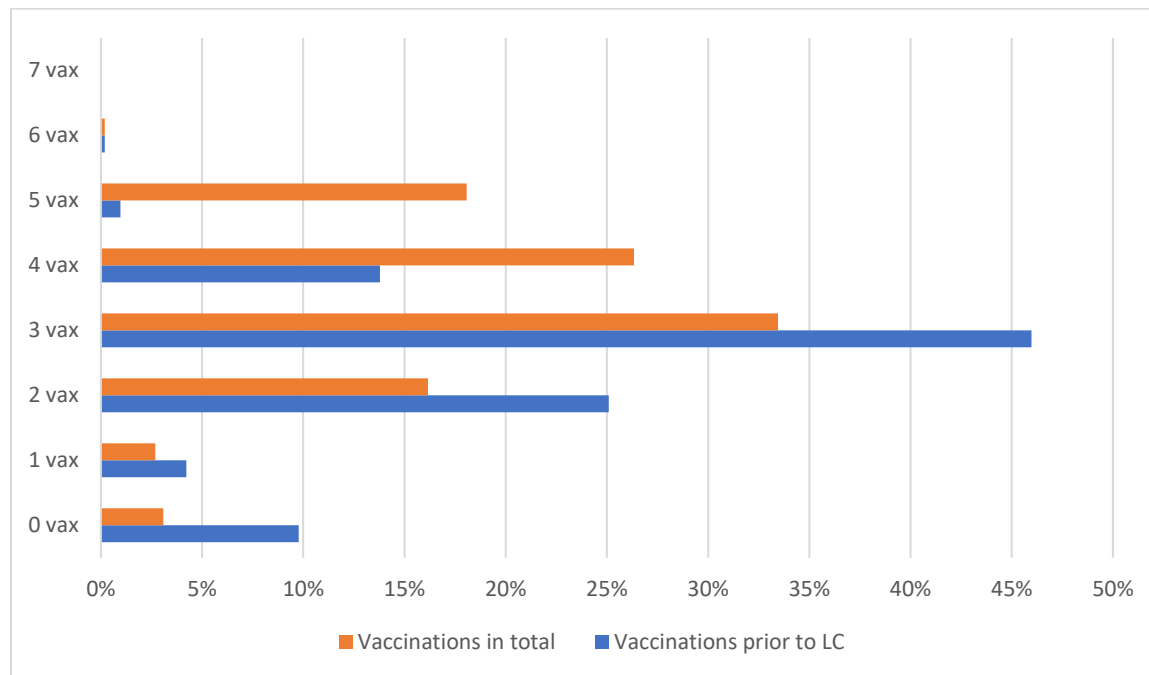


Figure 5: Number of COVID vaccinations prior to developing Long COVID against total vaccinations received

In sharing about their COVID-19 vaccination experience, reactions to the vaccine varied across the respondent group with some reporting no or mild reactions, whilst others had moderate or severe reactions.

Those who reported moderate or severe reactions tended to express hesitation with continuing with vaccinations:

*“Caused significant side effects for about two weeks [with] each vaccine. I have been hesitant since developing Long COVID to get another, and since I have also had COVID three times, [I] have decided against further vaccines. This is supported by my integrative GP so as not to put extra stress on my body and immune system during this time.”*

*“I got extreme vomiting from my third vaccination and haven’t had any since.”*

Some people with severe reactions were advised by health professionals against further vaccinations:

*“Rheumatologist advised against further vaccinations due to my reaction to the vaccinations.”*

*“Two GPs that we have consulted with who are treating Long COVID believe the vaccine is the cause of my son's Long COVID issues.”*

Those that reported severe reactions often required urgent healthcare:

*“I was anaphylactic to Pfizer and ended up in an ambulance.”*

*“After the second vaccine had [a] severe mental breakdown. Could not work. Could not sleep. Had severe outbursts. Insomnia so bad. Was hysterical and very unwell mentally.”*

*“I had the Pfizer vaccine and reacted to the first one and had to see if I should get the second one...They said that I did not react enough and to go ahead and have the second. About 20 hours after the second vaccine, I was in hospital with chest pain, difficulty breathing and in a very bad way. Was like this for nearly four months after the second vaccine.”*

Interestingly, 12 respondents reported experiencing adverse and irregular effects on their menstrual cycle post-vaccination:

*“Following my first vaccination, I experienced onset of my period. My period also immediately increased from three days of light to moderate bleeding, to five days of heavy bleeding with clots.”*

A small group lamented that the vaccine did not appear to offer any protection:

*“It did nothing to prevent me from becoming severely sick/disabled with Long COVID.”*

### **5.3. Antivirals and reinfections**

Antivirals were identified as an ongoing concern both from an access and affordability perspective in the survey design process. It is important to note that antiviral medication may not have been available to the community at the time of infection or reinfection for some respondents. The survey found:

- Only 8% of respondents (n=39) were offered antivirals when they were first infected with COVID-19
- 30% of respondents (n=157) noted that they had been reinfected with COVID after developing Long COVID and 29% of those (n=62) were prescribed antiviral medication when they were reinfected
- 16% of respondents noted being able to access antivirals through the Pharmaceutical Benefits Scheme (PBS) (n=60)
- Of those who had been reinfected, 83% had been reinfected once, 15% had been reinfected twice and 3% had been reinfected three or more times.

## 6. Results – Impacts of Long COVID on daily life and wellbeing

The effects of Long COVID are long reaching and ripple through the community. People living with Long COVID experience a range of impacts to their physical and mental health, they are financially worse off, often socially disconnected and experience a myriad of challenges in daily life. Further, the impact Long COVID reaches beyond the individual and has impacts on carers and families, workplaces and more. This section looks beyond the medical aspects of Long COVID to examine the repercussions across many of the determinants of health.

### 6.1. Areas of life impacted by Long COVID

Respondents were asked to nominate which areas of their life have been impacted on by Long COVID, choosing from three options as shown in Figure 6. Most respondents indicated impacts across all three areas of their life with the most common being social impacts (91%), impacts on mental and emotional health (86%) and financial concerns (70%).

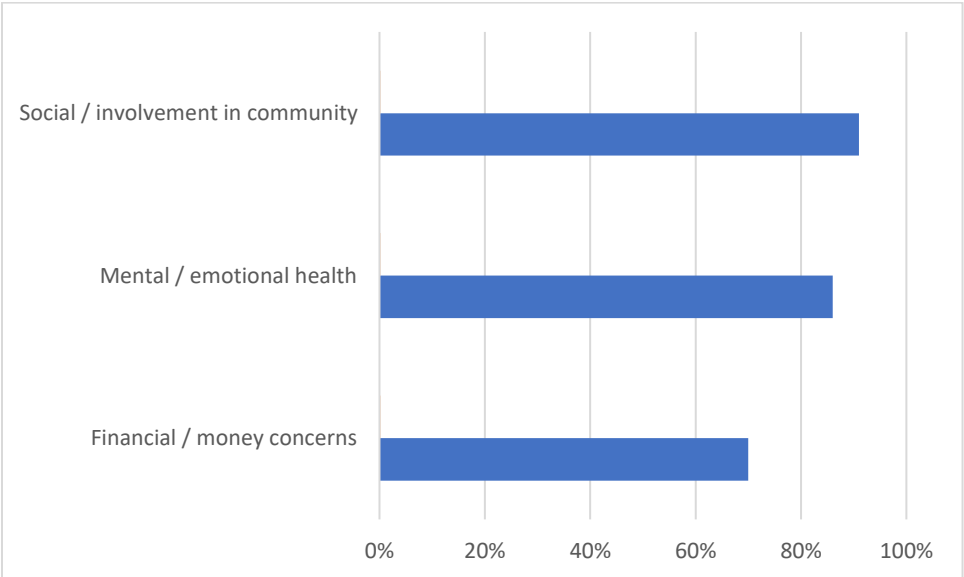


Figure 6: Areas of life impacted by Long COVID

### 6.2. Daily life and Long COVID

Survey respondents rated a series of specific aspects of daily life and the degree to which Long COVID has impacted their ability to undertake them. Most respondents noted some or high impact across each of the five dimensions of daily life that were listed. The vast majority of respondents noted an impact on leaving the house (95%), cooking (94%) and cleaning (93%). Further, 71% noted impacts in taking a shower and 59% in getting dressed (Figure 7).



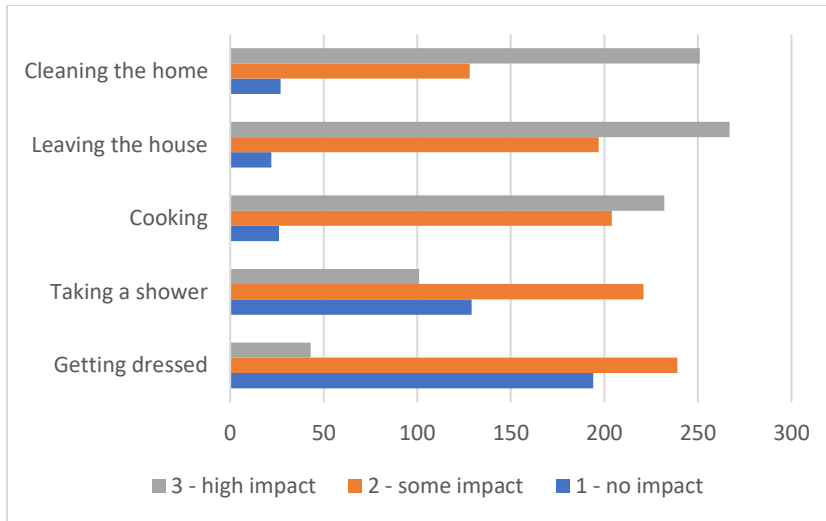


Figure 7: Impact of Long COVID on performing daily activities

The levels of challenge and fatigue that went into managing daily life were reflected in these key themes and illustrative quotes.

- Living with uncertainty as a fact of life:

*“Please don’t forget about us!! We are truly battling every day, doing our best every day whilst the goal post shift every day!! WE NEED HELP 🙏”*

- Quality of life that is severely compromised:

*“You are too sick to go to family and if they come to you, it can be very hard as well as you seem very demanding by saying don’t come if you are sick, or that I am too sick for visitors today. You don’t want to go out into the community even if you are feeling a little better, because I have been told that I should not get COVID again if I can avoid it as it will be very bad for me...I have been suicidal as I feel that my family would be better off without me. They would not have to look after and care for me, I wouldn’t be a financial drain on them as I am now, they would not have to drive me to all my doctor’s appointments as I no longer am able to drive, they could go back to living their lives. My children are 19 and 21 and should not have to be helping my partner look after their mother (50). They should be out there enjoying their young adult lives. I sometimes/a lot of the time feel like I am a forgotten person in this world. Overlooked by the government who want to class COVID as just like a cold or the flu. Well step into my shoes and see how the flu feels for a year and see if you like it. I sure don’t and have no recognition or financial support from the government to even hope to get better, or at least maybe improve my quality of life. Doesn’t everyone deserve some quality of life?”*

### 6.3. Sources and level of support to manage Long COVID

Respondents were asked where they sought and found support to manage their condition and to rate the level of support they received from low to high. What support looked like was not defined but was interpreted to include psychological support (e.g. believing in you), physical support (e.g. taking you to appointments, buying supplies) and medical support (e.g. appointments when needed). Note that 86 respondents indicated that they had no support. Figure 8 shows the percentage of respondents who indicated they had high support from each of the various sources included in this question. Most respondents (63%) noted their partner/spouse and the online community/forum as providing a high level of support.

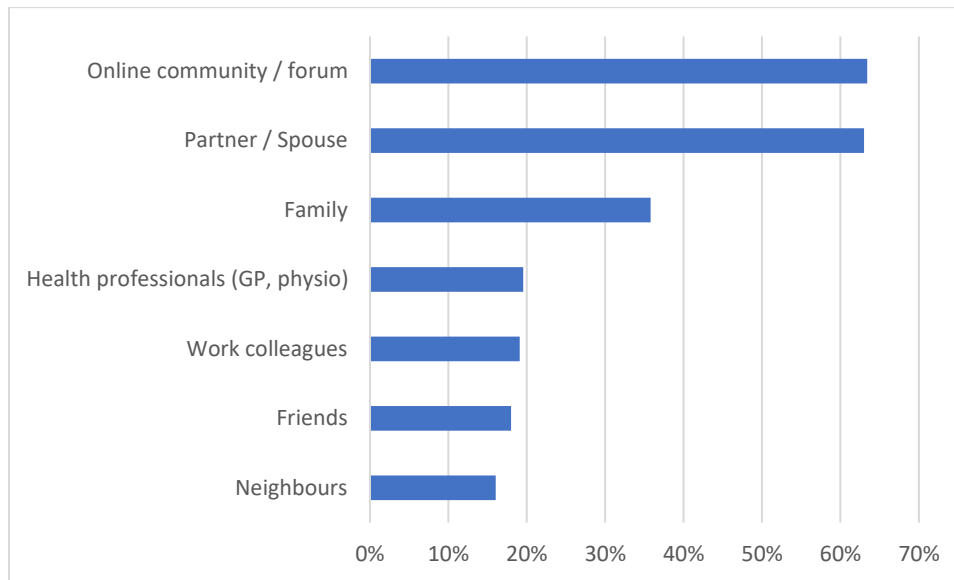


Figure 8: Level of support received by the respondents for managing Long COVID

### 6.4. Long COVID and disability

Respondents were asked whether they considered themselves as living with a disability in relation to their experience of Long COVID, with 76% responding that they did. Further, 84% of respondents indicated that they thought people experiencing Long COVID should be eligible for support under the National Disability Insurance Scheme (NDIS). These responses further highlight the significant impacts on daily life and functioning and the burden of living with Long COVID for many.

When asked to comment on Long COVID in relation to disability support and/or access to NDIS, the responses recognised complexity (of the system and health issues) and showed a wide range of experiences.

- Overall there was a sense that more support, assistance and services were needed for Long COVID sufferers (n=56):

*“People need more support and to know where to go. Long COVID is absolutely a disability. It can stop you from being able to do almost everything.”*

*“Financial strain is huge! I was denied temporary disability parking although I couldn’t walk 50 metres.”*

- For those severely impacted by Long COVID, access to disability support and/or NDIS was critical (n=55):

*“For me to have a future, I need support. For this to happen, Long COVID must be recognised as a disability.”*

*“Long COVID has ruined my life. I can’t leave my apartment without fear. I can’t work. But I need to soon financially. I had to in the first year for six months between infections due to finances. I am appalled by the government’s response. I am terrified for the future. We should have access to NDIS and Long COVID needs to be deemed a disability. Our lives are over. We have no future.”*

*“Long COVID is life changing and completely debilitating.”*

- Further access to support was a social justice issue:

*“I am unable to work, and health services are very expensive. My OT alone charges \$350 for appointment, plus associated admin per session – but she is the only professional who has specialised skills in the cognitive rehab that offers hope of recovery that will allow me to return to work (I am an academic). COVID is a social disease. Without social preventive measures it continues to spread, and some of us will continue to disproportionately bear the burden of disease that results. Not only is disability support necessary, it is a matter of social justice and fairness.”*

- Being well enough to apply for support was a challenge:

*“I have been preparing my application for over a year but I’m so sick I needed the help but don’t have capacity to prove in the application that I meet the requirements. There needs to be more automatic support for housebound sick people.”*

- Some focused specifically on the financial support desperately needed (n=37):

*“The government is doing little to suppress transmission, therefore should be providing SOME KIND of financial support to those of us they have allowed to get infected and have developed Long COVID.”*

*“I am only alive right now due to the goodness of my friends and partner who have rotated as being full-time carers for me. All of them have experienced burnout due to my level of disability. This situation is not sustainable. I desperately need to be able to access support through the NDIS so that I can live with dignity and not leave my friends exhausted.”*

- Others acknowledged that the NDIS does not easily identify nor exist to address the needs of those with Long COVID (n=12), but how Long COVID was experienced was diverse:

*“It’s really hard, the NDIS is set up for ongoing and severe disability. The science is not yet in for the real long-term basis [of Long COVID]. I’d prefer to see support based on disabling symptoms that are diagnosis agnostic rather than hitch outcomes to the diagnosis. Fatigue and memory loss are both independently and severally disabling and that should be enough. It’s important to*

*have appropriate support for Long COVID but I'm hesitant to say that all cases of Long COVID should be NDIS eligible."*

*"I had a chat with someone who works in the area and was told that I would have a better chance of getting onto NDIS by saying I had depression and anxiety. Apparently Long COVID is just a 'medical condition', so it doesn't count for NDIS. Excuse me? Are not paraplegia and brain damage also medical conditions? Are those people also excluded from support?"*

- For those who identified developing Long COVID before any vaccinations existed (n=9), the impacts have been severe, drawn out and isolating. Recognition and support for the condition was seen as vital:

*"Long COVID in Australia is mostly seen through the lens of post-vaccinated COVID. Post vaccination Long COVID has better long-term outcomes but for those who are unlucky enough to have caught it prior to vaccines being available or have very severe long-term COVID, their illness does leave them having lower capacity for work, for engaging with society and for living a fulfilling life. Long COVID not being formally recognised as a disability also means that many people, workplaces and services are not adapting to meet those people's needs and are blind to their conditions. Long COVID can have devastating effects on the individual who is sick and their families and workplace. With no formal support or recognition in place, people are suffering and struggling to get support."*

- Five respondents indicated they were already on NDIS or other disability support payments for other conditions, not Long COVID.

#### **6.4. Employment and Long COVID**

The majority (83%) of respondents were in some form of paid work prior to developing Long COVID (Figure 9), with the majority of respondents (over 55%) working full time. Of those working, 97% reported that Long COVID impacted their ability to work.

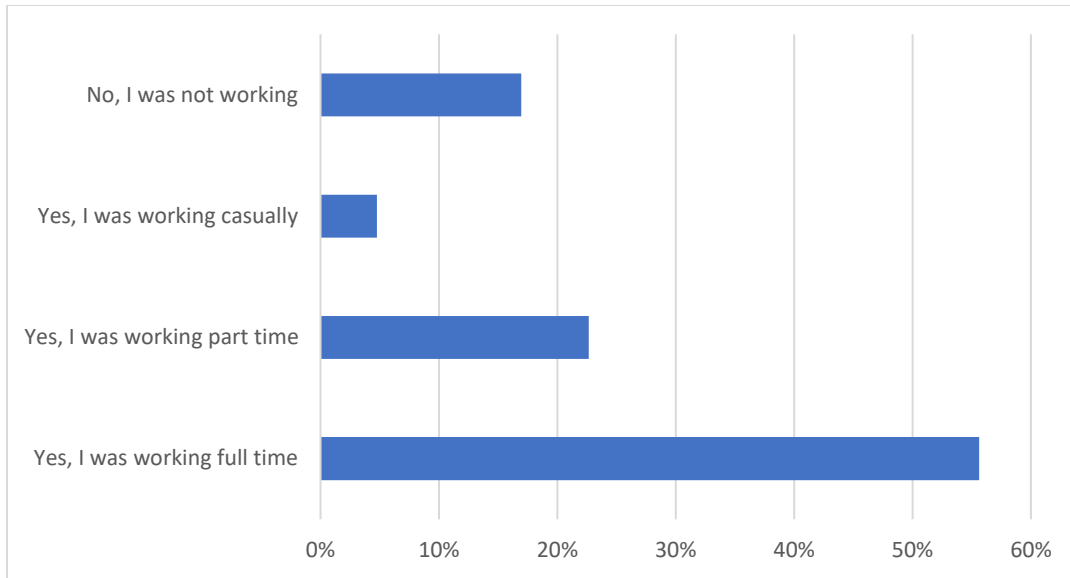


Figure 9: Types of employment prior to developing Long COVID

The impacts and results of Long COVID on people’s employment were wide ranging. Respondents reported:

- Many simply were unable to work anymore (n. 201):
  - Using up their entitlements as they were too unwell to work:
 

*“I take sick leave when I just can’t manage, but that will run out eventually.”*
  - Being encouraged or deciding to quit:
 

*“Quit because I was not coping in July 2022.”*

*“Reduced hours, requirement to change hours and days, ended up resigning from one role (I had two part-time projects).”*
  - A small group reported being retrenched when unable to resume former duties:
 

*“I was fired [in] May 2023 because I was unable to attend work and incapable of working properly due to brain fog and physical conditions.”*
- Many had reduced capacity to work due to tiredness and declining cognitive ability (n=154):
 

*“I couldn’t work for six months then went back casually for a while. I’m now working two days instead of my three before COVID and it wipes me out.”*

*“I had several attempts at RTW [return to work] before stabilising at two hours for three days a week. I deteriorated significantly at eight months with the onset of POTS [postural orthostatic tachycardia syndrome] and have been unable to work for the last seven months. I lost a position and leadership development opportunity. I have now run out of*

*sick leave and have had a significant salary drop, now onto income protection payments.”*

*“I am unable to work full time, and even part-time work is difficult or impossible at times when [I have] severe flare-ups.”*

- Some were able to change their scope of work (n=44), including more work-from-home options or taking on easier duties where possible:

*“I’m still on a graduated return to work program after 18+ months. My job has had to be altered to accommodate my limitations.”*

*“Can only work from home now, unable to take the chance of being around people.”*

*“I have been very fortunate and my supervisor has supported a role change and allowed me to work from home when needed but I am extremely unreliable now so I’m not sure how long it will last.”*

- Not all sectors seemed able to provide greater flexibility such as teaching in primary and secondary schools, working in retail and physically demanding jobs:

*“I am unable to do my job as a cleaner.”*

- And the self-employed were often at risk of losing their businesses:

*“Totally incapacitated for months. Almost lost my physiotherapy clinic (self-employed). I was unable to stand for more than 20 mins without fainting. Cognitive decline. Tachycardia. Unable to function in my role as physiotherapist or business owner.”*

*“Long COVID meant I lost my business as a sole trader and have had to move home with my mother at 48 years old so I could survive. This is the most debilitating condition, it affects so many areas of our bodies, it has unpredictable ‘episodes’ that can last days or weeks. Good days do not equal better. This condition needs to be approached from a whole body system perspective. The dysautonomia at the root of so much of this is overlooked by most specialists. Long COVID may be the reckoning we need to shine a light on how limited the western medical model is at treating human conditions.”*

- Some identified career progression as impacted, including halted or severely slowed down (n=20):

*“Not as energetic, demoted, not as much stamina.”*

*“Work is much more difficult because of fatigue and brain fog and I missed the opportunity for promotion because of it.”*

- A smaller group were simply pushing through and living with the repercussions, often at the expense of their health (n=15):

*“I still work full time for financial reasons but it is extremely difficult and I cannot do anything on top of work.”*

*“Debilitating – performance declined. Also, work had impacted my Long COVID. I got COVID when we were super busy and swamped with everything and did not take sufficient rest. I had to work overtime which exacerbated my Long COVID symptoms much worse.”*

*“I have reduced hours in my private practice from about 39 hours a week to about five hours a week. I have also had about six months entirely off work and believe longer would be helpful, but we just can’t afford it.”*

- Several respondents noted the pressure of proving their worth at their workplace:

*“Now working part time – two days, rest day, two days – to manage fatigue. Contemplating taking leave full time to try to recover. Having to start early to work around medical appointments. Cannot travel to/from work. Taking sudden leave. Needing to take unexpected rest breaks. Trying to prove still valuable can mean later hours while managing symptoms.”*

- A number of respondents reported having their illness queried or disbelieved (n=4):

*“Barely worked for many months, now on a return-to-work plan which is not realistic nor accommodating to the realities of Long COVID. Any measure that might help, like working in a room with natural light or working some time at home is not allowed. They also feel entitled to ask me a lot of personal questions.”*

*“Workmates think I’m a hypochondriac or just put it down to me ‘getting old’.”*

Respondents were invited to share what, if any, workplace supports were provided. Whilst 71% indicated employers offered support, the understanding and quality of the support varied.

- Those that reported good support (n=82) had a range of positive experiences, ranging from formal structures (such as human resource systems that supported gradual return to work or WorkCover claims), through to informal systems where managers advocated on behalf of the person:

*“My boss has been supportive. For the first 10 months I was affected he allowed me to continue on my full salary even though he knew I could not manage full time hours.”*

*“They have made changes to my role and been very supportive and flexible.”*

*“Able to work from home and work part time. Very supportive boss so am able to rest and sleep at any time during the day for as long as I need.”*

- Those that reported mixed or some support (n=112) included experiences where there was good support initially that waned over time; feeling pressured to return to work before ready; being believed by some but not all:

*“Mostly they have been supportive, but 18 months in, their patience is wearing thin. I’m under pressure to push past my window of tolerance to keep my job.”*

*“Informally, I have received compassionate and generous interpersonal support and understanding. Navigating insurance claims while unwell is an absolute nightmare – HR at my university showed none of the compassionate concern that my colleagues thankfully did. Without them I may not have successfully submitted the paperwork that allows me to receive benefits.”*

*“Yes, in the way that they haven’t dismissed me earlier but they’ve put me through a fit-for-work assessment to see if I need to medically retire.”*

- Poor support was characterised by little communication or follow-up with employees, through to little or no understanding and accommodation of Long COVID (n=7):

*“Lots of platitudes. But no more sick days left means my job will soon be over.”*

*“My workplace has ignored me completely. My manager has rang me once in 15 weeks, it makes it even more isolating.”*

*“They legally had to accommodate reduced hours for a period of time however that was it. My workplace continued to allocate workloads larger than my medical certificates allowed and continued to pressure and place immense stress on me. There was no demonstration of understanding of what Long COVID was. No empathy – if I had had a heart attack it would be a different story. The last words after I resigned due to Long COVID and not being able to do the workload allocated was from my manager who said she was disappointed I didn’t do the marking. I was devastated at the lack of support nor contingencies being in place.”*

- For 13 respondents, compensation was specifically identified as a significant supporting feature – the majority of which were WorkCover claims:

Lastly but importantly, respondents were asked what changes and supports they would like to see in the workplace. As one respondent pointed out, this is not an easy ask:

*“That is such a hard one. Employers still need to run their business in tough times so often can’t be flexible with hours, etc. Hard to explain to an employer that some days you feel ok, then other days you crash. Some bigger businesses can handle the changes better than others. Some roles can be changed to remote working but obviously not all jobs can pivot. We also need to accept that we might not be able to be in the same role as before and we need to find something that can suit our new reality.”*

- Overall, there was a sense of the need for more workplace support (n=229):

*“Acknowledge it’s real, allow accommodations such as remote working and working with access to natural light. Listen when we say a certain task is too cognitively demanding.”*

*“Mitigation, education, knowledgeable reintegration – at the moment it’s all on you to manage the process even if they say they have a system. The systems are rubbish for chronic conditions.”*

*“Accept that part time may be all that they can do and be supportive. Allow pacing.”*



*“Flexible work-from-home arrangements and flexitime. Awareness of limitations and not pushing employees.”*

- Many respondents highlighted the need for recognition of Long COVID within workplaces as a vital first step (n=106):

*“Acceptance and understanding needs to come first and then we may be able to get the support needed to get back to work.”*

*“Acknowledge it is a thing and not making excuses.”*

*“Understanding and some humanity... we worked hard to get where we were and it’s been taken away through no fault of our own.”*

- The need for a financial safety net was also raised, with options such as extra sick leave, compensation, access to disability payments or other government subsidies identified by the respondents (n=43):

*“To be honest, I wasn’t fit for work. I was self-employed but if I was an employee, I would not / should not have been in the workplace. I should have been home recovering / on disability payments / NDIS.”*

*“Wish the government would work faster. I applied for Centrelink 10 weeks ago, still waiting. Savings long gone no income so had to stop my medications.”*

- Whilst some respondents agreed that changes and supports were needed, they were unsure what those measures needed to be (n=24).

- Many respondents noted that there was a need for broader recognition of a Long COVID as a disability or chronic health issue (n=19), within, but also wider than, the workplace:

*“Education and recognition that Long COVID is a disability. Through the tireless efforts of my GP, I have a disability car parking permit (temporary for the moment, in the hopes I might get better, which doesn’t seem likely at this stage). Yet, broadly Long COVID is not recognised as a disability. If it were, I could see how much that would change the approach to conversations and additional support that could and should be provided to us with Long COVID. We need to be supported broadly in the workplace and in legalities from the government. We didn’t ask for Long COVID and yet we all seem to be paying the ultimate price because our bodies couldn’t overcome an incredible infection – we need more support and recognition.”*

- Respondents also felt that better COVID safety measures needed to be adopted by workplaces to increase safety for people experiencing or had experienced Long COVID (n=19):

*“Better ventilation and mask-wearing encouragement (at the very least).”*

*“Having appropriate infection mitigation policies in place to protect people with Long COVID.”*

- Several respondents raised their desire to see legislative change to protect workers from dismissal (n=8):

*“My employer gave me more time to get better than is in the contract. I think that is going to need to be standard. In NSW (I think this is Industrial Relations law), the rule is something like if you have more than three months off for sickness (even if you have that much sick leave owing), they can ask you to leave under ill health separation. Long COVID people probably need a year.”*

## 6.5 Study and Long COVID

Similar to Long COVID and work, the survey sought to capture the impact of Long COVID on study. Around a quarter (23%, n=122) of respondents were studying prior to developing Long COVID (Figure 10). The study varied from full-time to casual studies and encompassed a broad range of study, including primary school through to university studies and short courses.

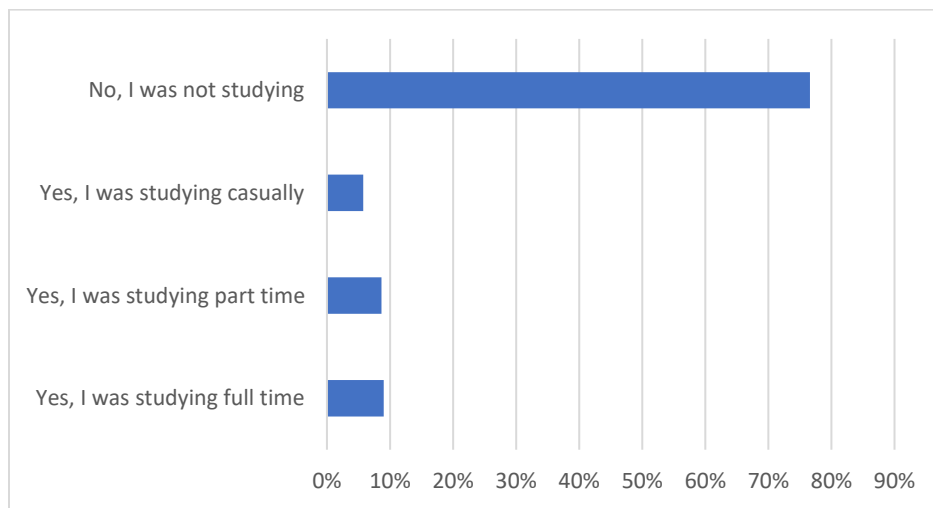


Figure 10: Study status of respondents prior to developing Long COVID

Of those who were studying before Long COVID, 85% reported that their study status had changed since developing Long COVID.

The changes included:

- Unable to continue to study or elected to withdraw (n=43)
- Deferred or took a leave of absence (n=20)
- Reduced their study load to manage e.g., if full-time went down to part time (n=18)
- Sought extensions (n=5)
- Absenteeism (n=4)
- Received poorer grades than usual (n=4)
- Failing (n=2).

Whilst the report shows that Long COVID affects all ages, in the area of study there were significant differences between children and teenagers compared to adults. Study and education is important for many people but when it comes to children and teenagers, it becomes a slightly different landscape. It is compulsory for children and teenagers aged 6–16 years to attend school, meaning options such as

deferment or withdrawal are not available. At least eight respondents had experiences that related to primary- or school-aged children (including parents/carers that may have responded on behalf of their child/dependent):

*“Can only attend school for 50% of my lessons. I got the academic scholarship for years 11 & 12 and am a high achiever. It is frustrating that I cannot concentrate for a full lesson and I cannot study and achieve results that I used to be able to achieve. Am concerned now for my tertiary studies.”*

*“I missed term 1 & 2 of grade 2 in 2022, and went to school part time term 3 & 4 of 2022. I am now back at school full time.”*

Respondents were invited to share what, if any, educational supports were provided, with 51% indicating places of study offered support. Often the support was allowing students to defer, withdraw or, in some instances, the granting of extensions.

Those that felt supported described varying supports and adjustments including:

- alternative assessments
- administration support to look at other options
- accommodating absenteeism as needed
- allowing for a slower pace or extra time to complete work
- not charging fees for late subject withdrawals
- developing disability access plans
- agreeing to shortened school days
- allowing more study from home.

Those undertaking study were asked what changes and supports they wanted to see.

- There was an overwhelming desire to see greater flexibility and adjustments (n=59):

*“Any or some of the breaks that have to be taken from study to not count towards the total normally allowed. Access to audio versions of texts.”*

- Easier access to extensions and special consideration were also raised as viable options to assist students struggling with Long COVID (n=33):

*“Longer extended unpaid leave. As a PhD student I can only have a max of one year of leave during my candidature. After that I lose my scholarship and prestigious grant. That is why I have to try to study part time, even though my GP is not sure if I’m ready for study (but I have no choice).”*

- The need for understanding and acknowledging the symptoms and impact of Long COVID were raised again, this time in the context of studying and education (n=24):

*“He can’t learn when pain is extreme. Encourage acceptance.”*

*“Educating staff about the illness.”*

- That COVID safety measures were still needed (n=7):

*“There should be an option for online classes. There also needs to be masking rules in place again to reduce COVID transmission. Buildings need ventilation.”*

### **6.5. Long COVID, stigma and discrimination**

Respondents were directly asked about stigma and discrimination in the latter part of the survey. More than half (54%) of respondents reported having experienced stigma or discrimination, 25% were unsure and 21% had not experienced stigma or discrimination as a result of Long COVID.

Those who reported experiences of stigma or discrimination were asked to comment. It was found:

- A lack of understanding about Long COVID in the wider community (n=123):

*“From people who didn’t know anyone with Long COVID, so the surprise that it’s ‘real’.”*

*“People think I am either making it up or contagious.”*

*“Being a school student, all of my friends thought that it wasn’t real and tease me about it. It is an invisible illness.”*

*“Friends and family not making any form of adjustment to accommodate my condition. And they get mad or upset when I try to tell them I am unable to do something. It is an unseen disability and their ignorance or reluctance to accept it has made being surrounded by them an often exhausting or miserable experience. My wife is trying but still makes mistakes and gets mad at me when I am upset after we try to see friends and I am left feeling angry at how I was treated by them.”*

- This lack of understanding about Long COVID and the symptoms also led to many being disbelieved (n=99):

*“Been dismissed as making it up. Been told ‘You don’t look sick’ etc.”*

*“Some people think that I’m exaggerating or making it up.”*

- Respondents felt that many health professionals did not understand or even recognise Long COVID (n=44):

*“I feel dismissed by my GP (my original one left but she was understanding). I have been told several times that the medical world doesn’t know enough about it. Some people dismiss it and now I don’t even bother talking about it unless it’s my family.”*

*“I feel judgement from my medical centre as my doctor laughed at me when I asked did COVID cause this, he laughed and said no.”*

*“Some health professionals have implied that the symptoms are psychosomatic.”*

*“Health professionals have been a mixed bag. Of gaslighting and belief with limited support.”*

- A number of respondents described shaming or abuse if they took precautions in public, such as wearing masks (n=11):

*“Just aggression from anti-masking COVID deniers in public.”*

*“I have [been] belittled for my wearing of masks, strict hygiene and non-attendance at risky events.”*

*“Mask-wearing is also pretty side-eyed upon sometimes.”*

- That there is an unwillingness to discuss or even a silence exists around Long COVID (n=4), with a few respondents choosing to disguise their condition (n=3):

*“My friends aren’t interested or don’t ask about my health.”*

*“Generally people close to you don’t acknowledge it or feel it is of serious concern.”*

*“Lost a friend or two who don’t believe in it. I don’t talk about it outside those who are sympathetic. I just call it CFS [chronic fatigue syndrome] with an immunity dysfunction.”*

The survey revealed that discrimination was felt by people experiencing Long COVID at multiple levels, including from within social and family groups, in the workplace, in parts of the health sector and in the public domain. Interestingly, in order to manage and cope with stigma and discrimination, a small cohort reported opting not to disclose their condition or made attempts to conceal their condition and try to pass as ‘normal’.<sup>v</sup>

Further the theme of invisibility was present in this question and across many of the responses on people’s experiences of Long COVID. There is a long history of stigma and discrimination attached to invisible chronic illnesses and invisible disabilities<sup>vi</sup> that were borne out within this survey and the result was often a sense of feeling unseen, unheard or worse disbelieved:

*“It’s hard to have people who have not experienced Long COVID or another chronic disease to understand. We may look ‘normal’ on the outside but feel broken, sick and unwell on the inside.”*

*“People, even close friends, do not believe that I am as sick as I am sometimes as I don’t necessarily look sick. They don’t realise that I have planned out what I have to do when I know that they are coming over by resting beforehand, taking strong pain medication so that I am able to handle a one hour visit from them. Then I have to go and lay down after they have gone. They might notice the stuttered speech when I am trying to find a word or have lost comprehension, but other than that, I don’t look sick. I don’t have plaster on or bandages. Sometimes I think it would be easier if I did wrap my head up or my chest so that I ‘look’ sick.”*

Respondents also asked that they not be forgotten:

*“I feel like I no longer participate in life. I find it hard to participate in activities I used to enjoy due to chronic fatigue. My friend circle has diminished. I am isolated and alone. I’m worried that I’ll lose my job and become homeless as I am not entitled to any benefits.”*

*“I’m scared, exhausted, frustrated and worried. The lack of supports available have shocked and saddened me. I feel as though broader society does not care and I feel all of us with Long COVID*

*have been somewhat cast aside and forgotten. It's incredibly sad and so difficult. My partner has also been impacted significantly, and I feel so bad for all families affected."*

## 7. Future focus

### 7.1. Research

In the first half of 2023, the Federal Government announced an investment of \$50 million for Long COVID research. Those with lived and living experience of Long COVID in this survey were asked where they thought research efforts should be focused. Responses were rated on a 5-point scale from ‘not at all important’ to ‘very important’. Table 13 shows the research priorities from highest to lowest rating noting that most respondents considered every topic as ‘important’ or ‘very important’. The top five rated topics included: investigating treatment options for Long COVID, developing health professional awareness and knowledge of Long COVID, understanding how Long COVID develops and affected various parts of the body, developing diagnostic tests to support accurate and early diagnosis of Long COVID, and development and evaluating Long COVID services and models of care. Each of these top five priorities rated as 4.7 or higher (or a possible 5) and were considered ‘important’ or ‘very important’ by between 93% and 99% of respondents.

In open-ended responses, it was broadly experienced amongst respondents that there was a lack of data, measurements and research on Long COVID in Australia, with a sense that Australia was lagging behind many other comparable countries in its efforts to understand, reduce infection and treat Long COVID.

Area of research focus	Weighted average	Important or very important
<b>Investigating treatment options for Long COVID</b>	4.90	99%
Developing health professional awareness and knowledge of Long COVID	4.83	98%
Understanding how Long COVID develops and affects various parts of the body	4.71	96%
Developing diagnostic tests to support accurate and early diagnosis of Long COVID	4.70	93%
Developing and evaluating Long COVID services and models of care	4.67	95%
Developing public awareness and knowledge of Long COVID	4.47	89%
Understanding how Long COVID affects children and adolescents	4.33	81%
Understanding the mental health impacts of Long COVID	4.29	83%
Understand how Long COVID affects people living with a disability	4.29	76%
Understanding the economic impact of Long COVID	4.19	82%
Understanding how vaccination affects Long COVID	4.16	74%
Understand how Long COVID affects older people	4.13	75%
Improving air quality to reduce transmission	3.97	68%

*Table 13: Priority areas of future research from those with lived and living experience of Long COVID*

When asked to comment on what research would improve the lives of those living with Long COVID, respondents reported:

- Effective symptom management (n=199)
- Optimal care pathways (n=103)
- Curative treatment options (n=78)
- Understanding the underlying biology (n=75)

- Diagnostics for Long COVID (n=69)
- Collaboration for working across disciplines (n=14)
- Financial impact research (n=11)
- Psychological impact research (n=8).

## 7.2. Education in the health sector

Respondents were asked what would be ideal ways to educate people in the health sector about Long COVID noting the context of previous responses where people reported unsatisfactory, challenging and dismissive experiences in the health care sector.

- Professional development was seen as critical, with suggestions ranging from mandatory in person training or webinars, conferences, through to incentivising health professionals to upskill (n=153):

*“Paid educational workshops.”*

*“Immediately and compulsorily.”*

*“Mandatory e-learning modules, conferences with patient advocates, professional development courses.”*

*“System-wide approaches for compulsory PD [professional development], delivered by trustworthy groups, and backed up by evidence/best-practice knowledge. Support for this via professional associations. PD to include conversations with those with lived experience of Long COVID.”*

*“Doctors on the ground need to be intensely trained they have no idea of the current research in regard to Long COVID and are incredibly dismissive.”*

- The need to incorporate the voices of lived experience into educational mechanisms was also seen as essential, which could take the form of case studies through to codesigning training packages (n=89):

*“Letting them hear lived experiences. Educating them that it is not all psychological and respecting the person they are treating. And giving them the most up-to-date advice on treatment options and investigations that should be performed.”*

*“Compulsory training on Long COVID to keep registered. A series of video episodes and tests. Even a visit to the local Long COVID clinic to hear first-hand what those doctors are dealing with on a large scale. This could be a video as well.”*

- The development of evidence-based resources, including toolkits, models of care, protocols or guidelines were also suggested as options to assist health professionals to treat and support patients (n=80):

*“A standardised checklist. A resource for research across Eastern and Western medicine.”*

*“Having a set protocol that looks at the impact on all areas of the body.”*



- Raise awareness and access to resources through communication campaigns including through peak bodies and social media e.g., Medscape (n=17).

*“Have a website available for them to inform them.”*

*“Conferences, constant updated information, colleagues helping each other, health professionals working together.”*

- A focus on multi-disciplinary, collaborative care practices (n=10):

*“Run courses or clinics using real patients or notes from real patients, and what is being done to help them. Usually it is a variety of [specialists] that need to come together and work as a team to help Long COVID patients as they are suffering from so many different symptoms in so many different parts of their body.”*

### **7.3. Awareness in the community**

Respondents were asked to identify the priorities for raising awareness of Long COVID in the public domain.

- The primary concern was around making Long COVID visible and known (n=143):

*“1. That Long COVID is real and exists; 2. The reasons why people get it; 3. The debilitating effects of Long COVID in lives; 4. Prevention is priority; 5. Support is desperately needed.”*

*“Not even GPs know much or the latest research, and many people’s friends, family and colleagues can make us feel as if we are crazy because they don’t understand the severity of it. It’s another invisible illness and more needs to be done to educate everyone, children, adults, at school and through advertising campaigns.”*

*“LONG COVID IS REAL! It is not in our mind. Some days we are ok and others we cannot even get out of bed. Have patience with us and DO NOT FORGET ABOUT US just because we cannot do the things we used to be able to do. We are still the same people, friends, family, but we just might need extra time for planning to go somewhere. Understand that every day is different and that we never know how we are going to feel until we wake up on that day. Be patient, be aware, but still remember to include us please!”*

*“That it can be serious and can take a substantial amount of time to recover from. That invisible illness doesn’t mean no illness or that it’s a state of mind or something. That there is a huge mental health cost to getting Long COVID.”*

- The second area of priority was access to more information and resources on what Long COVID is, along with messages of what to do and where to go if you have Long COVID (n=93):

*“Knowing how bad it can be and that it can affect anyone without previous health concerns, including children.”*

*“The varied symptoms, the impact and where to find appropriate help OR education on its prevalence; how to recognise it; how to support people with it.”*

*“A public health campaign to communicate that anyone is susceptible might help people understand that they could be next.”*

- Respondents also wanted to see campaigns that educate about the diversity of symptoms and the broad impacts Long COVID has on people’s lives. Importantly, it needs to be grounded in lived experience:

*“Remind people that COVID is horrible and you can develop Long COVID. USE actual consumers who have experienced it (whether it’s carers or people who have suffered).”*

*“Real life impact – including but not limited to economic impacts.”*

- The importance of continuing to practice prevention strategies (n=69):

*“Manage transmission of COVID better, saying it’s just like a cold is very dismissive to sufferers of Long COVID symptoms.”*

*“Awareness of transmission risks and personal risk, given we will get COVID over and over and especially children in schools. We need to stop infecting kids over and over in schools, a place that is supposed to be safe but might be giving them brain damage and ruining their longer-term health even without getting Long COVID in the near term.”*

- Lastly, there was commentary on the role of government and media in awareness and education:

*“Public health campaigns to educate everyone so people might be motivated to reduce transmission again.”*

*“No more of this ‘COVID is over’ and ‘Long COVID isn’t that bad actually’ messaging. The science is in, but the messaging in media and by government is focused on minimising and preventing public fear rather than accurately portraying the reality. Long COVID is scary. People should know that so they can protect themselves. We do a grand disservice to public health by pretending otherwise.”*

## 8. References

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- <sup>iii</sup> Commonwealth of Australia (2023). *Sick and tired: Casting a long shadow. Inquiry into Long COVID and repeated COVID infections*. House of Representatives Standing Community on Health, Aged Care and Sport, Canberra. Available at: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc\\_pdf/SickandtiredCastingalongshadow.pdf](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc_pdf/SickandtiredCastingalongshadow.pdf)
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- <sup>v</sup> Joachim G. & Acorn S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248.
- <sup>vi</sup> Earnshaw V.A., Quinn D.M. & Park C.L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness*, 8(2), 79–88.