



**Lung  
Foundation  
Australia**

# **Inquiry into Long COVID and Repeated COVID Infections**

**Lung Foundation Australia**

**November 2022**

Level 2, 11 Finchley Street, Milton QLD 4064

PO Box 1949, Milton QLD 4064

ABN: 36 051 131 901

**1800 654 301**

[Lungfoundation.com.au](https://lungfoundation.com.au)

[enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au)

## Table of Contents

Executive summary .....	3
About Lung Foundation Australia .....	5
The COVID-19 pandemic and LFA .....	5
Overview of LFA commissioned global rapid review .....	5
Overview of LFA community survey .....	6
Comments on Terms of Reference .....	7
<i>TOR 1: The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;</i> .....	7
All Australians .....	7
Those living with a lung disease or other chronic health condition .....	8
<i>TOR 2: The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;</i> .....	9
Supporting Patients .....	9
Supporting Healthcare Professionals.....	9
<i>TOR 3: Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia;</i> .....	11
A. Risk factors.....	11
B. Effects.....	11
C. Prevalence .....	12
D. Management and treatment .....	12
All Australians .....	12
Those living with a lung disease or other chronic health condition .....	13
<i>TOR 4: The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;</i> .....	14
A. The mental and physical impact of ongoing symptoms for all Australians.....	14
B. The experience of those who care or cared for someone with COVID-19 .....	14
C. Groups that face a greater risk of serious illness.....	15
The impact of ongoing symptoms for people living with a lung disease .....	15
Those with another chronic health condition .....	16
<i>TOR 5: The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and</i> .....	17
<i>TOR 6: Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.</i> .....	19
International response to long COVID .....	19

The future of the long COVID response in Australia .....	20
Recommendations to respond to long COVID .....	21
1. Adopt a national long COVID definition to enhance data collection and research .....	21
2. Transition long COVID clinics to multipurpose respiratory clinics .....	21
3. Ensure access to quality information and tailored support to manage COVID symptoms and recovery.....	22
4. Utilise and strengthen both telehealth and face-to-face healthcare.....	22
5. Create a health-professional strategy and COVID-19 training.....	22
6. Harness acceptance of vaccinations now and expand the National Immunisation Program ....	23
7. Fund respiratory nurses to support people with ongoing symptoms.....	23
8. Enhance physical activity and self-management through pulmonary rehabilitation.....	23
9. Address the unique mental health needs of Australians living with a lung disease.....	24
10. Invest in the National Preventive Health Strategy .....	24

## Executive summary

Lung Foundation Australia (LFA) is pleased to provide feedback for the Inquiry into Long COVID and Repeated COVID Infections. We welcome and strongly support the inquiry and acknowledge the importance of subsequent recommendations that will be made. The emergence of COVID-19 caused significant burden on the Australian health system, with the disease spreading rapidly causing in some cases severe disease and death. As we now learn to live with COVID-19 (supported by vaccinations and other transmission mitigation strategies), attention is turning to a related new chronic illness, commonly referred to as long COVID. Although the full effects of this condition are still largely unknown, it is clear, that following an acute COVID-19 infection many are experiencing long COVID, which is causing ongoing debilitating symptoms. Australia no longer implements mandatory public health measures to prevent the spread of COVID-19, and the world is opening back up, and subsequently infection rates are continuing to increase across the nation as we pass 10 million COVID-19 cases. More COVID-19 infections will ultimately result in more cases of long COVID and thus, we can no longer ignore the impacts felt by Australians living with long COVID and the burden on their health and wellbeing.

Quantitative and qualitative data collected in a recent Lung Foundation Australia survey, and the LFA commissioned rapid literature review, emphasises the significance of long COVID symptoms and the detrimental impacts of these ongoing symptoms on everyday life. Australia currently lacks information and support for those living with long COVID and more must be done by both federal and state governments. As COVID-19 continues to spread across the nation, we are now facing a new health challenge requiring tailored care and support from a strengthened healthcare system. The present health system cannot support Australians living with long COVID and health professionals lack the funding, training, and resources to provide suitable care to Australians living with long COVID. Based on the current evidence and findings from the Lung Foundation Australia commissioned global rapid review and community survey, we strongly recommend the Government:

- 1. Adopt a national long COVID definition to enhance data collection and research**
- 2. Transition long COVID clinics to multipurpose respiratory clinics**
- 3. Ensure access to quality information and tailored support to manage COVID symptoms and recovery**
- 4. Utilise and strengthen both telehealth and face-to-face healthcare**
- 5. Create a health-professional strategy and COVID-19 training**
- 6. Harness acceptance of vaccinations now and expand the National Immunisation Program**
- 7. Fund respiratory nurses to support people with ongoing symptoms**
- 8. Enhance physical activity and self-management through pulmonary rehabilitation**
- 9. Address the unique mental health needs of Australians living with a lung disease**
- 10. Invest in the National Preventive Health Strategy**

Lung Foundation Australia's 2022 community survey found long COVID can cause significant impacts to the daily life of individuals, and we hope this Inquiry shines a light on these unique challenges and makes a range of recommendations that are tailored to at risk groups, to ensure no Australians are left behind when it comes to long COVID and ongoing symptoms.

Additionally, with the high burden of chronic health conditions within Australia, it is important to understand the unique experience of such populations and how we can strengthen the healthcare system to accommodate the needs of all Australians throughout COVID recovery. As of 2020-21, nearly 50% of Australians had at least one chronic health condition, with the National Strategic Framework for Chronic Conditions acknowledging, "*a focus on prevention can significantly reduce the volume and severity of chronic conditions and provide long-term saving and better health outcomes.*"<sup>1</sup>

The emergence of a new respiratory condition, and broadly the COVID-19 pandemic, has highlighted the importance of good lung health and being able to breathe freely for all Australians. Lung health has never been more important, and we need to continue to improve the support for the one in three Australians living with a lung disease. Lung Foundation Australia are committed to working with the Australian Government to protect the lung health of all Australians, and we welcome the opportunity to discuss our findings and recommendations further.

Thank you for the opportunity to provide feedback. If you would like to discuss the recommendations further, please contact Paige Preston, Senior Manager, Policy Advocacy and Prevention at Lung Foundation Australia at [paigep@lungfoundation.com.au](mailto:paigep@lungfoundation.com.au).

Sincerely,

A handwritten signature in black ink, appearing to read 'Mark Brooke', with a stylized flourish extending to the right.

**Mark Brooke**  
Chief Executive Officer  
**Lung Foundation Australia**

## About Lung Foundation Australia

Lung Foundation Australia (LFA) is the only national charity and leading peak-body dedicated to supporting anyone with a lung disease including lung cancer. For over 31 years we have been the trusted national point-of-call for patients, their families, carers, health professionals and the general community on lung health. There are over 30 different types of lung disease currently impacting one in three Australians. Lung Foundation Australia is also formally recognised as the peak lung health organisation under the Australian Government's Health Peak and Advisory Bodies Program.

Our mission is to improve lung health and reduce the impact of lung disease for all Australians. We will continue working to ensure lung health is a priority for all, from promoting lung health and early diagnosis, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease, and championing equitable access to treatment and care. As a patient representative charity, we have partnered with patients, health professionals, researchers, medical organisations, and the Australian community to drive reform in the delivery of health services in Australia to benefit more than seven million Australians impacted by lung disease and lung cancer.

### The COVID-19 pandemic and LFA

Since the beginning of 2020, COVID-19 has disrupted the everyday lives of Australians, causing disease and death across the country. With the development of effective vaccinations, treatments, and anti-viral medications we are now able to live alongside COVID-19. However, for many Australians COVID-19 is unlike any disease, causing ongoing symptoms and severely impacting their capability to live a full and healthy life. In the following submission, we will highlight the experience of Australians living with ongoing COVID-19 symptoms and provide a unique insight into the perspective of those living with a pre-existing lung disease and/or other chronic health conditions. The emergence of long COVID has created a new health crisis for Australia and as COVID-19 continues to spread in the community it is important we are able to effectively support Australians who are experiencing ongoing symptoms now and into the future.

Given the impact of COVID-19 infection on respiratory health, the potential respiratory impacts of long COVID, and the unique challenges we heard from our lung disease community, LFA committed to reviewing and adding to the evidence base. To do so LFA commissioned a global rapid review of the long COVID evidence, and conducted a community survey.

**The full report *COVID-19: A roadmap for recovery*, and accompanying infographic are attached in the Appendix (Appendix 1 and Appendix 2), which provide a detailed summary of the commissioned research and survey results.**

### Overview of LFA commissioned global rapid review

Lung Foundation Australia partnered with The George Institute for Global Health to understand the relationship between long COVID and lung disease. The review titled *Characteristics and impact of long COVID-19 in people with lung disease* was prepared by Dr Agnivo Sengupta and Professor Christine Jenkins AM in August 2022.<sup>2</sup> The rapid review analysed data from 84 studies, with most of the studies undertaken in European countries.<sup>3</sup> The results showed that long COVID may cause a spectrum of symptoms, including fatigue, myalgia, palpitations, muscle or joint pain, chest pain or tightness, dyspnoea at rest or on exertion, sleep difficulties, loss of smell and taste, gastrointestinal

complaints (diarrhoea, nausea), headache, and hair loss. <sup>4</sup> People with long COVID symptoms reported mild to moderate limitations in undertaking activities, including an inability to perform their usual activities and experiencing pain and discomfort. <sup>5</sup> The review concluded that people with an increased risk of long COVID include those over 40 years, females, people with higher BMIs, and people who were admitted to ICU due to COVID-19. <sup>6</sup> It highlighted the need to distinguish between long COVID and slow recovery, and pointed to a lack of agreement in Australia around the clinical definition of long COVID. <sup>7</sup>

Importantly, it was concluded that currently there is not a consistent link between ongoing COVID-19 symptoms and underlying respiratory disease. <sup>8</sup> However, people living with a lung disease may experience ongoing symptoms for a longer time before returning to their initial baseline. <sup>9</sup>

**See Appendix 1 and 2.**

**Overview of LFA community survey**

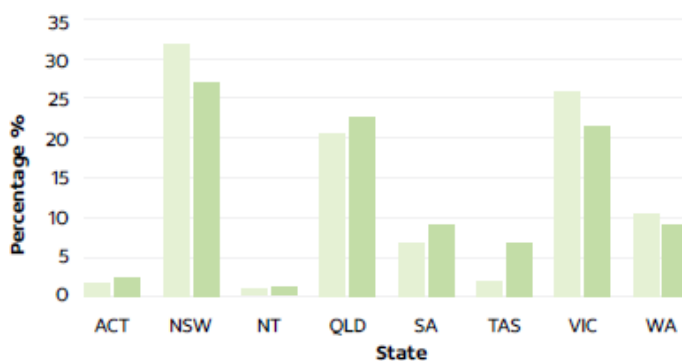
LFA is pleased to share the results of our survey into the patient experience of ongoing COVID-19 symptoms and the impacts this has caused. From the 6 July 2022 to the 27 July 2022, we received 2,196 responses and key perspectives from people who had experienced a COVID-19 infection, people who had cared for someone with COVID-19 and people living with a pre-existing lung condition or other chronic condition. We hope our survey results, and our experience as a health organisation supporting those with lung disease, provides valuable insights into long COVID and how Australia can best support those living with long COVID now and into the future.

The survey respondent population can be described as:

- Close to equally split between those who had COVID-19 (53%) and those who had not (47%)
- Aged from 18 years, with representation higher in the survey for people aged 55 years and over (57%)
- Representing each Australian state and territory (Refer to Figure 1)
- More female (72%) than male
- Having a vaccination status representative of the Australian population. Some 95.5% of respondents had received two or more vaccine doses compared to the national rate of 96.2%<sup>10</sup>.
- In terms of diversity,
  - 8% of respondents identified as Aboriginal and/or Torres Strait Islander
  - 9% of respondents identified with being from a culturally and linguistically diverse background
- 9% of respondents cared or had in the past cared for someone with COVID-19
- 54% of respondents were living with a chronic health condition
- 46% of respondents were living with a lung disease or lung cancer.

**Figure 1:**  
Representation in each Australian state and territory

State population  
Survey respondents



**See Appendix 2**

## Comments on Terms of Reference

Lung Foundation Australia are pleased to provide feedback in direct response to the consultation terms of reference.

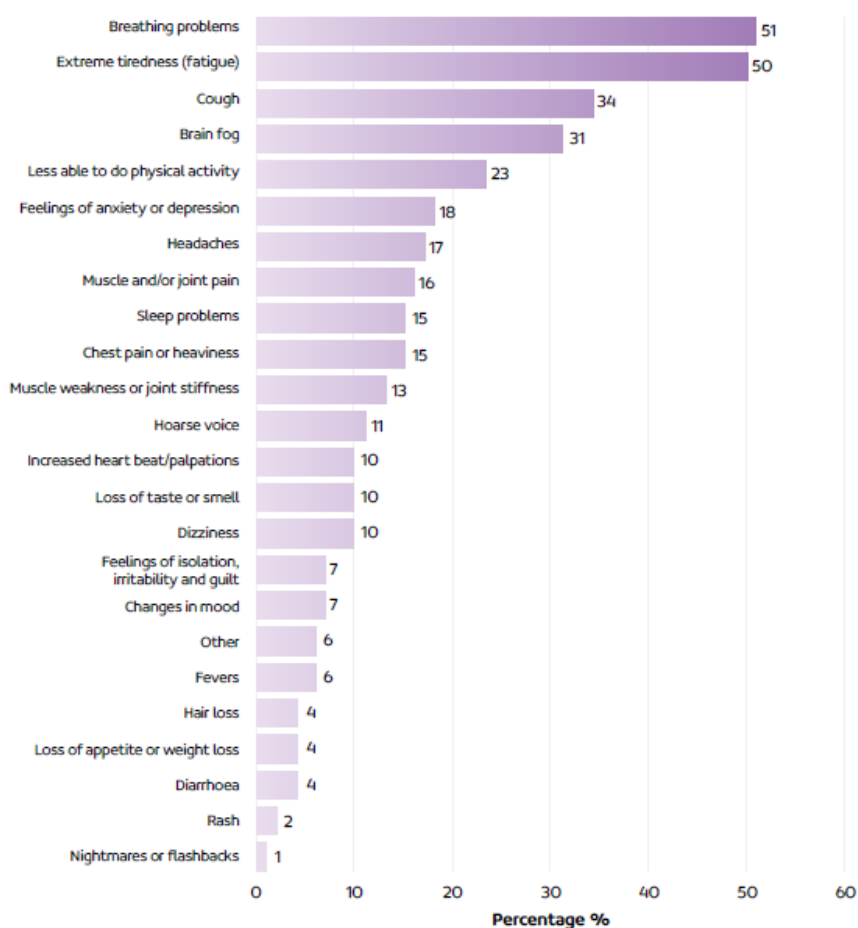
### TOR 1: The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment:

Lung Foundation Australia recognised a critical gap in the understanding of long COVID in the Australian context, resulting in the development of an extensive survey to provide context of the prevalence of ongoing symptoms and the impact for Australians. The survey provided us with insight into the lived experience of Australians with ongoing COVID-19 symptoms and the impact these symptoms are having on their lives. To consider the patient experience from multiple perspectives, we have grouped responses into two categories below A) all Australians, and, B) those living with a lung disease or other chronic health condition. Despite not having an agreed national definition of long COVID in Australia, 45% of respondents with ongoing COVID-19 symptoms stated that their health professional referred symptoms as long COVID. However, 12% of respondents reported that they did not know if their health professional referred to their ongoing symptoms as long COVID. For more on the patient experience around diagnosis and treatment, see TOR 3 Section D.

#### *All Australians*

The survey revealed that one in two respondents had experienced ongoing COVID-19 symptoms, which was defined as symptoms continuing beyond the four weeks following an initial infection. The reported symptoms which most impacted normal life for the general population included breathing problems (51%), fatigue (50%), cough (34%), brain fog (31%) and being less able to do physical activity (23%) (Refer to Figure 2).

**Figure 2: Ongoing COVID-19 symptoms that have most impacted normal life**





*"Am very anxious of contracting another bout of COVID, fearful of getting so sick again!"*

*- VIC resident who had COVID-19*

*"My COVID was very mild, literally two days, that's why I was so surprised to get breathless and long COVID symptoms."*

*- WA resident who had COVID-19*

*"I contacted covid April 2020 and have now been diagnosed with long covid. I have shortness of breath, joint pain, muscle aches, headaches, fatigue, cognitive issues, anxiety and still have no smell or taste."*

*- TAS resident who have COVID-19*

### *Those living with a lung disease or other chronic health condition*

The survey found that people living with a lung disease (57%) or chronic health condition (58%) had a higher reported incidence of ongoing COVID-19 symptoms. The rate for those without a chronic health condition was 51%. Of those who reported ongoing COVID-19 symptoms, fewer than one in two people living with a lung disease or another chronic condition (44%) reported that their ongoing symptoms had mostly or completely resolved. In comparison, respondents with no chronic disease were less likely to report current ongoing symptoms, with 56% reporting symptoms had mostly or completely resolved. Three in five people living with a lung disease (61%) reported that breathing problems were the most significant ongoing symptom affecting their life. Conversely, for almost one in two people living with a chronic condition other than a lung disease (44%), breathing problems were reported as the ongoing symptom most impacting normal life.

*"The symptoms haven't gone, it has truly impacted my life, especially the shortness of breath and the non stop coughing."*

*- NSW resident living with a lung disease*

*"It has affected my breathing severely. I hope in the future my lungs improve and that I do not catch covid again. I hope the immunisations improve to stop us catching it."*

*- NSW resident living with a lung disease and chronic health conditions*

## **TOR 2: The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections:**

Lung Foundation Australia is a non-government organisation that provides a range of health services to support both consumers and clinicians across Australia. As the leading lung health charity, we deliver consumer services including an information and support service, telephone based respiratory nurses and lung cancer nurses, lung cancer social worker and peer support programs. We additionally work closely with health professionals and create designated resources to ensure they are equipped with the knowledge to provide best practice patient care.

### *Supporting Patients*

Lung Foundation Australia has provided integral support to those living with a lung disease and lung cancer throughout the COVID-19 pandemic. In 2022 Lung Foundation Australia created a short video discussing tips on COVID-19 recovery, and the video is now the most popular COVID-19 on-demand short video on the Lung Foundation Australia website. Lung Foundation Australia also presented six webinars for those living with a lung disease and lung cancer to provide tailored information and support regarding COVID-19 and its interaction with specific lung diseases.

The need for information and support grew significantly through the pandemic with:

- a 62% increase in Lung Foundation Australia website traffic during the peak of the pandemic
- over 134,000 visits to our digital COVID-19 resources and information
- an increase in calls and requests for information on COVID-19 and their disease, and
- a surge in reports of distress among both patients and carers.

The Information and Support service at Lung Foundation Australia has received frequent enquiries over the last 12 months regarding the availability of a COVID support group. Due to the lack of a support group available, people were referred to Beyond Blue's COVID support system which offered three options to connect: an online chat feature with a counsellor, speaking with a counsellor directly over the phone or there was an online forum. Since the release of the COVID-19 report by LFA, the organisation has created a long COVID support group, providing individuals with the opportunity to share their experiences and challenges with those living with long COVID.

Additionally, if people were seeking medical advice or health professional guidance around long COVID symptoms, information on long COVID clinics and services was provided for those who had not been referred to them already. LFA created an internal directory of the clinics across the state that we share with consumers.

### *Supporting Healthcare Professionals*

Acknowledging the presence of ongoing COVID-19 symptoms in the community, in 2022 Lung Foundation Australia presented a health professional webinar regarding post-acute and long COVID care.<sup>11</sup> The resulting presentation received more than 650 registrations for the event, and thus evidentially health professionals are seeking guidance and information on how to provide the best care possible for patients experiencing ongoing COVID-19 symptoms.

### *Healthcare Professionals and their experience with long COVID patients*

Healthcare professionals are raising concerns about lack of funding to support patients post COVID causing increased strains to the burdened health system. The recent announcement of the closure of the Austin Hospital long COVID clinic due to a lack of funding will cause unbearable strain on the remaining long COVID clinics. The few long COVID clinics in Australia provide the necessary care but

for many this will come too late, with wait times now reaching 11 months at both St Vincent's and the clinic at the Royal Melbourne Hospital. <sup>12</sup>

*"Unfortunately, despite Western Sydney's high COVID infections over the past 3 years, we have been unsuccessful in gaining funding to support patients post COVID and had to divert funds from other services (thus resulting in decreased access for other patients). It has become unsustainable."*

Healthcare professional, NSW

**A health professional working in a long COVID clinic in Australia shared their experience with LFA**

*"We currently lack the funding and staffing resources to service the volume of patients with long COVID, leaving many having to wait months to access our service. Doctors and allied health professionals need to be upskilled to support patients with long COVID and GP's need training to know when to refer patients to long COVID clinics. Many people cannot get a referral from a GP, as some doctors don't believe in long COVID. Before arriving at a long COVID clinic, many people are seeing two or three specialists who cannot find any underlying cause of their symptoms, and this is financially draining. Individuals with long COVID need access to a multi-disciplinary team that can provide tertiary care from a hospital. We are seeing improvements in patients who present with long COVID, people are getting better."*

### **TOR 3: Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia:**

Lung Foundation Australia is actively participating in building and translating the evidence around COVID-19 and long COVID and are pleased to share the following insights from our commissioned global rapid review of the evidence, and other published evidence, which provides further clarity around the risk factors, effects, prevalence and management and treatment.

#### **A. Risk factors**

As previously noted, Lung Foundation Australia partnered with the George Institute for Global health to understand the relationship between long COVID those living with a lung disease. The rapid literature review titled *Characteristics and impact of long COVID-19 in people with lung disease* was prepared by Dr Agnivo Sengupta and Professor Christine Jenkins AM in August 2022. The review concluded that people with an increased risk of long COVID include those over 40 years, females, people with higher BMIs, and people who were admitted to ICU due to COVID-19.<sup>13</sup> The prevalence of long COVID varies because of changing virus variants, testing requirements, severity of acute infection of COVID-19, and access to antivirals and vaccinations. The review determined that both hospitalised and non-hospitalised people may experience long COVID.<sup>14</sup> Although an Italian study of hospitalised patients with COVID-19 showed longer resolution of abnormal diffusing capacity in those with asthma compared to those without, due to the lack of confirmatory data it could not be concluded if this represented a true indication of increased risk of long COVID or a susceptibility to persistent respiratory symptoms or new abnormalities for people living with a pre-existing lung disease.<sup>15</sup> The review concluded that currently there is not a consistent link between ongoing COVID-19 symptoms and underlying respiratory disease. However, people living with a lung disease may experience ongoing symptoms for a longer time before returning to their initial baseline.<sup>16</sup>

#### **B. Effects**

The rapid review analysed data from 84 studies, with most of the studies undertaken in European countries.<sup>17</sup> The results showed that long COVID may cause a spectrum of symptoms, including fatigue, myalgia, palpitations, muscle or joint pain, chest pain or tightness, dyspnoea at rest or on exertion, sleep difficulties, loss of smell and taste, gastrointestinal complaints (diarrhoea, nausea), headache, and hair loss.<sup>18</sup> People who were hospitalised, mechanically ventilated, or had a more severe infection in the acute phase were more likely to develop long COVID.<sup>19</sup> Psychological symptoms associated with long COVID included anxiety and depression, with many indicating poorer self-reported quality of life.<sup>20</sup> Other symptoms often reported included poor sleep quality, cognitive impairment, lack of concentration and memory lapses.<sup>21</sup> People with long COVID symptoms reported mild to moderate limitations in undertaking activities, including an inability to perform their usual activities and experiencing pain and discomfort.<sup>22</sup>

Studies involving imaging and diagnostics have commonly identified Pulmonary Fibrosis (thickened and scarred lung tissue).<sup>23</sup> However, the proportion of patients with radiological abnormalities varies from 0.01% in community-based populations to over 50% in patients who were followed up after hospital or ICU admission.<sup>24</sup> Chest CT scans commonly identified abnormalities such as ground glass opacities and consolidation, with many lung studies concluding there was impaired diffusion capacity (gas transfer) in the lung four weeks post a COVID-19 infection.<sup>25</sup> However, improvements in lung function tests at six months were reported for people who had moderate to severe COVID-19 infections.<sup>26</sup>

As previously mentioned, and as per the report, **reported symptoms which most impacted normal life for the general population included breathing problems (51%), fatigue (50%), cough (34%), brain fog**

**(31%) and being less able to do physical activity (23%).** Furthermore, three in five people living with a lung disease (61%) reported that breathing problems were the most significant ongoing symptom affecting their life. Similarly, for almost one in two people living with a chronic condition other than a lung disease (44%), breathing problems were reported as the ongoing symptom most impacting normal life.

*"[I want] more follow-up from GP, hospital, or Health Dept. if they know you are living with a lung disease... I am still testing positive after four weeks and I can't physically see my GP to get my lungs and breathing checked - both of which I feel have been hit hard... coughing is more laboured, constant, and sleeping more."*  
- NSW resident living with a lung disease

## C. Prevalence

The prevalence of long COVID is poorly understood and estimates around the world vary, making it difficult to comprehend the extent of the issue. A study completed by the University of New South Wales identified 5% of people diagnosed during the first wave of COVID in NSW still had persisting symptoms three months after their initial COVID infection.<sup>27</sup> However, Sengupta and Jenkins suggested that the prevalence of long COVID ranges from 3% to 12%.<sup>28</sup> Conversely, international data suggests prevalence may be much higher, with research from the University of Oxford concluding that one in three people may experience at least one long COVID symptom in the three to six months post infection.<sup>29</sup> Additionally, a global meta-analysis and systematic review, identified a global post COVID-19 condition prevalence of 43%.<sup>30</sup>

**The prevalence of long COVID is difficult to determine in the context of Australia as we have no official long COVID definition or register to understand the extent of long COVID.** Recent research by the Australian National University concluded nearly one-third of Australian adults who have had COVID-19, experience symptoms lasting for longer than four weeks.<sup>31</sup>

As mentioned previously, almost 50% of respondents from Lung Foundation Australia's community survey reported that they experienced ongoing COVID-19 symptoms, with only 12% of people reporting that their symptoms had completely resolved.

*"Still have ongoing symptoms and I have been isolating more I also have to work in childcare my career. I hope not to be reinfected with a different strain. I hope they find a solution soon."*  
- NSW resident living with a lung disease

## D. Management and treatment

### *All Australians*

Lung Foundation Australia's community survey found only three in five respondents (58%) had sought medical advice or treatment for ongoing symptoms. Of those who had, this advice was mainly being acquired from a general practitioner (GP) (65%), allied health professional (15%), psychologist or other mental health professional (8%) and pharmacist (8%).

Almost one in two respondents with ongoing symptoms (44%) had a health professional refer to their ongoing symptoms as long COVID. A follow-up appointment with a GP was the most reported recommendation (49%) followed by medical tests or investigations (44%), rest (43%), prescribed medications (42%), referral to a specialist (28%), time off work (23%), over-the-counter medication (20%), referral to another health service (16%), lifestyle changes (11%) and no recommended follow-up (7%). The information provided was noted as easy to understand by 55% and provided verbally for 48%. Despite this, less than one in three respondents (27%) stated the information gave them

confidence to manage their ongoing symptoms. Only around one in ten of this group (12%) received information in writing to which they could later refer to.

Following an appointment with a health professional, more than two in five respondents (43%) looked elsewhere for information to help manage or understand their ongoing COVID-19 symptoms. Additional information was sought via the Department of Health (45%), another medical practitioner (38%), international health websites (30%) and another website (30%). When asked what type of information would be helpful to manage ongoing COVID-19 symptoms, people reported: treatment options (74%); stories from others experiencing ongoing symptoms (43%); a written management plan (43%); mental health support (42%); and lifestyle changes (36%).

### *Those living with a lung disease or other chronic health condition*

Nearly three in five respondents living with a lung disease (59%) sought medical advice or treatment for their ongoing symptoms, with 95% of those mainly seeking medical advice from a GP. In 92% of cases, the health professional recommended follow-up. By comparison, 68% of respondents with other chronic health conditions sought medical advice or treatment for their ongoing symptoms, with 54% mainly seeking advice from a GP. For 97% of these respondents, the health professional recommended some sort of follow-up. Health professionals recommended a variety of management and treatment options. However, follow-up with a GP was the most common recommendation. For one in three people living with a lung disease (33%), a health professional referred to their ongoing symptoms as long COVID. Some 30% looked for further information elsewhere to help them manage or understand their ongoing COVID-19 symptoms following a discussion with a health professional. For respondents with other chronic disease, two in three (67%) looked elsewhere to help them manage or understand their ongoing COVID-19 symptoms.

*"Accessing specialists post-infection has been impossible. It's a 12-month wait to access a respiratory specialist on the Gold Coast. There are no long COVID clinics in Qld."*

- QLD resident who had COVID-19

*"My life has been turned upside down. Long COVID support in regional Victoria needs to be improved."*

- VIC resident who had COVID-19

*"[I want] easier and more access to long COVID support, more information from reliable sources provided for people."*

- VIC resident who had COVID-19

*"The pandemic brought on new feelings of anxiety. After having COVID, I struggled for a while with shortness of breath and brain fog and as did many of the people I knew. However, we had no information on this and when it would clear. I hope for the future more research is available."*

- NSW resident who had COVID-19

**TOR 4: The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;**

Lung Foundation Australia's survey aimed to understand the impacts of long COVID and as such has provided key insights into the physical and mental health impacts, carers and the unique experiences of people who face a greater risk of serious illness such as those living with a lung disease or lung cancer, or other chronic condition.

**A. The mental and physical impact of ongoing symptoms for all Australians**

The survey found people experiencing ongoing COVID-19 symptoms were severely impacted in their everyday lives, highlighting the need for further support. Among the 54% of people who reported having ongoing symptoms more than four weeks post COVID, some 46% said that their ability to do household chores and activities was always or often impacted. This impact on regular activities is certain to have flow-on effects, and add to the impacts on physical wellbeing (with the ability to exercise being impacted for 63%) and emotional wellbeing (42%). The need for further supports for Australians who are experiencing ongoing COVID-19 symptoms is clear.

*"Our life has not been the same since the kids became unwell seven months ago. I've been unable to work, they've been unable to participate properly in school or any other aspects of their former lives. The lack of knowledge about children and long COVID is very poor, and some medical professionals have proven to have limited understanding of invisible illnesses."*

– VIC resident who had COVID-19

*"I am looking at doing work that has less emotional and physical exertion. I hope that there will be more public education about what to do if you have COVID, what to do if you have long COVID."*

– ACT resident who had COVID-19

*"It has had a huge impact on my life as a health care worker and a person with long COVID symptoms now. I have lost hope that work will get easier and that the pandemic will ever be over. Every new strain fills me with dread. I am considering leaving my profession which I love but cannot go on working under those conditions."*

- VIC resident who had COVID-19

Infection rates are higher than at any other time during the pandemic have increased many people's fears of contracting COVID-19. When asked how anxious they were about future COVID-19 infections and long COVID, **44% of respondents reported that they were extremely or very anxious**. Interestingly, respondents who had not had COVID-19 were more anxious (54%) compared to people who had contracted COVID-19 (36%). Similarly, **people living with a lung disease and who had not had COVID-19 were more anxious (63%) compared to those who had contracted COVID-19 (44%)**.

**B. The experience of those who care or cared for someone with COVID-19**

The LFA COVID-19 survey received 206 responses from people identifying as caring for someone with COVID-19. Some 66 of these cared for someone with a pre-diagnosed chronic health condition, with 34 of these caring for a person with an underlying lung disease. People who are or were caring for someone with COVID-19 fell primarily into the categories of partners (33%), children (19%) and parents (17%).

Some 36% of carers reported a decrease in the level of care and support available for people living with an existing chronic health condition, when compared to before the pandemic. Over 50% of carers who were caring for a person with a lung disease or other chronic condition reported that the person they cared for had an appointment, test or procedure cancelled or delayed due to COVID-19. This caused an impact for four out of five of those affected, with specific impacts including worse mental health (47%), a worsening of condition or symptoms (36%) and additional physical pain (30%). Carers reported high use of telehealth services with three in four carers (74%) reporting the person they care for accessed the service. Carers often provide crucial care and support for people living with a lung disease or other chronic condition. They need tailored information to provide the best care possible and to feel confident in doing so.

*"[I] have researched sources unsuccessfully. Requested medical teams to inform us of treatments and plans but there has been very limited contact made. Doctors who we have seen have said they do not have access to the information we require."*

- Carer QLD

*"A lot of GP's don't know what is available to help their patients so then the patients don't know either."*

- Carer NSW

From the survey, carers identified a range of information that would be useful in assisting in caring for someone with ongoing COVID-19 symptoms including treatment options/how to improve symptoms (69%), stories from others experiencing ongoing symptoms (43%), mental health support (49%), written management plan (43%) and personal connections with others from individuals experiencing symptoms following COVID-19 (25%).

Carers primarily refer to medical practitioners (52%) and the Department of Health (50%) as their main sources of information in caring for someone who is experiencing ongoing symptoms. It is clear carers want information from medical practitioners and the Department of Health, thus it is important that they can access information to guide their care and support. With ongoing COVID-19 symptoms emerging as an area of need within healthcare, it is essential that carers have access to adequate information. Almost one in two carers (46%) identified as being extremely or very anxious about future COVID-19 infections, long COVID, and the potential impact on their health and ability to care for others, as well as impact on their life more broadly. Only 8% of carers were not at all concerned.

### **C. Groups that face a greater risk of serious illness**

#### *The impact of ongoing symptoms for people living with a lung disease*

One in three Australians are living with a lung disease and due to their pre-existing condition, have a unique experience with managing COVID-19 recovery and ongoing symptoms. Three in five people living with a lung disease (61%) reported that breathing problems were the most significant ongoing symptom affecting their life.

*"As I have mild COPD that I take a medication for every day I have found since having COVID my breathing has become worse and I had all the vaccines. This has affected my ability to do physical chores and meal preparation etc."*

- VIC resident living with a lung disease

*"I'm still very tired and have no energy I'm finding it so hard to do things around the house."*

- QLD resident living with a lung disease

*"I fared quite well during the pandemic until I caught COVID-19. Since then, my health has been a real struggle. I had COPD and asthma prior to being infected. I*



*had to have CT scan to check my lungs after my illness due to shortness of breath, more so than usual."*

- VIC resident living with a lung disease

*"I really don't think that I had enough information about the possible effects of 'long COVID'. I was not very sick during my isolation period with COVID so I did not request home care. However, when long COVID hit after, I was left struggling for breath and didn't feel that I was receiving any help. My respiratory consults were over the phone and I don't think they understood just how much I had been impacted."*

- TAS resident living with a lung disease

Ongoing COVID-19 symptoms can greatly impact an individual's ability to live a full life with ongoing COVID-19 symptoms affecting the ability to exercise for three in four people living with a lung disease (75%), the ability to complete household chores for more than one in two (54%), overall life (50%), emotional wellbeing (46%), social activities (46%), work, school or university (35%) and relationships with family/friends (28%). It is clear ongoing symptoms are greatly impacting life for many, particularly those living with a lung disease, causing not only a significant physical health burden but also to fundamental life aspects and mental wellbeing.

### *Those with another chronic health condition*

Chronic diseases are becoming increasingly common and an important area of action for the healthcare sector. In 2020-2021, one in two Australians had one or more of ten selected chronic diseases, meaning many Australians are living with a pre-existing health condition.<sup>32</sup>

For the 44% of survey respondents living with a chronic condition other than a lung disease, breathing problems were reported as the ongoing symptom most impacting normal life. Ongoing symptoms greatly impacted the ability to exercise (46%), household chores and activities (42%), overall life (39%), emotional wellbeing (39%), work, school, or university (35%), social activities (33%) and relationships with family/friends (23%).

*"I think people who are experiencing long COVID need better monitoring of their ongoing symptoms, and ongoing testing including lung X-rays need to be done. I still have a partially collapsed lung nine weeks after diagnosis."*

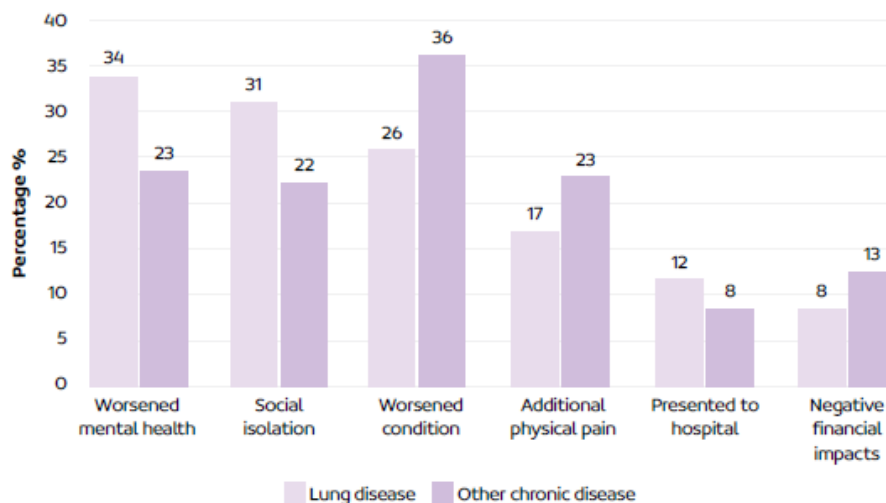
- QLD resident living with chronic health conditions

**TOR 5: The impact of long COVID and/or repeated COVID infections on Australia’s overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and**

Australia currently lacks consistent, timely and accurate data on long COVID prevalence, and thus it is difficult to truly understand how long COVID is impacting the health system. Some of this data is being captured and reported on by other organisations, however, we need to capture the health system impacts from the patient's point of view. The health system needs to be equipped to handle those living with long COVID as we have a new cohort of individuals with a new chronic health condition that can cause significant symptoms which impact daily life. The Australian health system experienced considerable strain throughout the pandemic and continues to struggle as COVID cases remain high. The health system in Australia is has been significantly strengthened to handle outbreaks of acute COVID-19 infections but remains unable to adequately support long COVID patients due to a lack of funding and investment. Whilst each state and territory remain primarily responsible for long COVID clinics and subsequent long COVID support, the federal government must also provide funding to ensure states and territories can provide equitable services for COVID recovery.

Almost one in two people living with a lung disease or other chronic health condition in this survey (49%) reported that they were unable to receive the same level of care and support for their existing condition compared to before the pandemic. This is likely due to restrictions, lockdowns, and an increased burden on the healthcare system. However, this may also be due to hesitancy on the part of individuals to seek care due to fear of contracting COVID-19.

**Impact of an appointment, test or procedure being cancelled or delayed**



*"I have end-stage COPD and I had a lot of trouble accessing appropriate help from a GP when I was feeling unwell. There has to be a better way..."*  
 - SA resident living with a lung disease

*"Keep access to lung specialist open. No testing or physio available in Townsville for a long time, all appointments are on hold or long overdue."*  
 - QLD resident living with a lung disease

LFA's survey also found that 70% of people living with a lung disease or chronic condition used telehealth services to access medical appointments throughout the pandemic. Almost 50% of people living with a lung disease and 55% of people with other chronic conditions had an appointment, test or procedure cancelled or delayed due to COVID-19. For two in three respondents (70%) the delay or cancellation had an impact. People living with a lung disease reported higher rates of worsened mental health, social isolation, and presentation to hospital.

*"I was unable to get a lung-function test for nearly two years as a result my lung function had dropped from 55% down to 46%, I have seen a physician recently and got it all sorted. Was very tired and had no social life."*

- VIC resident living with a lung disease

*"Do not restrict or limit treatment for non-COVID related health issues. I could not get into a lung clinic because I didn't have COVID and this in my opinion exacerbated my breathing and hear- related crisis now controlled by medicines and under observation."*

- SA resident living with a lung disease

The *My Health Can't Wait Research* by Johnson and Johnson in March 2022, found those more likely to be currently experiencing a significant impact on availability of health service due to COVID had a respiratory infection (25%).<sup>33</sup> Aligning with our findings, Johnson and Johnson found that 32% of those who have delayed a medical appointment reported poorer mental health and 20% reporting additional physical pain.<sup>34</sup>

Qualitative data from the survey highlighted accessibility issues to respiratory specialists throughout COVID-19, causing significant service days. Additionally, to prevent the spread of COVID-19, respiratory spirometry testing was delayed, which is an essential diagnostic tool and is the most common type of lung function or breathing test. This can be seen in the use of the MBS item for respiratory spirometry, whereby diagnosis has decreased by 44% and monitoring by 67% in 2022 compared to 2021 (Refer to Figure 3). Significant reductions in spirometry (both diagnosis and monitoring) means many living with lung disease such as Chronic Obstructive Pulmonary Disease (COPD) remain undiagnosed and without the care and support they need to effectively manage their condition. As a result, the true prevalence of respiratory disease in Australia will be unknown and importantly the health system is likely to experience a significant burden in the future if this is not addressed.

**Figure 3: Medicare item reports – number of services for spirometry in primary care 2019- 2022<sup>35</sup>**

	2019	2020	2021	Jan-July 2022
MBS item number 11505 Spirometry (Diagnosis)	88,905	57,797	49,480	18,683
MBS item number 11506 Spirometry (Monitoring)	213,856	96,117	70,170	24,538

## TOR 6: Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

### **International response to long COVID**

The United Kingdom (UK) are arguably leading the way in long COVID support providing long COVID clinics, designated information for long COVID in children, including support groups and chat functions on websites. The National Health Service (NHS) in the UK has established 90 post COVID services, providing access to specialist diagnosis, treatment, and rehabilitation.<sup>36</sup> Since July 2021 over 60,000 people have received specialist assessment in these services and 100,000 follow-up appointments have taken place.<sup>37</sup> Additionally, 14 post COVID specialist children and young people's hub have been created.<sup>38</sup> To ensure care is accessible, significant investments have been made to help general practice support patients and enable more consistent referrals to clinics which significantly increased the recording of people diagnosed with post COVID, from 1,540 to 3,720 clinical codes per week between June 2021 and March 2022.<sup>39</sup>

Navigating the journey with ongoing COVID-19 symptoms can be challenging, and for this reason Asthma and Lung UK has developed a long COVID assessment tool to help guide people on what to do next and what help is available.<sup>40</sup> The post-COVID Hub created by Asthma and Lung UK supports people with long COVID symptoms, providing assistance for navigating the healthcare system and where to find help for symptoms related to long COVID. Due to the diversity of long COVID symptoms, many health professionals are needed to provide comprehensive rehabilitation support, and this forms the basis of the post-COVID hub. Likewise, The Ministry of Health for New Zealand has incorporated resources to support and manage long COVID, linking to national and international resources for tailored information for common long COVID symptoms.<sup>41</sup> Importantly, not only is there information for patients, but also for clinicians such as factsheets, a tool for symptom mapping and the *Clinical rehabilitation guideline for people with long COVID in Aotearoa New Zealand*. The guideline provides clinical guidance on long and is an evidenced based summary covering the definition and diagnosis of long COVID.<sup>42</sup>

It is clear Australia can and should be doing more to support Australians living with long COVID, and international data and resources should be used to guide our long COVID response, as long COVID research in Australia remains limited. Australia currently provides limited information and support for the community with long COVID, and the implementation of tailored support and care that is accessible is overdue.

## The future of the long COVID response in Australia

The influx of COVID-19 infections in Australia from late 2021, has led to an increased rate of people experiencing symptoms consistent with long COVID. We are now experiencing a new public health burden related to the COVID-19 infection, requiring immediate attention and action as a large cohort of individuals remain undiagnosed, unsupported, and alone on their health journey with ongoing COVID-19 symptoms. According to LFA's community survey, nearly **three in four respondents (73%) think that the government should invest in increasing support and information for people experiencing ongoing COVID symptoms**, indicating that many believe the government is not currently meeting support and care needs.

The survey responses clearly identified significant physical and mental wellbeing impacts as result of long COVID. The symptoms of long COVID are beginning to be understood around the world; however, we acknowledge evidence for treatment of long COVID remains limited. Regardless, it is vital for Australia to provide support, information and services which align with the best practice care at the time and ensure Australians are guided in management of symptoms. Despite long COVID being new and 'unknown', many of the symptoms experienced by individuals with long COVID are well researched and it is important to use this knowledge to guide patient care as we continue to learn how to best support such patients.

Australia currently lacks information and support for long COVID patients outside of long COVID clinics, which are quickly becoming overwhelmed by Australians needing care. Long COVID clinics deliver critical support for long COVID sufferers, by providing access to a range of specialist health professionals to help patients manage the diverse range of symptoms. However, many Australian states have limited access to long COVID clinics, with no clinics in the Northern Territory and no clinics outside of capital cities, meaning many must travel to receive care. The few long COVID clinics in Australia are unable to handle the overwhelming interest across the country. The current measures are clearly inadequate, and we need strong investment and a co-ordinated approach between federal, state and territory governments to implement strengthen measures for support, care, and system change.

## Recommendations to respond to long COVID

Considering the rapid global review, community survey data collected, and the current response to long COVID in Australia, Lung Foundation Australia has developed 10 key recommendations. These are explained below, with each recommendation underpinned by the need for equity. Despite the health system dealing with an additional and ongoing burden, all Australians have a right to receive the information, support, and services they need for COVID-19, COVID-19 recovery, and management of any co-morbidities, in an equitable and timely manner. To help achieve this Lung Foundation Australia recommends the following:

### **1. Adopt a national long COVID definition to enhance data collection and research**

Internationally the definition of long COVID is contested, leading to a lack of consistency in long COVID reporting and understanding of the condition. In the rapid review by Sengupta and Jenkins, long COVID was defined as *"a post COVID-19 condition occurring in individuals with a history of confirmed COVID-19 where signs and symptoms of COVID-19 last for more than 4 weeks and cannot be explained by any other diagnosis"*.<sup>43</sup> Conversely, Healthdirect states, *"a person is usually considered to have long COVID if their symptoms have continued for longer than 12 weeks after their initial infection"*.<sup>44</sup> As Australia currently does not have a working clinical definition for long COVID there is confusion amongst health professionals and downstream impacts on the communication, monitoring and reporting that can occur.

We commend the Australian Government for funding an Australian COVID-19 Register and linked dataset, to be developed by the Australian Institute of Health and Wellbeing. This further strengthens the need to employ a consistent long COVID definition, to ensure consistent long COVID data is captured within the dataset. Clarity on the definition of long COVID must be provided and without such agreement, Australia may experience under-reporting of long COVID and a lack of support for Australians with ongoing symptoms. Ongoing COVID-19 symptoms remain poorly understood, prompting the need for enhanced research in this field to guide best practice and treatment into the future. With emerging evidence and research, it is important regular reviews are undertaken and sufficient funding is provided to ensure best practice guidance and care can be delivered in a consistent manner.

### **2. Transition long COVID clinics to multipurpose respiratory clinics**

Long COVID clinics have been established around Australia with New South Wales, Victoria, Queensland, and the ACT each having one clinic and South Australia having several. Western Australia and the Northern Territory have no dedicated long COVID clinics, and Tasmania is expected to launch a long COVID navigation and referral service. Long COVID clinics have the potential to provide support for a multitude of respiratory diseases outside of COVID-19, which becomes increasingly important as we move into the endemic phase. However, we note that current demand is high, with long wait times for appointments being reported. Appropriate consideration would need to be given to ensure current and then additional services provided through these clinics are accessible in a timely and affordable manner.

In addition, ensuring that appropriate data capture, linkages and learnings can be applied across jurisdictions and clinics will aid in ensuring that these services are fit for purpose and meet the broad needs of the community. Transitioning the long COVID clinics into multipurpose respiratory clinics would expand the reach and meet the needs of the broader respiratory disease community, who have struggled throughout the pandemic in managing their conditions. Placed-based respiratory nurses (linked with Recommendation 1) would expand access to vital support and care and helping to create a network of respiratory care nurses.

### **3. Ensure access to quality information and tailored support to manage COVID symptoms and recovery**

There is a clear gap in the support, resources, and information available to Australians experiencing ongoing COVID-19 symptoms. An essential need for immediate action and investment to ensure Australians can access the care they deserve is desperately required. Information and resources must be developed to support the increasing number of people experiencing ongoing COVID-19 symptoms and who suffer from ongoing respiratory symptoms such as breathlessness. Such resources should be designed in conjunction with this growing community. Australians experiencing ongoing COVID-19 symptoms need access to clear information and tailored support that acknowledges the changing environment of symptom management and treatment, given that further research is needed to fully understand ongoing symptoms. Furthermore, this will support carers who care for people with ongoing COVID-19 symptoms and guide their care.

As the peak lung health organisation in Australia, Lung Foundation Australia has established a website for COVID recovery information. This framework could be expanded to meet the needs of the affected community, identified by respondents to this survey. Australians require evidence-based information on managing symptoms and the impact on everyday tasks after COVID, and currently find this difficult to access. With appropriate funding Lung Foundation Australia has the resources and mechanisms in place to meet the needs of people in this evolving area, in providing information and support and responding to emerging evidence in a timely way. Lung Foundation Australia engages key opinion leaders in respiratory disease as well as expert consumers to ensure that all information is accurate and relevant. A targeted campaign to promote these resources is essential to ensure that all Australians are aware and can access them readily.

### **4. Utilise and strengthen both telehealth and face-to-face healthcare**

The Australian Government has recognised the importance of a robust healthcare system due to the impacts of COVID-19. Health equity has been a persistent challenge across the nation, as many Australians continue to face ongoing challenges in accessing the healthcare they need. Health services must ensure prompt diagnosis and address management of chronic disease – of which those living with a lung disease or lung cancer are a prime example. Telemedicine services have filled a substantial gap in healthcare delivery and have enabled improved healthcare access for those living in rural and remote communities. Returning to face-to-face healthcare poses challenges for many. As the health system grapples with ongoing high demand, many may be unable to access the support and care when needed. This is a particular concern for those living with a chronic condition, such as a lung disease or lung cancer. Telehealth services must be reviewed on an ongoing basis to gain an accurate understanding of the impacts and benefits such services provide and to evaluate whether the evolving health system is adequately and effectively meeting patient's needs. The evidence that telemedicine can be delivered with equal success to in-person consultations in achieving optimal clinical outcomes must be gathered especially as healthcare systems adopt it more widely.

### **5. Create a health-professional strategy and COVID-19 training**

Australia needs to develop and implement a health professional engagement strategy to assist health professionals in understanding and providing evidence-based care and to support people with ongoing COVID-19 symptoms. With new research emerging and advice constantly evolving, it is important that health professionals understand how to effectively guide patients who have ongoing symptoms and know what services are available for referral. Because information, resources and services are constantly changing, the training and education needs of health professionals must be addressed as part of a health professional engagement strategy. The federally funded Lung Learning Hub curates the highest quality, evidence-based respiratory health training and education from a range of providers into a central repository website. It has been developed with wide stakeholder

engagement, to help primary healthcare professionals easily find and complete training that will optimise their provision of care, their career and ultimately the outcomes for people living with a lung condition. Expanding this work to ensure COVID-19, ongoing symptoms, and emerging lung impacts are included is vital and is achievable through the strong partnerships already established as part of this program.

## **6. Harness acceptance of vaccinations now and expand the National Immunisation Program**

The COVID-19 pandemic has emphasised the importance of vaccinations in preventive health and protection. This increased awareness and understanding provides an integral opportunity to continue the momentum and expand the National Immunisation Program, removing barriers and increasing access to essential vaccinations. Despite their vulnerability, many people living with a lung disease are currently not covered under the National Immunisation Program and must pay out of pocket to access vaccines that would protect against severe respiratory disease, such as the pneumococcal vaccination. The National Immunisation Program identifies people with COPD, chronic emphysema, severe asthma, and interstitial and fibrotic lung disease, as being at increased risk of pneumococcal; however, does not provide free pneumococcal vaccinations to those affected. Now is the time to review and amend the criteria for free vaccinations and the delivery model, which could encourage vaccination uptake and effectively utilise the enhanced awareness and support for vaccinations.

## **7. Fund respiratory nurses to support people with ongoing symptoms**

With the community of people with ongoing symptoms increasing, additional resources, support and investment will be required. Respiratory nurses, available both on the ground and via telehealth (following Lung Foundation Australia's respiratory care nurse model) could provide assistance specifically for people with ongoing COVID-19 symptoms. They could assist people with recovery, information, and management of their condition, including discussing treatment and medical tests with an individual's health professional. Such support alongside resources for symptom management and how to live with ongoing COVID-19 symptoms, would ensure people were receiving important care to aid in recovery. Some 70% of respondents reported that they would be interested in accessing a free Lung Foundation Australia COVID-19-specific telephone-based respiratory nurse to help manage symptoms following COVID-19. Expansion and promotion of this service to the community would ensure more people can access this free, evidence-based support.

## **8. Enhance physical activity and self-management through pulmonary rehabilitation**

While research on the subject is limited, exercise may assist with COVID recovery and reduce the burden of ongoing COVID-19 symptoms. For the clinical rehabilitation management of breathing impairment in adults with post COVID-19, the World Health Organization suggest a combination of education and skills on self-management strategies including nasal breathing and pacing approaches alongside physical exercise training (for those without post-exertional symptom exacerbation).<sup>45</sup> Exercise completed under guidance of a medical professional – such as the pulmonary rehabilitation (PR) currently offered for people with respiratory conditions – aims to reverse an individual's cycle of inactivity and increase independence through daily activities and tasks, a fundamental of self-management. A PR audit completed by Lung Foundation Australia in September 2022 identified that 59% of PR programs were supporting patients with long COVID, with referrals primarily originating from long COVID clinics. This is a good example of using current practice to support people to be active. However, these services need to be consistently referred to, and funded, to ensure equitable support for Australians regardless of their location and financial position.



## **9. Address the unique mental health needs of Australians living with a lung disease**

We found that people living with a lung disease have unique mental health needs and require tailored support to assist with anxiety prior to, during, and following a COVID-19 infection. With a growing number of people experiencing poor mental health, particularly due to the social and economic impacts of the COVID-19 pandemic, the federal, state, and territory governments are providing increased investment to enhance support and access to mental health services. Peer support services should be recognised as an important element of connecting Australians, along with dedicated social work programs for those with unique psychosocial and practical needs and challenges. Organisations such as Black Dog and Beyond Blue are leading significant support activities in this area. A partnership approach to ensure the nuances and intersects of lung disease specifically on mental health are addressed would be invaluable.

Peer support would assist by bringing people with ongoing COVID-19 symptoms together to share their experiences and help each other cope with the challenges they may experience. This would complement formal support services. Peer support provides the opportunity for people to share their lived experience with someone who 'gets it'. Being able to connect with others who can empathise and let you know you are not alone can be incredibly helpful to many.

Funding for social workers is crucial as they can help individuals to navigate the practical and emotional impacts of living with ongoing COVID-19 symptoms and provide emotional and mental health support. Ongoing COVID-19 symptoms can be debilitating, leaving many unable to resume work or needing to work at reduced capacity. This in turn can lead to severe financial strain and stress.<sup>46</sup> The Lung Cancer Social Work pilot program implemented at Lung Foundation Australia is a free telephone-based service to support people living with lung cancer to navigate the practical and emotional impacts. This model could be replicated for people living with ongoing COVID-19 symptoms and other lung diseases. It would provide the necessary support and help improve mental wellbeing for this group so that members experience significantly higher rates of social, practical, and emotional wellbeing.

## **10. Invest in the National Preventive Health Strategy**

Preventing disease creates a more productive society, reduces the burden on the health system, and reduces the cost to individuals and government, both directly and indirectly. The *National Preventive Health Strategy* highlights the need for further investment in preventive health, noting investment will be raised to 5% of the total health expenditure across the federal, state, and territory governments by 2030. This important national strategy outlines a range of evidence-based recommendations and policy priorities, of which Lung Foundation Australia is extremely supportive. Australians are more aware than ever of the benefits of preventing disease, with the emphasis of preventing COVID-19 infection being a focus for over a year. We need to harness this acceptance by implementing the policy priorities outlined in the *National Preventive Health Strategy*, which will require a greater investment in preventive health across the lifespan and a commitment to bold and innovative policy solutions.

- 
- <sup>1</sup> Australian Health Minister s' Advisory Council 2017, National Strategic Framework for Chronic Conditions 2019, <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>
- <sup>2</sup> Sengupta, A and Jenkins, C, 2022 characteristics and impact of long COVID-19 in people with lung disease, The George Institute for Global Health
- <sup>3</sup> Ibid 2
- <sup>4</sup> Ibid 2
- <sup>5</sup> Ibid 2
- <sup>6</sup> Ibid 2
- <sup>7</sup> Ibid 2
- <sup>8</sup> Ibid 2
- <sup>9</sup> Ibid 2
- <sup>10</sup> Department of Health, 2022, Vaccination numbers and statistics, <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/numbers-statistics#total-national-doses>
- <sup>11</sup> Lung Foundation Australia, 2022, Health professionals COVID-19, <https://lungfoundation.com.au/lung-health/protecting-your-lungs/coronavirus-disease-covid-19/health-professionals/>
- <sup>12</sup> Mannix, L 2022, Long COVID clinics 'inundated' with patients, and doctors can't cope. <https://www.smh.com.au/national/long-covid-clinics-inundated-with-patients-and-doctors-can-t-cope-20221109-p5bwqp.html>
- <sup>13</sup> Ibid 2
- <sup>14</sup> Ibid 2
- <sup>15</sup> Ibid 2
- <sup>16</sup> Ibid 2
- <sup>17</sup> Ibid 2
- <sup>18</sup> Ibid 2
- <sup>19</sup> Ibid 2
- <sup>20</sup> Ibid 2
- <sup>21</sup> Ibid 2
- <sup>22</sup> Ibid 2
- <sup>23</sup> Ibid 2
- <sup>24</sup> Ibid 2
- <sup>25</sup> Ibid 2
- <sup>26</sup> Ibid 2
- <sup>27</sup> Liu et al. (2021) Whole of population-based cohort study of recovery time from COVID-19 in New South Wales Australia. The Lancet Regional Health – Western Pacific, 12 (2021) 100193. <https://doi.org/10.1016/j.lanwpc.2021.100193>
- <sup>28</sup> Ibid 2
- <sup>29</sup> Taquet M, Dercon Q, Luciano S, Geddes JR, Husain M, Harrison PJ (2021) Incidence, co-occurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19. PLoS Med 18(9): e1003773. <https://doi.org/10.1371/journal.pmed.1003773>
- <sup>30</sup> Chen Chen, Spencer R, Hauptert, Lauren Zimmermann, Xu Shi, Lars G. Fritsche, Bhramar Mukherjee, Global Prevalence of Post-Coronavirus Disease 2019 (COVID-19) Condition or Long COVID: A Meta-Analysis and Systematic Review, The Journal of Infectious Diseases, 2022;, jiac136, <https://doi.org/10.1093/infdis/jiac136>
- <sup>31</sup> Biddle, N & Korda R, (2022), The experience of COVID-19 in Australia, including long-COVID – Evidence from the COVID-19 Impact Monitoring Survey Series August 2022 [https://csm.cass.anu.edu.au/sites/default/files/docs/2022/10/The\\_experience\\_of\\_COVID-19\\_in\\_Australia\\_-\\_For\\_web.pdf](https://csm.cass.anu.edu.au/sites/default/files/docs/2022/10/The_experience_of_COVID-19_in_Australia_-_For_web.pdf)
- <sup>32</sup> Australian Institute of Health and Welfare, 2022, Chronic disease, <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview>
- <sup>33</sup> Johnson & Johnson Medical Pty LTS, 2022, My health can't wait. <https://www.jnjmedtech.com/en-AU/my-health-cant-wait>
- <sup>34</sup> Ibid 33
- <sup>35</sup> Services Australia, Medicare Item Reports: Australian Government; 2022 [Available from: [http://medicarestatistics.humanservices.gov.au/statistics/mbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/mbs_item.jsp) .
- <sup>36</sup> NHS England 2022, The NHS plan for improving long COVID services, [https://www.england.nhs.uk/wp-content/uploads/2022/07/C1607\\_The-NHS-plan-for-improving-long-COVID-services\\_July-2022.pdf](https://www.england.nhs.uk/wp-content/uploads/2022/07/C1607_The-NHS-plan-for-improving-long-COVID-services_July-2022.pdf)
- <sup>37</sup> Ibid 36
- <sup>38</sup> Ibid 36
- <sup>39</sup> Ibid 36
- <sup>40</sup> Asthma and Lung UK 2022, Post-COVID Hub, <https://www.post-covid.org.uk/>
- <sup>41</sup> Ministry of Health New Zealand, 2022, long COVID, <https://www.health.govt.nz/covid-19-novel-coronavirus/covid-19-health-advice-public/about-covid-19/long-covid>
- <sup>42</sup> Ministry of Health New Zealand 2022, Clinical rehabilitation guideline for people with long COVID in Aotearoa New Zealand, <https://www.health.govt.nz/publication/clinical-rehabilitation-guideline-people-long-covid-aotearoa-new-zealand>
- <sup>43</sup> Ibid 2
- <sup>44</sup> Health direct 2022, Understanding post-COVID-19 symptoms and long COVID, <https://www.healthdirect.gov.au/covid-19/post-covid-symptoms-long-covid>
- <sup>45</sup> World Health Organisation 2022, Clinical management of COVID-19 patients: living guideline, <https://www.who.int/publications/i/item/WHO-2019-nCoV-Clinical-2022.2>
- <sup>46</sup> Davis, H et al., 2021, Characterizing long COVID in an international cohort: 7 months of symptoms and their impact, Journal of Eclinical Medicine, 38 (101019), <https://doi.org/10.1016/j.eclinm.2021.101019>