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CENTRE FOR  
POSTTRAUMATIC  
MENTAL HEALTH

# Inquiry into Long COVID and Repeated COVID Infections

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Phoenix Australia Centre for Posttraumatic Mental Health Ltd



# Summary of Recommendations

The Australian Psychological Society (APS) and Phoenix Australia - Centre for Posttraumatic Mental Health Ltd (Phoenix Australia) commend the Australian Government on conducting the *Inquiry into Long COVID and Repeated COVID Infections* and we look forward to the Government's response and future initiatives that address what will potentially be a significant health issue for a large number of Australians. Throughout this response, we advocate for a number of ways to support people with this condition and manage the future national impact of long COVID, such as:

## Diagnosis, prevention and treatment

- Implement models of diagnosis, treatment and support that align with emerging research and practice-based evidence that indicate that effective long COVID care should be:
  - Individualised, person-centred and wholistic, recognising the mutual interaction between physical and mental health.
  - Driven by co-ordinated multi-disciplinary models for diagnosis, prevention and treatment.
  - Available early at the onset of symptoms.
  - Flexible to offer high-quality care to all Australians irrespective of their location and to accommodate the relapsing/remitting nature of long COVID.
  - Responsive to the needs of families and carers.

## System drivers

- Recognise the need for an intersectionality-informed approach to policy responses to long COVID.
- Include long COVID in the *National Strategic Framework for Chronic Conditions: Reporting Framework* to enable the collection and analysis of the data needed to inform future funding decisions.
- Fund access to high-quality diagnosis, prevention and treatment for long COVID, including psychological care by:
  - Improving the Medicare Chronic Disease Management (CDM) items.
  - Retaining the 20 per annum Medicare Better Access sessions for psychological treatment.
- Revise eligibility criteria to enable people experiencing the disabling impacts of long COVID and their families much needed access to social and financial support services.
- Provide resources and training to employers, HR professionals and employees to destigmatise the long COVID experience and enable the implementation of policies and employment-related assistance for workers with long COVID.

## Workforce issues and training

- Address the critical workforce shortages facing psychology to ensure patients suffering from long COVID have access to high-quality psychological and neuropsychological healthcare.
- Upskill GPs to correctly identify patients suffering from long COVID and to refer and partner with other health professionals, including allied health professionals, to holistically assess and manage the physical, psychological and cognitive components of the condition.
- Provide ongoing training and education programs for allied health professionals, including psychologists, to enable them to remain abreast of emerging research and practice developments in the identification and treatment of long COVID symptoms and functional impairments.
- Provide resources and support to individual healthcare workers who are self-managing long COVID symptoms and/or those treating their peers.

# Summary of Recommendations (cont.)

## **Public health approaches**

- Roll out a consumer public health information campaign that provides clear, accurate information for the community about long COVID, including how to identify it and where to seek help for physical, psychological and cognitive symptoms and functional impacts.

## **Research**

- Fund ongoing and sustained support for interdisciplinary and holistic research into the effects of long COVID with particular attention on early intervention and psychological and cognitive treatment approaches.
- Fund research into the role health anxiety can play in exacerbating long COVID symptoms and worsening quality of life and opportunities for prevention and early intervention.

**The APS and Phoenix Australia would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and clinical evidence to the development of this submission.**

# Introduction

The Australian Psychological Society (APS) and Phoenix Australia - Centre for Posttraumatic Mental Health Ltd (Phoenix Australia) welcome the opportunity to provide a response to the *Inquiry into Long COVID and Repeated COVID Infections (the Inquiry)* and commend the Government on appropriately investigating this issue which could have major implications for the health care sector as well as national employment, education, wellbeing and productivity impacts.

Long COVID presents a significant challenge to global and national efforts towards achieving Sustainable Development Goal 3: “Ensure healthy lives and promote well-being for all at all ages”<sup>1</sup>. There is an urgent need in Australia to invest in national planning and research and learn from other parts of the world to ensure that we are taking the best possible steps to minimise the impact of long COVID on the lives of Australians and to ensure the best health and wellbeing outcomes.

As evidence informed organisations, the APS and Phoenix Australia have drawn on the emerging research about the impact, features and best practices related to the treatment of long COVID to present a series of recommendations. Where possible, in the preparation of this response, we have also drawn upon the clinical experience of APS members working with patients experiencing long COVID.

The current limited availability of research and practice-based evidence about the long-term impacts of COVID on individuals and communities means that there are many gaps in knowledge. Given this, we have also drawn upon research and practice about neural mechanisms; neurological, neurodevelopmental and functional disorders with similar phenomenology to long COVID (such as chronic fatigue syndrome and fibromyalgia); and adjustment disorder and trauma-informed care to guide understanding about the impacts of long COVID on patients and best practice approaches to providing treatment and support. We acknowledge that conclusions based on similar conditions must be tentative at best and that this cannot replace good quality research directly focused on long COVID. As new evidence becomes available, our recommendations may change.

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

Given that long COVID has only been identified since 2020<sup>2</sup>, long-term systematic research on many aspects, including the lived experience of this condition, is limited. In response to this Term of Reference (TOR) 1, we have mostly utilised lived experience reports and clinical reports from APS members who are psychologists providing care to patients affected by long COVID. We acknowledge that there are other organisations which will be better able to directly represent the valuable lived experiences of patients with long COVID.

Supporting the emerging scientific evidence, APS member observations of people attending the Royal Melbourne Hospital (RMH) COVID Recovery Clinic have included:

- Patients have experienced not being believed by peers, family and work colleagues about the impact of their long COVID symptoms and are concerned that their experience may be considered ‘malingering’ by health professionals and/or others<sup>3,4</sup>.
- Patients report feeling uncertain about the timelines for a likely resolution of their symptoms and the disruption to their life trajectory or identity<sup>4,5</sup>.
- People with long COVID report feeling worried about keeping up with their previous work standards and fear being seen as incapable at work due to the fatigue, cognitive and psychological symptoms they are experiencing.
- A large number of people with long COVID have found it very difficult to advocate for themselves. Many report that their problem-solving skills have been impacted, and with increased anxiety levels it has been hard for them to ‘navigate the system’ to get assistance and try to make sense of the symptoms alone<sup>3,4</sup>.

Many patients report that before COVID they were fit and healthy and high functioning at work and other aspects of their lives, whereas now they feel like a totally different self – exercising less, socialising less, and feeling less capable<sup>3</sup>. In turn, this markedly impacts their confidence and self-esteem. They report being affected by the ‘unknowns’ of their situation – they worry about their long-term health and wellbeing and that they may never get better, and experience fear about what this may mean for their future and that of their family<sup>6,7</sup>.

Evidence from a systematic review suggests that patients report symptoms fluctuating over time<sup>8</sup>. Despite the symptoms not being severe enough to require immediate hospitalisation, functional impairment can still be very high, even many months after the initial infection<sup>8</sup>. Patients describe the marked discordance between their own expectations, as well as expectations from employers and the public, to be functioning at pre- infection levels, and their lived experience of severe and ongoing debilitation due to long COVID symptoms<sup>8</sup>.

These experiences result in frustration, self-stigmatisation and community stigma<sup>8,9</sup>. Importantly, we know from previous research that intersectionality may exacerbate the impacts of that stigma<sup>10</sup>. Many patients report distress and adjustment difficulties in accepting this ‘new self’ that they perceive as ‘lesser’ than their former selves<sup>4,6,7</sup>. Given this, it is essential that a person-centred<sup>11</sup>, individualised approach to care is taken, which involves listening to the patient’s story and recognising their specific needs<sup>12</sup>. Practitioners also play an important role in supporting patients to adjust to changing functional capacity that may wax and wane over time<sup>13</sup>.

It also important to note the process that patients must endure to be ‘successfully’ diagnosed as suffering from long COVID. As will be described in the response to TOR 3, patients experience a wide variety of symptoms which can complicate the identification and ultimately the treatment of long COVID. Similarly to patients’ experience with somatoform-type disorders (disorders involving clinically significant but unexplained physical symptoms<sup>14</sup>), APS members tell us that patients have to undergo worrying repeat medical visits and testing to eliminate differential diagnoses<sup>15</sup>. Using

insights gained from patients suffering from chronic fatigue syndrome, the need to make ‘sense of symptoms’ is seen as crucial both for understanding oneself and to provide legitimacy in relation to health professionals, friends and family members<sup>12</sup>. Further, following diagnosis, the treatment approach can be unclear and the recovery timeline uncertain<sup>5</sup>. We highlight here the need for a well-supported consumer public health campaign that provides clear, accurate, and evidence informed messages to the Australian community to help them identify long COVID and provide advice about where to seek help for the physical, cognitive and psychological aspects of care.

Ongoing uncertainty about patient’s health status can lead to fear, anxiety, and stress; and the potentially traumatic aspects of long COVID following previous experiences of lock downs and restrictions. It is not surprising that patients experiencing repeated COVID infections and/or long COVID would also be more likely to suffer from health anxiety, an excessive fear of having or contracting an illness or disease<sup>16,17</sup>. We advocate for research into the role health anxiety can play in the exacerbation of long COVID symptoms (identifying opportunities for prevention and early intervention) as well as the contribution of ongoing anticipation of contracting COVID to worsening quality of life.

Self-funding treatment is challenging for many with long COVID due to the considerable costs associated with treatment of the persistent physical and mental health sequelae and functional impacts over a long period, including impacts on the ability to work and earn income. We advocate for more funding to enable long COVID sufferers to access high quality diagnosis and the treatment they need, as well as being able to access social and financial support. The challenges of paying for treatment are even more pronounced for already disadvantaged and vulnerable Australians, including those from low SES backgrounds and who have an existing disability or health condition. Individuals experiencing the disabling impacts of long COVID may be able to make a claim through income protection insurance in their superannuation but struggle to demonstrate eligibility for the National Disability Insurance Scheme (NDIS), the Disability Support Pension (DSP) or Workcover<sup>7</sup>. It is for these reasons, amongst others, that we suggest that policies relating to long COVID take an intersectionality-informed approach that considers the impact of age, gender, disability, geographical location, socio-economic status, ethnicity, migrant status, Aboriginal and Torres Strait Islander status<sup>18</sup>.

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

Psychologists at the RMH COVID Recovery Clinic report experiencing challenges associated with the lack of evidence based psychological and cognitive treatments and interventions for long COVID. Clinicians indicate that there are difficulties associated with the absence of strong evidence about whether psychological and cognitive issues have a clear biological basis, or are secondary responses or reactions to the other factors related to long COVID (i.e. medical complications, fatigue etc)<sup>19-21</sup>. This impacts on the type of psychoeducation the psychologists can provide to patients, and whether first line treatment approaches should be restorative/symptom targeted or acceptance and compensatory based. Given this, we strongly advocate for ongoing research into psychological and cognitive treatment approaches to best equip psychologists and other health professionals to provide high-quality evidence informed practice (please also see response to TOR 3).

APS members also noted that, in contrast to other patient cohort groups, they are seeing a high number of healthcare workers through the RMH COVID recovery clinic, and this includes healthcare workers from their own service. This has implications regarding potentially needing to work with patients they have treated through the clinic as colleagues at a later time-point. The psychologists report they believe it has also impacted on the ability of healthcare workers to feel completely psychologically safe in the treatment space, and that they may be reluctant to disclose the true

extent of the difficulties they are experiencing in case it impacts on their employment (i.e., due to a perception that the healthcare service they work for, and are being treated by, has access to their confidential information).

### 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

#### Effects

Emerging research indicates that although patients' experiences and particular symptom clusters may differ, there are some commonalities. The Office for National Statistics in the UK undertook a study of people who self-reported experiencing long COVID<sup>25</sup>. Similarly to other research conducted<sup>26-29</sup>, the most common symptoms were:

- Fatigue (69%)
- Difficulty concentrating (45%)
- Shortness of breath/dyspnoea (42%)
- Muscle ache (40%)

Others symptoms include headaches and loss of taste or smell, memory problems, as well as other neurologic, neuropsychiatric and systemic symptoms<sup>9,21,26-28,30</sup>. It is important to note that symptoms of long COVID are similar to many common symptom clusters found in neurology, infectious diseases and rheumatology specialities<sup>21</sup>.

Fatigue is considered to be one of the most common and debilitating symptoms associated with long COVID<sup>26,27,29,31</sup>. Importantly, if fatigue is a primary symptom, it can be associated with, and may compound, many secondary sequelae associated with long COVID. These may include sleep problems and mental health impacts such as depression as well as psychosocial impacts (e.g., social isolation and functional impacts (e.g., inability to perform daily activities)<sup>31</sup>. Functional and psychosocial impacts are described in more detail in the response to TOR 4.

Anxiety is also commonly reported in patients who have contracted long COVID<sup>4</sup>. This may be due to a number of reasons, including it being an aftereffect of the infection itself, exacerbated by the implications of having long COVID or repeated COVID infections (e.g., impacts on employment, relationships, not being believed etc.<sup>8,31</sup>), as well as the result of a traumatic experience related to the COVID infection (e.g., treatment in the ICU)<sup>32</sup>.

#### Neural basis of long COVID

International research is currently underway to attempt to understand the neurological underpinnings of long COVID. It is important to note, however, that despite the dedicated efforts from leading researchers, the evidence is still very much in its infancy. There are increasing numbers of reports in the scientific literature that suggest that the neural processes which occur in neurodegenerative disorders are similar to those in long COVID<sup>33</sup>. Recent evidence using brain organoid models suggests that the 'pruning' process of eliminating the synapses (important for brain cell communications) is overactive after exposure to SARS-CoV-2<sup>33,34</sup>. Excessive synaptic pruning is very closely associated with cognitive impairment<sup>35</sup>. Importantly, evidence suggests synapse loss occurs in both neurodegenerative disorders<sup>35</sup> (e.g., Parkinson's and Alzheimer's diseases) and neurodevelopmental disorders (e.g., schizophrenia<sup>36</sup>).

Other investigations are looking at the neural mechanisms underlying COVID and possible treatment options. For example, ferroptosis has been proposed to be the neural mechanism by which the neuropsychiatric symptoms and brain injuries occur in long-term post COVID infection<sup>37</sup>.

In addition, there is current research being undertaken at Griffith University to investigate the extent to which the biological impairments underlying long COVID are those shared with chronic fatigue syndrome<sup>38</sup>.

The similarity of experience and symptom clusters found in long COVID and many functional, neurological, chronic, unexplained or rheumatological conditions has, according to Burke and del Rio<sup>21</sup> exposed the ineptitude of modern health care. Different medical and allied health specialities have differing hypotheses and understandings of the underlying mechanisms which 'explain' long COVID. Importantly, these approaches are not mutually exclusive and, as will be described later, a multi- and inter-disciplinary approach is the best way to guarantee that knowledge is synthesised and combined to ensure that patients receive coordinated and complimentary health care.

Recent evidence suggests that experiencing psychological distress\* before SARS-COV-2 infection is associated with an increased risk of developing long COVID and an increased risk of daily impairment<sup>39</sup>. It is hypothesised that the body's natural reactions to stress can increase a 'silent' inflammation response. If this distress is ongoing, then the immune system adapts and essentially 'downgrades its responsiveness to new threats'. It is possible, therefore, that prior psychological distress makes it harder to fight the infection of COVID and, in turn, increases the risk of long COVID<sup>40</sup>. This relationship further emphasises the importance of the management of psychological distress in the Australian population. As the APS has previously advocated<sup>24</sup>, we strongly urge the Government to maintain the 20 sessions of psychological treatment per annum to ensure that the Australian population has access to sufficient psychological care, especially during the uncertainty of the present time.

### Risk factors

Evidence is still emerging to characterise which people are more likely to develop long-COVID, but it is currently understood that risk factors include:

- **Severe illness** – in patients who experienced more than five symptoms during the first week of contracting COVID is associated with long COVID<sup>41</sup>. It is important to note, however, that long COVID may also develop in people who only experienced a mild or even asymptomatic initial infection.
- **Preceding psychological distress and brain health** – experiencing psychological distress<sup>2</sup> before SARS-COV-2 infection was associated with a 1.3-1.5 times increased risk of developing self-reported long COVID and an increased risk of daily impairment<sup>39</sup>. There is also emerging evidence to suggest that optimising brain health before COVID can help mitigate against long-term consequences<sup>42</sup>.
- **Vaccination history** – emerging evidence suggests that being vaccinated reduces the likelihood of developing severe long COVID<sup>41,43</sup>.
- **Multisystem Inflammatory Syndrome (MIS)** – people who developed MIS during or after their acute COVID infection are more likely to experience long COVID<sup>41</sup>.
- **COVID reinfection** – the risk of contracting long-COVID increases with each reinfection<sup>44</sup>.
- **Socio-demographic characteristics** – In a UK self-reported study conducted by the Office for National Statistics<sup>25</sup>, long COVID was found to mostly occur in females, respondents aged 35-39 years, those working in social care, living in lower socio-economic areas, living with a disability or another health condition which limited their activity, and adults (aged over 16) not working and not looking for work when considered as a proportion of the UK population. Higher Body Mass Index (BMI) is also associated with a greater risk of experiencing symptoms of long COVID<sup>45</sup>.

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\*Psychological distress in this context being: depression, anxiety, perceived stress, loneliness, and/or worry about COVID<sup>39</sup>



## Prevalence

As previously described, long COVID is associated with a number of non-specific symptoms<sup>41</sup> which, we know from analogous research investigating somatoform-type disorders, is notoriously difficult to diagnose, particularly in primary care settings<sup>14</sup>. Given the challenges associated with identification, a lack of universal definition and the methodological approach between research groups, it is, therefore, difficult to provide an accurate estimate of the prevalence of long COVID<sup>41,46</sup>. Given this, there is still active debate in the literature with estimates ranging widely<sup>26-28,47,48</sup>.

A recent Australian study found that 20% of patients will still experience COVID symptoms after one month and 5% will still experience symptoms after three months<sup>48</sup>.

In the UK, approximately 3.5% of the population (2.3 million people) self-reported they were experiencing long COVID. Of those, 72% said that long COVID symptoms adversely affected their ability to undertake day-to-day activities.

In the USA, the American Psychological Association reported that more than two thirds of patients who are treated by the Johns Hopkins Post-Acute COVID Team still experience cognitive dysfunction four months post-infection<sup>49</sup>. Similarly, in an Italian study including recovered patients who had been hospitalised for COVID, 87.4% reported experiencing at least one persisting symptom<sup>29</sup>.

## Treatment

Typically, it appears that the management of long COVID symptoms is undertaken by general practitioners (GPs), at least in the first instance<sup>27</sup>. However, similarly to other functional or somatic disorders<sup>14</sup>, it is important to note that some patients have found it difficult to find a GP who can correctly identify long COVID and who will believe the symptoms are real<sup>4</sup>. In addition, accessing care has been difficult, with telehealth overcoming some but not all barriers<sup>8</sup>. Given this, we advocate for GPs to be supported and upskilled to enable them to correctly identify patients who may have long-COVID and refer them to the appropriate health professionals or dedicated long COVID clinics for diagnosis and access to the physical and psychological treatment. Allied health professionals, including psychologists, also need to be upskilled to appropriately assess and treat the symptoms and any underlying factors which exacerbate the effects of long COVID.

Psychologists are well placed to not only address the mental aspects of living with long COVID (e.g. anxiety, depression, adjustment), but also have expertise in the neurocognitive and physical aspects of health. As will be discussed in response to TOR 6, it is essential that psychological care is delivered as part of a multidisciplinary team to achieve the best outcomes for patients.

## Research

Despite the progress that has been made in a remarkably short time, there is still much to learn about the prevention, causes, trajectory, treatment and neurological underpinnings of long COVID. Given this, the APS strongly advocates for the ongoing support of research into long COVID, well beyond when the 'waves' of acute infections have subsided. In particular, there is a critical need for more research about treatments for psychological and cognitive symptoms associated with long COVID. Given the complex nature and pervasiveness of the cluster of symptoms associated with long COVID, it is essential that a holistic and interdisciplinary approach is taken.

It is important to note that there is already some research currently being undertaken to investigate the health system approaches and translations of treatment, as well as patients' physical functioning and mental health and wellbeing<sup>50</sup>. For example, the psychologists in the RMH COVID Recovery Clinic team are currently gathering quantitative evidence about the prevalence, and extent of, various mental health and cognitive symptoms and how these might change over time. Data is currently collected at both intake and end of treatment time points, and plans are underway for longer-term (e.g., 6-month post treatment) follow-up data collection. Data on depression and anxiety symptoms, functional cognitive self-report abilities and patient's confidence in the use of cognitive strategies is also being collected. The aim is for this data to add to the currently small

evidence base that is available on psychological and cognitive recovery in long COVID sufferers, and the efficacy of interventions being utilised.

## 4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections

A recent meta-analysis of data from studies that followed COVID-infected patients between 3 to 6 months after symptom onset identified that many experienced reductions in functional capacity (36%) and quality of life (52%) associated with the physical and cognitive symptoms of long COVID<sup>51</sup>. Lived experience reports and emerging research data have provided more detailed insights into the key functional and quality of life impacts of long COVID symptoms for individuals, families and communities – as summarised below and in the response to TOR 1.

### Activities of daily living and self-care

Long COVID can significantly impact people's day-to-day life and functioning, making it a struggle for individuals to fulfil their normal everyday activities and responsibilities. For people with severe symptoms, long COVID is disabling<sup>7</sup>.

Sufferers report high levels of fatigue and respiratory issues that drastically reduce physical activity and which impacts on activities such as housework and gardening, domestic roles such as caring duties, self-care and engagement in long COVID treatment<sup>7,52</sup>. People experiencing the disabling effects of long COVID report having to severely ration their energy and activities to those needs of the highest priority, or if they push beyond this they risk a 'crash' or relapse requiring extended periods of recovery<sup>4,52-55</sup>.

### Employment

As identified in the response to TOR 1, the psychologists working in the RMH COVID Recovery Clinic have expressed concern about the high level of functional impact on patients' employment. Many long COVID sufferers can still work, but not at the same level as prior to COVID infections and they fear no longer being able to meet expectations at work and potential workers' compensation/employment implications. Patients indicate a lack of workplace systems, capacity or support for job role adaptations in their workplace that would assist them to maintain employment such as changed responsibilities (e.g., less seniority), adjusted pace/volume of work or working flexibly or part-time. Patients state that they are scared to ask for adjustments for fear of jeopardising their employment.

Thus, maintaining employment and income may be very difficult for long COVID sufferers due to the considerable impacts of fatigue, neurocognitive symptoms (e.g., executive function, attention, memory and language) and psychological and mental health difficulties associated with long COVID<sup>3,56-58</sup>. A recent meta-analysis identified that 2 in 10 people with long COVID experienced work impairment or had failed to return to work 3-6 months after infection<sup>51</sup>, while another survey found that employment was impacted by long COVID for two in three people<sup>59</sup>. Those who do return to work have reported concerns about reduced performance, anxieties about making mistakes and in some cases require more monitoring and checking of their work or changing to less senior roles<sup>56</sup>.

In the worst-case scenario, reduced performance because of long COVID symptoms could lead to job loss and loss of income<sup>6</sup>. Recent data indicates that those with long COVID symptoms extending beyond one month are 7% less likely to be employed compared to those who have experienced COVID symptoms for less than one month - while this does not establish a causal link

between long-COVID and job loss the size of correlation is large and warrants further investigation<sup>60,61</sup>.

### **Stigma, social isolation and loneliness**

Lived experience reports and research studies highlight the sense of self-stigma, social isolation and loneliness that people with long COVID feel<sup>56,57</sup>. These feelings are associated with a number of aspects including not being believed about their illness or discredited or dismissed by health professionals, employers, family and friends (medical gaslighting), guilt or shame about not returning to their previous levels of day-to-day functioning at home or at work, and an inability to connect with family and friends and be part of the broader community due to the disabling nature of long COVID symptoms<sup>55,56,58,62</sup>.

Health-related stigma is a known barrier to health seeking behaviour, engagement in care and treatment adherence<sup>63,64</sup>. Further, health-related stigma intersects with other aspects of inequality and social marginalisation such as social-economic status, co-morbidity and disability with complex impacts for individuals including exclusion and discrimination by others<sup>10</sup>.

Social isolation and loneliness are worldwide public health issues that significantly contribute to health system costs due to the detrimental impacts on health and wellbeing and reduced productivity and functioning in daily life<sup>65</sup>. Specifically, social isolation and loneliness are associated with an increased risk of mental conditions and physical ill-health, including depression, anxiety, paranoia and suicidality<sup>66</sup>, poorer cardiovascular health, coronary heart disease and stroke<sup>67</sup>, and mortality risk<sup>68,69</sup>.

### **Family, friends and relationships**

Given the impacts of long COVID on employment and in some cases the inability to take care of oneself and a household, people with long COVID are relying on friends, family, and partners for a range of supports (e.g., financial, domestic activities, caring for children, supporting long COVID treatments and rehabilitation)<sup>3</sup>.

People who have stepped into these informal care-giving roles, particularly intimate partners, have noted that they can sustain the added caring, financial and other responsibilities for a period of time, but are concerned that situations may persist longer-term and will add pressure and burden on these relationships<sup>7</sup>. The relapsing and remitting nature of long COVID can also be challenging for friends, families and partners given the uncertainty surrounding when a full recovery can be expected<sup>58</sup>. Frustration may occur when the person with long COVID cancels social or other commitments. Research has shown that people with chronic illness like long COVID experience shrinking social circles<sup>55</sup>.

In Australia, there are already more than 2.5 million Australians (i.e., 10%) who are informal carers<sup>70</sup>. Caring can be stressful and impact physical and mental health<sup>71,72</sup>. Fifty-five percent of carers report low wellbeing compared to 20% of the broader population, or in other words, carers are 2.5 times more likely to experience poorer wellbeing than non-carers<sup>73</sup>. In a recent Australian carers survey, most people reported experiencing many challenges related to their informal carer role: 67% feared for the future of the people they cared for; 64% did not usually have time for themselves, over 40% experienced negative health impacts and relationships, and only 19% of carers were able to easily organise someone to help them in their carer role if they are unwell or need a break<sup>73</sup>. Carers are also at a higher risk of experiencing social isolation, loneliness and stigma<sup>74</sup>.

### **Impacts on productivity and the economy**

Long-COVID is already significantly impacting employment and productivity. In the United States it has been estimated that long COVID reduced the workforce by 1.6 million full time workers in the first 20 months of the pandemic<sup>75</sup>. Mid-year Treasury data showed Australia lost 3 million working

days in the first half of 2022 and that 31,000 workers a day, or 12%, were calling in sick in June 2022 because of long COVID<sup>60</sup>. Analysis by Impact Economics and Policy based on Treasury's figures has estimated that long COVID is costing the national economy \$100 million a week and up to \$5 billion a year<sup>60</sup>.

## 5. The impact of long COVID and/or repeated COVID infections on Australia's overall health system...

We have not specifically addressed this TOR as other organisations are better placed to provide a response. Comments relevant to TOR 5 have been integrated into other sections.

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

### Best practice models for prevention, diagnosis and treatment

As noted in TOR 2, there are challenges for health professionals due to a lack of evidence informed standard protocols for prevention, diagnosis and treatment of long COVID<sup>76</sup>. However, best practice responses for long COVID prevention, diagnosis and treatment are emerging based on research and practice-based evidence as has been demonstrated throughout our response to the previous TOR. As summarised below, the indications at this time are that long COVID care needs to encompass the following elements and approaches:

- **Individualised, person-centred, holistic care**

The person experiencing long COVID must be at the centre of their care and be empowered to partner with health professionals to take an active role in the assessment and treatment of long COVID.

As noted in the responses to earlier TOR 1, long COVID patients have experienced not being believed about the impact of their symptoms or considered to be 'malingering'<sup>3,4</sup>. Thus, first and foremost health professionals must provide holistic relationship based care, hear the patient's story and validate their experience<sup>76</sup>. Practitioners can also encourage self-management and support self-advocacy at work or home to help patients maintain personal and professional roles while managing the impacts of long COVID<sup>46,76</sup>.

- **Co-ordinated multidisciplinary prevention, diagnosis and treatment**

Given the variety of symptoms in people presenting with long COVID, as we reported in the response to the earlier TOR 3, there is a need to ensure they have access effective coordinated multidisciplinary team care models<sup>46</sup>. Multi-disciplinary team care for long COVID needs to include physical, neurocognitive and mental health specialists who adopt a biopsychosocial person-centred perspective that recognises the interface between physical, psychological and cognitive symptoms<sup>77</sup>.

Accessible and effective multidisciplinary care will require much stronger links and co-ordination between primary and allied health care<sup>76</sup>. Straightforward and timely referral pathways from general practitioners to allied health professionals are required for initial multidisciplinary assessment to inform diagnosis and treatment planning and the delivery of expert care and treatment.

- **Prevention and early intervention**

Drawing on prevention and early intervention science, investing early in a disease process can help to prevent more complex presentations and longer-term disability which can have devastating impacts for individuals and families<sup>78</sup>. Once symptoms and impacts are entrenched, including resulting patterns of behaviour, these can be harder to remediate through intervention. Psychologists in the RMH COVID Recovery Clinic have noticed that patients presenting with the longest duration of long COVID symptoms, appear to have more entrenched issues with their mental health and functional cognitive difficulties.

As previously identified, there is no one test for long COVID and differential diagnosis processes can be lengthy, at least 6-12 months, to rule out other conditions before a long COVID diagnosis can be made<sup>46</sup>. Treatment and support should be available to long COVID patients as early as possible in their experience of physical, psychological and neurocognitive symptoms and functional, psychosocial and other impacts. Patients should not have to wait until they have a definitive diagnosis which risks further compounding of symptoms and the impacts for themselves and their family<sup>46</sup>.

- **Flexible, longer-term models of treatment and support**

As we have indicated throughout this response, treatment success for long COVID may mean full recovery for some but for others successful treatment may involve a reduction in the experience and impact of symptoms, improvements in psychosocial connection, and adjustment to functioning according to new level of capacity. Based on experience to date, reaching these treatment milestones may take months or even years, not weeks. More research is needed to determine what support is necessary throughout the life course.

Telehealth expansion during the COVID pandemic has benefitted the Australian community by increasing access to healthcare. Given that people with long COVID may experience difficulties attending in person appointments due to the nature of the physical, psychological and neurocognitive symptoms of long COVID, telehealth will be a critical factor to enable them access to treatment and support. Models of access to care, will however need to be flexible to meet the needs of the person with long COVID<sup>8</sup>. Health professionals, in consultation with their patients, are well positioned to determine the most appropriate mode of delivery for psychological services delivery, whether that be in-person or via telehealth<sup>79</sup>.

- **Social support services for patients with long COVID and their families**

As identified, long COVID can have significant impacts on employment and the ability to self-care and support oneself financially, practically and emotionally. There are also the added costs associated with accessing diagnosis, preventive care and treatment. People with long COVID will need access to social services and support, in addition to access to treatments for symptoms. Psychosocial and social services support should also be easily accessible to friends, family, and partners who provide care for long COVID sufferers. Currently, however, some long COVID patients and their families are struggling to access social and financial support through existing channels (e.g., disability support pension, Workcover) due to ineligibility.

### **Psychological treatment approaches for long COVID**

Psychologists have a critical role in providing support to patients to adapt to and manage long COVID symptoms and impacts. As noted in the response to TOR 3, data collection is underway to evaluate the efficacy of the RMH COVID Recovery Clinic clinical psychology and neuropsychology services for long COVID sufferers. Their work aligns with broader evidence informed practice for psychological care and offers some early practice-based insights into long COVID psychological care<sup>77</sup>. In the context of a comprehensive allied health assessment followed by individual psychological assessment and treatment planning, they utilise telehealth and face to face

approaches to provide a range of psychological treatments (e.g., psychoeducation, psychological therapies), including trauma-informed care.

At this stage, the following approaches have been identified as effective when providing psychological and neuropsychological care to long COVID sufferers: working towards acceptance and understanding, building clients confidence and skills to manage their situation, implementing strategies to assist with managing the symptoms and functional impacts of COVID (e.g., attention and memory strategies, pacing and building in and/or being accepting of taking breaks, fatigue management) and present-centred therapy that focuses on increasing adaptive responses to current life circumstances and stressors.

Given the chronic, longer-term nature of long COVID, and evidence pertaining to other chronic diseases such as chronic fatigue syndrome, there is concern that short-term, single-point-in time psychological therapy may be of limited value for patients with long COVID. As previously noted, more evidenced-based practice and practice-based evidence specific to long COVID is urgently needed to investigate this and identify gold standard psychological treatments for long COVID that incorporate trauma-informed care and culturally appropriate practices<sup>80</sup>.

### **System drivers for the delivery of best practice models for prevention, diagnosis and treatment of long COVID**

Implementing the identified best practice approaches to prevention, diagnosis and treatment will require government and health system enablers to be in place over the long-term, ideally taking an intersectionality approach. For example:

- **Develop a comprehensive national approach for long COVID prevention, diagnosis and treatment**

Best practice models of care for long COVID, as identified above, require longer-term, multidisciplinary approaches to treatment and support, and the funding to match. The longer-term trajectory for people suffering long COVID is yet to be established but the potential for enduring/relapsing/remitting symptoms and associated functional impairment needs to be considered.

There is also a need to protect future funding and resources for long COVID prevention, diagnosis and treatment into the future. Currently, long COVID is topical and has the interest of the current government. However, without a national approach to long COVID that secures long term funding for research and implementation of high-quality long COVID prevention, diagnosis and treatment there is a risk that community sentiment, stigma and competing funding agendas may lead to the view that long COVID sufferers are no longer worthy of funding resources.

A national long COVID plan seems crucial for planning, monitoring and tracking prevention, diagnosis and treatment. Such frameworks are recognised as important elements of health-care improvement. The AIHW National Centre for Monitoring Chronic Conditions (NCMCC) currently oversees the 'bigger picture' for 10 chronic conditions in Australia by routinely tracking and reporting on these diseases via the *National Strategic Framework for Chronic Conditions: Reporting Framework*<sup>81</sup>.

We recommend that consideration be given to incorporating long COVID into this framework or developing a separate national long COVID framework as appropriate. This would enable the collection and analysis of the data needed to inform future funding decisions.

- **Fund universal access to high-quality diagnosis, prevention and treatment**

As previously noted, many people with long COVID are struggling to access treatment. There are only a small number of funded long COVID treatment clinics and these tend to be concentrated in metropolitan areas with long wait times, or are accessible only after definitive diagnosis<sup>46,82-84</sup>.

Alternatively, people with long COVID may be eligible for Medicare-subsidised multidisciplinary care in the community via the Chronic Disease Management (CDM) items initiated by GP Management Plan.

However, the number and length of these sessions (5 x 20 minute sessions per year) is inadequate to provide effective, evidence informed multi-disciplinary allied health treatment for long COVID given the complexity of needs<sup>85</sup>. The CDM items are also limited at present with regard to providing a mechanism for allied health professionals to provide expert inputs into diagnosis and treatment planning and ongoing monitoring and tracking of long COVID treatment.

CDM items are generally inappropriate for psychological service provision which typically requires 50-60 minute sessions and more than the five sessions per calendar year for sufficient treatment dosage.

Revising the CDM and Better Access initiatives to enable the provision of evidenced-informed practice and care at the correct dosage is essential to provide high quality care for those with long COVID. This is especially important for rural and regional Australians who may be less likely to have access to centralised long COVID clinics.

Without adequate treatment and support, people experiencing long COVID may continue down a chronic disease trajectory unabated. In turn, this has the capacity to lead to increased demand for more expensive hospital care, with flow-on effects likely to be an increase in the overall burden on the healthcare system. As previously discussed, more research is needed to understand the trajectory of this condition.

- **Grow and support the health professional workforce**

As an emerging field of study, up to date educational resources and ongoing training for health professionals, including GPs, psychologists and allied health professionals, are essential to ensure practitioners remain current regarding high quality, effective care for people with long COVID<sup>46</sup>. Psychologists can also play a role in educating medical professionals on the potential post-treatment cognitive and emotional symptoms and the role of psychological treatments<sup>77</sup>.

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