

HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH, AGED CARE AND SPORT: ***INQUIRY INTO LONG COVID AND REPEATED COVID INFECTIONS***

Issues Paper

The House of Representatives Standing Committee on Health, Aged Care and Sport is undertaking an inquiry into long COVID and repeated COVID infections.

This issues paper first sets out its purpose and the inquiry's terms of reference. Next, it provides a statement summarising the Committee's preliminary insights and considerations. The paper then identifies some emerging themes, and finally outlines the Committee's next steps.

Purpose

The purpose of this issues paper is two-fold. First, given the significant public interest in this inquiry, it provides interested parties with an update on the Committee's inquiry to date. Second, it aims to identify some of the issues and themes emerging from the Committee's preliminary investigations and to highlight gaps and areas that the Committee intends to examine during upcoming public hearings.

This issues paper does not replace the Terms of Reference. It is not intended to give prominence to some ideas or issues over others and it does not exhaustively cover all issues raised in the evidence before the Committee. This issues paper is not the Committee's final report.

Terms of Reference

The Committee's remit (its terms of reference) is to inquire into and report on:

1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;
2. The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;
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;
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;
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
6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

Committee statement

The Committee wishes to first recognise that the symptoms of long COVID are real and are being experienced by many Australians. The Committee acknowledges every individual who is experiencing long COVID or being otherwise impacted by long COVID. In particular, the Committee would like to thank all the individuals who, despite being personally impacted by long COVID, have gone to considerable effort to contribute to this inquiry.

In general, media attention has focused on the acute phase of COVID. This is understandable because of the huge impact the COVID pandemic has had on individuals, not least in terms of increased deaths (i.e. excess mortality). COVID has placed a significant strain on communities through lockdowns and other public health measures, and healthcare systems around the country have faced unprecedented challenges. While media coverage now often discusses ‘the new normal’ environment with fewer public health measures, for some members of the community COVID remains an enduring feature of their lives: these are the Australians impacted by long COVID.

With growing concern, the Committee has heard from hundreds of Australians about the impacts of long COVID at an individual level. These include symptoms impacting individuals’ physical and mental health, reduced or lost capacity to work, financial strain, difficulty performing daily living activities such as cooking or caring for children, and social isolation. The Committee has also heard of broader potential impacts such as the increase in global mortality rates that some hypothesise may be associated with long COVID, although the cause of this is unclear.

In addition, the Committee has heard from many individuals about their experiences regarding repeated COVID infections, the second, related focus of this inquiry. The Committee is similarly concerned about the potential impacts of long COVID and repeated COVID infections on Australia’s economy, including through lost productivity, in addition to the impacts on individuals. The Committee believes that long COVID and post-COVID complications are issues for both the Australian health system and its economy. Based on information received to date, the Committee anticipates that the greatest burden of care relating to long COVID and repeated COVID infections will fall on primary care providers, entry level services to the health system such as those provided by general practitioners (GPs).

The Committee notes that, based on anecdotal evidence received to date, the number of people with long COVID in Australia seems to be somewhat low compared to other countries. However, the Committee also notes that, for reasons including Australia’s federated system of government, funding limitations, and inconsistent types of data being collected, there is a lack of official, consistent data regarding long COVID in Australia, so the picture is unclear. The apparently lower prevalence of long COVID at this time may also reflect the fact that Australia experienced its more significant waves of infection later than the US, Europe, etc., and may not have seen the full scope of the after-effects of this condition.

The fact that Australia does not have a nationally consistent definition of long COVID is a related challenge, as this makes it difficult for data arising from different studies and segments of the population to be accurately collated and analysed. The Committee notes that long COVID seems to potentially involve symptoms being present at least 3 months after someone is infected with COVID, and notes that while symptoms vary between individuals, common symptoms include lethargy, myalgia, shortness of breath, cognitive impacts such as difficulty concentrating or memory problems, and lack of exercise tolerance.

Given that long COVID and repeated COVID infections are likely challenges which will confront Australia for the immediately foreseeable future, the Committee considers that this national inquiry is timely and of critical importance and will continue to progress this inquiry as a top priority.

Emerging themes

The following are key themes that have arisen from the submissions the Committee has received, and the first public hearing which was held on 12 October 2022.

Definitional framework

The Committee has heard that the lack of a clear, established and nationally consistent definition of long COVID in Australia poses problems for patients, healthcare professionals, researchers, and public policy makers. It is understood that part of the challenge in determining a suitable definition is the wide variety of symptoms associated with long COVID.

The Committee notes that some of the evidence gathered to date indicates that long COVID involves ongoing symptoms more than 3 months after a confirmed COVID infection. Additionally, it observes that based on current information, what is commonly described as ‘long COVID’ in the media may, in fact, comprise three potentially overlapping groups, that is, those people experiencing:

1. health complications after a COVID infection;
2. ongoing symptoms such as lethargy and brain fog after a COVID infection, which would be considered a post-viral syndrome; and
3. mental illness or mental health conditions after a COVID infection.

Expanding on point 1 above, the Committee notes anecdotal reports that long COVID may be associated with health complications such as strokes and stillbirths. The Committee has also received evidence indicating that there may be a link between long COVID and increased risk of the development of diseases and medical conditions such as diabetes or heart disease.

The Committee will continue to collect evidence to better understand long COVID, and to explore potential definitions of long COVID.

While Australia does not have a nationally consistent definition of long COVID, the Committee considers in the interim the World Health Organization’s (WHO) following clinical case definition of long COVID (referred to as ‘Post COVID-19 condition’) should be used:

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.¹

¹ World Health Organisation, www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1 viewed 1 December 2022.

Data and information

Another major theme raised by many contributors to the inquiry is the limited reliable and consistent data available in Australia regarding long COVID. This is a significant challenge because ideally, analysis based upon valid and reliable data sources provides an evidence base both to inform and evaluate public policy.

The limited data regarding long COVID in Australia seems to be in large part attributable to differences between how Australian states and territories collect relevant data, limitations on sharing data, unintentional siloes of information existing in the healthcare system, and privacy concerns about the sharing of health data. Many of these are long-term challenges that predate the COVID pandemic. Furthermore, the Committee has heard that some of the datasets available may not provide an accurate representation of the general Australian population. For instance, there may be an underrepresentation of people with long COVID who are from culturally and linguistically diverse backgrounds or Indigenous. This may limit the extent to which some datasets can be used to extrapolate to the broader Australian context.

Given the limited available data currently available in Australia, data from other countries regarding long COVID infections and/or repeated COVID infections may offer some insights. However, some stakeholders have expressed reservations about the extent to which findings based upon foreign data can be appropriately applied to the Australian context.

This is because Australia's experience of COVID is distinct from other countries: most Australians were vaccinated when they first contracted COVID, and most Australians were initially infected with the Omicron strain of the virus.

Some stakeholders have called for greater investment in data collection and research to address some of these issues. Others have noted that there may be a potential role for a centralised body in coordinating research work relating to long COVID and repeated COVID infections, to ensure new research is complementary. The Committee is interested to investigate these and other perspectives and ideas in greater detail and suggests that a national COVID database that includes data relating specifically to long COVID, and a dedicated national focus on data collection, may be required.

Emerging evidence

Possible causes, management, and treatment of long COVID

Illnesses can be treated more precisely if their causes are understood. Unfortunately, at the current time the cause or causes of long COVID are unknown. The Committee has heard multiple theories regarding the cause of long COVID, including that it may be an auto-immune disease triggered by COVID infection, or reactivation of a dormant virus such as the Epstein-Barr virus. There is apparent significant overlap between long COVID and some other chronic health conditions, such as chronic fatigue syndrome, however the nature of any relationship between long COVID and other chronic health conditions remains unclear.

The Committee has heard about different approaches to managing long COVID, including through GPs, specialist long COVID clinics, and via multidisciplinary approaches involving allied health services. The Committee sees that primary care will play an important and central role in supporting people with long COVID.

However, some submitters have reported challenges seeking help from GPs, partly due to limited GP knowledge and/or acceptance of long COVID as a condition, or lack of access to a GP in a timely manner.

There is currently a lack of consistency in relation to the long COVID clinics between how they operate including the referral processes, how they are funded, the services they provide, and their existence and accessibility across Australia. There also appears to be ambiguity as to whether and/or how these should be integrated into the healthcare system.

Reducing the risk of developing long COVID

In addition to supporting those who already have long COVID, another emerging theme is possible ways to prevent or mitigate the risk of individuals developing long COVID in the future. The best protection against long COVID is to avoid getting infected with COVID. Preventative strategies such as mask wearing, social distancing, workplace ventilation etc., by preventing COVID, are the best way to prevent long COVID.

The Committee has received some evidence that COVID vaccinations may reduce the risk of long COVID. Proponents call for greater government action to encourage vaccination and booster shots for this purpose.

Another theme emerging from the evidence is the potential role of COVID anti-viral medicines (medicines that help stop a virus infecting healthy cells or multiplying in the body) in reducing the risk of long COVID. There is preliminary but inconclusive evidence emerging around the effectiveness of antiviral medicines for treating COVID, and their potential flow-on effect to reduce long COVID.

The Committee also notes that it has received minimal evidence to date around the potential role of ventilation strategies in reducing the risk of long COVID.

Next steps

Parliamentary committee inquiries follow a standard process, set out in Figure 1. The Committee is currently in its evidence gathering phase for this inquiry. Submissions closed on 18 November 2022, and the Committee thanks all members of the public and organisations that made submissions.



Figure 1: Process for parliamentary committee inquiries

Over the next period, the Committee will hold multiple public hearings to receive oral evidence from a range of stakeholders including individuals with long COVID or loved ones of people with long COVID, researchers, peak bodies, and governments.

Please note that it is up to the Committee to decide who to invite to appear at a public hearing. If the Committee invites you to appear at a public hearing, the secretariat will contact you to provide the necessary information. In the upcoming public hearings, the Committee wishes to explore several questions, including the following.

Questions to investigate in upcoming public hearings

- What should an Australian definition of long COVID include, and what are key considerations in developing a definition?
- How can Australia improve its data collection regarding long COVID and/or repeated COVID infections, either in the short, medium, or long-term, including regarding its prevalence, severity, course, and response to treatment?
- How could Australia boost research into long COVID and/or repeated COVID infections, and how could this be done in a cost-effective manner and to maximise the impact?
 - o How can the government ensure that culturally and linguistically diverse and Indigenous patient experiences form part of this research?
- What are some cost-effective strategies to support individuals and families impacted by long COVID?
- What role should primary, secondary, and tertiary health care play in relation to long COVID?
 - o Depending on this, how can the government support these healthcare providers to better help patients with long COVID?
- What is the evidence for best practice management of long COVID?

Once the Committee has gathered sufficient evidence, it will consider the written and oral material it has received and draw conclusions that will be published in a report. In this way, the final report will be informed by broad consultation.

In its final report the Committee will make recommendations to the Australian Government. Sometime after the Committee's final report has been presented in Parliament, the Australian Government will generally make a formal written response to any recommendations in the Committee's report.

Contact information

If you have any queries in relation to this issues paper or the committee's inquiry process, please contact the secretariat:

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