# "Sick and tired" of waiting for a government response to the Long Covid Inquiry

## **Background**

The Health Minister Mark Butler MP referred the Federal Health Committee to inquire into and report on Long COVID and Repeated COVID infections. On 24 April 2023 the Committee published its report "Sick and Tired: Casting a Long Shadow," which included nine unanimous recommendations. Apart from an initial announcement of funding for Long COVID research from the Medical Research Future Fund, there has been, to date, no government response to the Health Committee's recommendations.

The Long COVID and Repeated COVID Infections Inquiry is a key pandemic health response measure, with its report aiming to improve Australia's response to Long COVID. Long COVID was identified by the Australian Government as a central focus area for Australia's COVID-19 response (alongside COVID-19 vaccines and treatments) in its National COVID-19 Health Management Plan for 2023. This plan emphasised the need to investigate the longer-term effects of the COVID-19 pandemic in Australia<sup>1</sup>.

The Health Committee was an appropriately qualified group to task with both investigating the impact of Long COVID/repeated COVID infections, and providing recommendations to the Health Minister so Australia can best address this chronic phase of the ongoing pandemic. It is a worthwhile exercise to evaluate this response so that the effectiveness of future pandemic Inquiries can be maximised.

#### **Positives**

## Health committee appointments

The appointments to the House Standing Committee on Health, Aged Care and Sport were exemplary and exceedingly well suited for this pandemic inquiry. The Health Committee was no group of career politicians in a Canberra bubble – it was populated by esteemed doctors with extensive experience in health and medical fields, eminently qualified to advise the government on how to deal with a complicated challenge such as Long COVID. The committee included

The Inquiry was

in good hands: it was conducted in good faith, in a timely manner, and took a strong evidence-based approach.

### High level participation

There was an unprecedented and highly significant response to the Long COVID and Repeated COVID infections Inquiry. The Inquiry received 566 submissions from a wide range of sources; these included world class experts, organisations, government bodies and a substantial number of Australian citizens, many of whom were patients grappling with Long COVID. It is testament to the importance of sharing their painful lived experience that this cohort of patients living with Long COVID and experiencing debilitating fatigue, pain and symptoms, nonetheless went to considerable effort to contribute invaluable submissions.

The Health Committee conducted four public hearings and round table discussions, hearing from and questioning a wide array of speakers; these included doctors, people living with Long COVID, an epidemiologist, an aerosol scientist, a world-renowned air quality expert, a schoolteacher representative, a well-respected microbiologist, and a phenomics expert. Indeed, the evidence given in the Inquiry's public hearings attracted global interest. In its report the Committee expressed its appreciation of "the strong public engagement in this inquiry, including from many individuals that have not participated in House of Representatives parliamentary committee inquiries previously".

# Comprehensive report

As promised, the delivered report was a "good, informative framework for the future". As well as a comprehensive resource covering definitions, it covered: research (both current and future); improvements to data collection; lived experience of Long COVID; tools to prevent Long COVID (including vaccines, antiviral treatments and measures to improve indoor air quality); healthcare response to Long COVID including diagnosis, treatment and management; and education and training of Australia's health workforce.

High quality, evidence-based, proportionate recommendations

The report's comprehensive recommendations included: data collection; research; vaccine communication; expanded eligibility for antiviral treatments; support and education for GPs (in areas of diagnosis/management of Long COVID, mental health and digital health resources); Indoor Air Quality Standards; funding for ME/CFS research and patient support; and a COVID summit<sup>3</sup>.

#### Negative

Significant delay in government action

As I submit this, it is approximately 280 days since Health Minister Butler received the Inquiry recommendations and there still has been no government response, despite assurances it would be tabled before the end of 2023. It is entirely unacceptable in a Long COVID public health crisis, growing by the day, that the government has not responded to the timely and high-quality advice of its Health Committee.

Since these recommendations were handed to the government, Australia has experienced two further significant waves with no action on any of the important and helpful recommendations. No action on expanding eligibility of antivirals or better vaccine communications, no data collection, no progress on IAQ, no education for GPs on how to diagnose Long COVID. It is likely that hundreds of thousands of Australians have been chronically disabled by Long COVID since Minister Butler received the advice. It is nothing short of a Public Health failure to have failed to act in a timely manner.

Indeed, the Australian public has taken more action than Minister Butler has, with a petition calling for the "Urgent Implementation of all Recommendations of the Long COVID Inquiry"<sup>2</sup>. Organised by the petition received nearly 7,500 signatures within the first two weeks of its launch. To illustrate the ongoing impacts of Long COVID on Australians, I have included below just a handful of the comments posted by those signing the petition.

#### Conclusion

The Federal Inquiry into Long COVID and Repeated COVID Infections was overseen by a high calibre committee delving into the complexities of the condition, consulting experts and patients, and providing credible, evidence-based recommendations formed through a comprehensive understanding of the issues. It was imperative that the government act swiftly to implement. Delaying implementation by nine months (and counting), especially in the face of subsequent waves of COVID and a growing number of Australians disabled, has only amplified the urgency. Each passing day without action exacerbates the impact on affected individuals and strains an already overburdened healthcare system.

Implementing the recommendations promptly would have demonstrated a commitment to public health, prioritising the well-being of Australian citizens. A timely response could have been pivotal in mitigating the long-term consequences of the pandemic on individuals, the healthcare system, the broader community and the economy.

It is deeply concerning that the recommendations continue to languish when they demand immediate attention. It undermines the purpose of seeking expert recommendations, means missed opportunities for timely interventions, and reflects a disregard for public health. Furthermore, such inaction undermines public trust, hinders effective policymaking and prolongs the suffering of those affected by Long COVID. It is important for future governments to recognise that pandemic inquiries regarding current challenges must be expedited and actioned urgently to safeguard public health. Thank you for the opportunity to submit to the Covid Response Inquiry.

# **Petition Comments**

- Implementation of the inquiry recommendations is long overdue. Meanwhile those of us with long COVID are suffering and feeling ignored and unsupported.
- As a person living with long Covid, who had other pre-existing medical conditions, I am appalled at the lack of medical help available. God help us if another deadly pandemic occurs as we have learnt nothing from this current one.
- I need the government to get serious about long Covid. The economy will tank with too many off forever sick.
- Very concerned about the lack of action on this when it is clear, there are severe health risks associated with long Covid. The health costs will be enormous, if it continues to be ignored, as well as a tragic cost to human health and happiness.
- Ignoring these recommendations is actively inflicting harm on Australians.
- I have long Covid. I am isolated, lonely and nervous for the future of wave after wave. We need help and support.
- There is an urgent need for a national plan.
- I have long Covid and I'm sick of having to fight for treatments and understanding from most of the medical fraternity.

- If recommendations are not carried out in full, this will end in great cost for the Australian government and citizens.
- Long Covid has the potential to cripple Australia economically, socially, culturally, and will also impact adversely on people's health and well-being.
- The recommendations make sense and implementing them is possible in this country.
- These recommendations should be a mandatory minimum effort to combat the continuing long Covid emergency.
- I have long Covid, and I feel more or less abandoned by the government and the medical profession. We need action and more resources devoted to long Covid.
- Enacting the recommendations will save the economy by improving health outcomes and preventing workforce dropout.
- Something needs to be done at a structural level to deal with Covid. Individual responsibility does not work.
- This is a national issue which needs national action.
- Long Covid is an urgent and severe problem. It deserves the highest priority from the Health Minister.
- The Australian government is dropping the ball on protecting the public from severe health outcomes of long Covid.
- Ignoring the recommendations risks our health and economic stability. Swift action is crucial for the well-being of all Australians, making the inquiry's findings not just valuable insights but essential directives.
- Well, we shouldn't need a petition to remind the minister to do his job. But here we are.
- I have been disabled by long Covid, and this will continue to be the fate of many others, unless our government takes these necessary steps.
- Implementing the recommendations of the long Covid enquiry is the very least this government should be doing to support people through the harm they are suffering.
- This report has been gathering dust on Mr Butler's desk for far too long. More people are acquiring long Covid every day, and they need urgent support. Ignoring this problem will not make it go away.
- This is so far past overdue those with Long COVID, the experts, and the health committee did great work, the
  recommendations are solid and much needed. Minister Butler needs to stop sitting on them and take urgent
  action to implement them all. Anything less is negligence.

#### References

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