Submission to the Department of Prime Minister and Cabinet Commonwealth Government COVID-19 Response Inquiry

Associate Professor Danielle Hitch PhD
Faculty of Health, Deakin University & Allied Health Division, Western Health

Introduction

Thank you for the opportunity to contribute a submission to this Inquiry and share the findings of our ongoing research into the impacts of the COVID-19 pandemic to improve response measures for future pandemics. I lead the Western Health COVID-19 Recovery Collaboration (WHCOVRE), and this submission incorporates co-researchers contributions from academia, clinical practice, and lived experience.

In late 2020, a group of clinician researchers at Western Health became increasingly aware of patients presenting with prolonged symptoms following COVID-19 infection. They initiated an informal multidisciplinary network of clinicians, researchers, and people with lived experience to investigate this new syndrome (later known as Long COVID) and develop guidance on best supporting these patients. The group evolved into the Western Health COVID-19 Recovery Collaboration (WHCOVRE), now including members from multiple institutions and diverse backgrounds. WHCOVRE has been an extraordinarily responsive and productive collaboration and continues to work closely with lived experience experts in its ongoing research program.

Key Messages & Recommendations

All Terms of Reference

Recommendation 1: A shared vision for Australia's response to future pandemics.

- **A shared vision would have multiple and significant benefits for Australia.** A shared vision will ensure that all levels of government and local communities work towards a common goal and reduce inconsistent strategies that lead to confusion, ineffective measures, and increased transmission risk. A coherent national approach will enable more efficient resource allocation and build community trust and investment in public health measures. The vision and goals will also provide a framework for more flexible responses as community needs change and evolve, which balances public health needs with economic activity and productivity.
- **The success of the vision and goals depends on their inclusiveness of diverse perspectives, which reflect all facets of modern Australia.** Imposition from the 'top-down' would fail to address a population issue that demands widespread participation and consensus. It would also amplify the social exclusion and health inequities bought so clearly to light during the COVID-19 pandemic.
- **Social determinants of health and other contextual factors on pandemic experiences and outcomes for Australians must be integrated and embedded within vision and goals.** As highlighted in our qualitative study of Long COVID lived experience[1], the impacts of the pandemic extend far beyond the health sector because many have their origins in existing social issues and challenges.

Broader health supports for people impacted by COVID-19 and/or lockdowns.

Recommendation 2: Increased funding for and access to allied health assessment and treatment.

- COVID-19 infection impacts all body systems and structures[2], and **the expertise of multiple allied health professionals is needed for optimal recovery**. For example, our research demonstrates occupational therapy is highly valued by patients receiving rehabilitation following COVID-19 infection for its ability to improve their participation and productivity in daily life[3]. Assessment and treatment by a range of allied health professions is recommended by both Australian[4] and World Health Organisation clinical practice guidelines[5].
- **People recovering from COVID-19 infection are not getting the rehabilitation and support they need to maximise their recovery and return to full function.** Equitable access to allied health professions is a

severe and persistent problem in Australia and is not unique to our pandemic response. Nor are allied health professions limited to working in clinical health settings – many are employed to support workers in other sectors like education, recreation, business, and trades. Medicare and private health insurance rebates are too small to provide professionals with a living wage, and there are extensive waiting lists for public allied health services (particularly in disadvantaged communities). Sustainable funding for the allied health workforce and investment in telehealth services are urgently needed to increase access in all communities.

- **Building a better allied health workforce should be a priority in future pandemic planning.** National allied health workforce shortages result from a need for more appropriately qualified practitioners and insufficient clinical placements[6]. We reiterate our recommendations to the recent Inquiry into Long COVID and Repeated COVID infections regarding the Allied Health Assistant (AHA) workforce. AHAs support allied health professionals by working within a specific scope of practice, including tasks delegated by an allied health clinician and regular supervision. Building a larger AHA workforce enables more efficient use of allied health professionals' expertise and could be achieved relatively quickly via the TAFE system. A strengthened allied health workforce would have widespread and cost-effective benefits for all Australians within and between pandemics.

Recommendation 3: Inclusion of carer needs and support in future pandemic responses.

- **Unpaid carers are the backbone of the Australian economy**, but Deloitte Access Economics[7] identified an increasing and substantial deficit in informal care over the next seven years. The impact of Long COVID and other pandemic challenges has a ripple effect far beyond the infected patient. As described by one of our research participants: *"Just the load on my family, on my husband. He works all day and half the night and half the weekend anyway, and normally travels. But [now] he is my son's primary carer, and he does the shopping and the cooking and he does everything. He's done an amazing job for eight months, but in the last couple of weeks I'm starting to see he's making mistakes"*. There are also many studies demonstrating the impact of the COVID-19 pandemic on unpaid carers for Australians with existing conditions and disabilities (e.g. [8-10]).
- **Women are particularly disadvantaged by a lack of support for carers during pandemics.** Many are 'compound' carers, informal carers with pre-existing caring responsibilities for multiple family members or loved ones[11]. Public health measures led to many Australian women taking on remote learning responsibilities for their children. Given that 76.3% of the Australian healthcare workforce is female[12], they also shouldered much of the formal or paid carer burden of the COVID-19 pandemic.
- **Carers are, therefore, crucial stakeholders in developing future pandemic responses.** Unpaid carers must be invited to co-produce the vision, goals and strategies designed to improve Australia's pandemic response to minimise the widespread impact of these events on the community.

Financial support for individuals

Recommendation 4: Recognition of post viral syndromes as a disability.

- **There is evidence that post viral syndromes can become a long-term disability for some people.** Our research identified that 86% of Australians with Long COVID experience reduced functional capacity and diminished ability to participate in daily life[13]. Many of the lived experience experts who have worked with WHCOVRE continue to experience significant disability almost four years after their COVID-19 infection. Survivors of the 2002-2003 SARS outbreak experienced psychological distress and post-traumatic stress for years after their infection[14], with another study finding only 12.7% had returned to work after 15 years[15]. A recent large COVID-19 study[16] also found that 25% of functional issues and disability for people who were not hospitalised during their acute infection experienced re-emergence of disabling symptoms at two years, indicating a long-term risk horizon for this virus.
- **Uncertainty about symptom duration is a barrier to accessing disability support and protection**. While many people eventually recover, there is a widespread misconception this occurs in all cases. Conditions must be considered permanent before being considered disabilities under the National Disability Insurance Scheme[17]. Therefore, people with post-viral syndromes (like myalgic encephalitis /

chronic fatigue syndrome and Long COVID) rarely qualify for support[18]. The same issue also impacts access to the protections afforded by the Disability Discrimination Act 1992. Without access to existing avenues for disability support, people with post-viral syndrome cannot receive the financial, therapeutic and workplace support they need to return to productive activities and maximise their financial circumstances.

Mechanisms to better target future responses to the needs of populations

Recommendation 5: Shifting from categorical to intersectional, integrated, and personalised approaches.

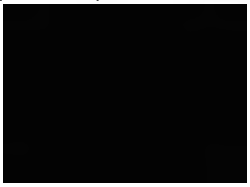
- **Future pandemic responses should include policies and practices that address multiple, overlapping forms of discrimination and disadvantage wherever possible.** A categorical approach to targeting responses for priority populations overlooks the complexities and nuances of individual identity and experiences. Addressing single aspects of identity may also lead to duplication of services and supports, as supports are designed and delivered to meet the needs of a single group. Many challenges and barriers are shared across multiple priority populations.
- **An integrated, intersectional approach is needed to match the complexity of pandemics.** Intersectionality describes how different aspects of a person's identity intersect in complex ways, and how the interconnections between them19 shape individual experiences of discrimination or inequity. As noted in our Perspectives paper for the Medical Journal of Australia[20], pandemic policies and strategies must recognise marginalised populations' multiple and complex disadvantages and co-produce solutions with community members with lived experience. This would require integrating health and social responses (under a shared vision) and embracing the full spectrum of care (including tangible strategies for prevention, early intervention, treatment, and long-term management).
- **A solution that provides personalised support already exists.** In our work at WHCOVRE, Australians with Long COVID have emphasised their desire for personalised care and support time and time again. WHCOVRE developed the COVid reCOVeRY Model of Care (DisCOVeRY-MoC) with six Long COVID consumers in late 2021[21]. The model includes streams for people with mild, moderate, and clinically significant disability arising from their COVID-19 infection and prioritises the use of pre-existing supports in their local community. A specially developed algorithm uses the person's responses to a patient-rated outcome measure (the COVID Check-In) to formulate a written guide for patients and their healthcare providers. This report identifies services and supports that address their unique symptom profile and self-management strategies to help patients maximise their functional abilities. For example, a woman from a culturally and linguistically diverse community would receive gender and culturally-appropriate guidance. To the best of our knowledge, the DisCOVeRY-MoC is the only Long COVID model of care co-designed with consumers, and we aim to make it freely available on the internet by mid-2024.

Conclusion

In conclusion, our research highlights the need for a cohesive, inclusive, and multifaceted approach to improving response measures for future pandemics. We advocate for a shared vision for Australia's pandemic response, increased funding and access to allied health services, action on carer support needs, recognition of post-viral syndromes as a disability, and the development of pandemic responses that recognise the diversity and complexity of lived experience and systemic impacts. We wish the independent panel and task force every success in their work on this vital task.

A/Prof Danielle Hitch

On behalf of WHCOVRE



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