

Australia Long Covid Facebook Support Group Hearing Response Document 1/3

We would like to thank the committee for the opportunity to participate in this process.

We were heartily encouraged by your commitment to understand the challenges and act on your findings. We acknowledge that even if there were a perfect solution, its implementation would be constrained by limited resources.

Before we acquiesce to doing what is possible with what we have, we would like to highlight that around the world healthcare systems designed to treat episodes of acute disease in discrete organs are failing in the face of chronic multisystem diseases. Based on this we recommend to you a sentiment expressed by Professor Martin Hensher, Long Covid 'is an extraordinary opportunity to do something new in this area'.

In what follows we offer two contributions. The first, a set of principles to guide future deliberations regarding our treatment and care. The second, a sketch of a model of care that if it were properly funded could support not only our needs but the needs of all those living in Australia with chronic complex conditions.

1. Principles for developing Long Covid care

1. Acknowledge challenges and act with integrity

Honestly evaluate the scale of the problem and the multi-system impacts it has on patients. A National Register of Long Covid patients and symptom tracking is a logical first step towards that evaluation. Understand that patients are often working caregivers in the prime of their lives. This means that the definition of who is vulnerable must urgently be revised to include women between the ages of 35 and 55. Acting with integrity includes acknowledging that Long Covid is but one of many post viral infection associated diseases. Therefore, it is important that we build on what is known and avoid repeating past mistakes.

2. National standards for managing Covid-19 infection

Act in the best interests of people and the economy. Choosing the economy over the health of the community is a false economy. Set higher standards for Covid infection surveillance, transparent data sharing and risk management that make collective risk management possible. Reinstate Covid on the Communicable Diseases list. In these ways you can enable individuals and the communities they create to make informed choices about managing the risks they are subject to. Ignorance is not a defence and future governments will carry the cost of current inaction, as will those of us with Long Covid and all who are subject to repeat infections.

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3. Living treatment guidelines for Health Professionals

Commit to synthesising and disseminating international best practice and developing local communities of practice that are well integrated into international networks. There is too much to learn, too much to do and too little time for Australia to go it alone. We are not exceptional but SARS-CoV-2 is. This is a time for generous and creative collaboration not petty point-scoring or siloed warfare. If GPs are to be the key providers of care, their education and training in Long Covid is urgent and vital. The lack of knowledge or support at GP level is a common theme in our group and this must be addressed moving forward.

4. Clear health messaging for the public good

Clear consistent public health messaging on the risks of Covid reinfections and risks of Long Covid is needed to encourage better choices around infection risk management. The changing and inconsistent messages around infection mitigation such as masking, social distancing and other mitigation measures have contributed to complacency and rising infection rates.

5. Support for patients while everyone waits for answers

Equitable access to diagnosis, treatment and care with dignity for all in a network of tertiary centres of excellence linked to specialists and GP networks, with patients offered care according to the impact of Long Covid on their ability to carry out basic functions of daily living. Funding for Telehealth, longer consultations, case management, and allied health. Financial support for those unable to work. Access to medicines including antivirals & off book use of existing medicines.

6. Partner with patients in devising solutions

Patients as partners in the co-creation of systems of care is gaining ground around the world. Our participation in this forum is a good start. We look forward to lived experience being included in all aspects of policy development, implementation and review

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2. Proposed Model of Care

National Post Viral Illness/ Long Covid centre of excellence <i>Data standards and collection—synthesis and distribution of international best practice—and coordination of a national research agenda</i>			
PRIMARY CARE	SECONDARY CARE	TERTIARY CARE	INPATIENT CARE
<ul style="list-style-type: none"> Initial diagnosis For those experiencing mild impact on activities of daily living: education (online) and symptom management (in-person GP or practice nurse) For those experiencing moderate impact on activities of daily living: Case management, referrals, rehabilitation by GPs with an interest and expertise in Long Covid For those experiencing significant impact on activities of daily living referral to relevant specialist(s) or a Long Covid clinic 	<ul style="list-style-type: none"> Investigation of significant and ongoing symptoms by relevant specialists Diagnosis and treatment of new conditions falling within the remit of a single speciality Where only one body system is significantly impacted, the associated specialist should assume coordination of care and/or work closely with a GP with an interest in and expertise in Long Covid. 	<ul style="list-style-type: none"> Investigation of complex cases including those with significant and ongoing symptoms impacting more than one system/organ Diagnosis and treatment of complex intersecting syndromes or conditions Coordination of care, including rehabilitation, for those with significant symptom burden and complex needs Engage in nationally coordinated research linking patients to relevant trials 	<ul style="list-style-type: none"> In patient care in regional centres of excellence in Long Covid care for those requiring urgent investigations and treatment in a hospital setting.

For a comprehensive patient-centred model please see, [Greenhalgh T, Sivan M, Delaney B, Evans R, Milne R. Long Covid—an update for primary care BMJ 2022; 378 :e072117 doi:10.1136/bmj-2022-072117](#)