Post-Infection disease: Australia's 10th National Health Priority Area Position Statement

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Summary

Emerge Australia strongly advocates for the Federal Department of Health to make post-infection disease Australia's 10th National Health Priority Area (NHPA). The number of Australians living with post-infection disease is rapidly increasing, predicted to be over half a million by the end of 2022, due to a new cohort of post-infection disease patients: those with Long COVID.[1] Such numbers will increase the already significant burden of post-infection disease on our health system, economy and society.

With very little known about post-infection disease, easy gains can be made with appropriate awareness and resources committed to this disease area. Making post-infection disease Australia's 10th NHPA, at a time when this disease group is rapidly increasing, will result in a significant reduction of disease burden for those already living with post-infection disease, and help to prevent worsening of disease in those showing persistent early symptoms. New data collection mechanisms will inform government about the true numbers of people living with post-infection diseases, and associated health, social, education and economic impacts.

Background

Chronic diseases are the leading cause of illness, disability and death in Australia.[2] There is gathering evidence that infectious diseases are the cause of many chronic illnesses. For example, in addition to the 75% of people with ME/CFS who report an infection-like episode preceding the onset of their illness,[3] recent research suggests multiple sclerosis may be caused by infection, in this case, Epstein Barr virus.[4] There is widespread acknowledgement that more research is urgently needed to fill gaps in our biomedical understanding of post-infection diseases like ME/CFS and MS, their etiology, pathophysiology, diagnosis, treatment and prevention.[5],[6],[7],[8]

Since 1999, the Federal Department of Health has sought to focus public attention and health policy on those areas considered to contribute significantly to the burden of disease in Australia, and for which there is potential for health gain.[9] As a collaborative effort involving Commonwealth, State and Territory governments, nine National Health Priority Areas (NHPAs) have been created: arthritis and musculoskeletal conditions, asthma, cancer control, cardiovascular health, dementia, diabetes mellitus, injury prevention and control, mental health conditions, and obesity.

An early report on the NHPA initiative noted its benefits in *"coordinating and focusing effort in health care research, services and prevention"* and ensuring *"limited health resources are used in accordance with government's priorities."*[10]

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Similarly, non-government organisations argued "the initiative has added weight and credibility to the respective disease groups and has assisted organisations in their requests for funding."[11] The NHPA has also delivered results to patients, although limited within priority populations, especially Indigenous health. For example, in cardiovascular health there has been a decline in smoking rates in adults, coronary heart disease death rates and stroke death rate.[12]

Evidence

Post-infection illness can be triggered by bacteria, viruses and parasites. The acute symptoms of these illnesses, and the organ damage they cause, can be very different. However, the lingering illness following each infection appears to be quite similar, both in symptomatology and underlying biology.[13],[14] The following table provides an overview of unexplained post-infection syndromes associated with documented infections:[15]

Pathogen	Name of post-infection syndrome
Viral pathogens	
SARS-CoV-2	Post-acute sequelae of SARS-CoV-2 infection (PASC) Post-acute COVID-19 syndrome (PACS) Long COVID
Ebola	Post-Ebola syndrome (PES) Post-Ebola virus disease syndrome (PEVDS)
Dengue	Post-dengue fatigue syndrome (PDFS)
Polio	Post-polio syndrome (PPS)
SARS	Post-SARS syndrome (PSS)
Chikungunya	Post-chikungunya chronic inflammatory rheumatism (pCHIK-CIR) Post-chikungunya disease
Epstein Barr Virus	No name
West Nile virus	No name
H1N1/09 influenza[a],[b]	No name
VZV[a],[b]	No name
Non-viral pathogens	
Coxiella burnetii	Q fever fatigue syndrome (QFS)
Borreliac	Post-treatment Lyme disease syndrome (PTLDS)
Giardia lamblia[c],[d]	No name

[a] Limited or very limited evidence base.
[b] Association with increased use of ME/CFS diagnosis in health registry
[c] Contradicting or unclear evidence base
[d] Supporting evidence derives from a single outbreak in Norway

Up to 1% of Australians live with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [16],[17], 75% of whom recount their symptoms starting after an infection. Despite ME/CFS impacting up to 1% of the population, biomedical research has been critically underfunded for decades, in Australia and overseas. The result is a poorly understood disease with no biomarker, nor proven treatments and a disease burden that costs the Australian economy an estimated $14.8 billion annually.[18] Patients continue to experience stigma, discrimination and unsafe management techniques that cause harm.

While COVID-19 is a new illness, post-acute sequelae of SARS-CoV-2 infection, or Long COVID, is most likely the latest post-infection illness in a long history. Current estimates suggest 3% to 11.7% of people who have had COVID-19 will still be experiencing symptoms after 12 weeks[19], and can therefore be classified as having Long COVID.[20]Australia has had an estimated 10million cases, although some of these will be reinfection.[21] This means that as many as 300,000 people may be living with Long COVID already, and this number will continue to grow as COVID continues to spread.

However, these numbers are estimates. There is no data gathering mechanism currently in place to confirm how many Australians have been diagnosed with Long COVID. To fully understand the health, social, educational and economic impacts of post-infection diseases, we need the appropriate systems in place to gather and analyse data. The impacts of post-infection diseases are rarely considered in national, longitudinal or one-off health and wellbeing research studies. This includes Australia's national disease survey, the Australian Burden of Disease Study (ABDS), conducted by the Australian Institute of Health and Welfare (AIHW), which has not listed ME/CFS as a separate disease since 2003. In the 2011 ABDS study, ME/CFS was excluded as a separate disease due to outdated prevalence estimates used in 2003.[22]

Emerge Australia's Position

Emerge Australia strongly advocates for the creation of a 10th National Health Priority Area, for Post-Infection Disease. For too long, post-infection disease has been overlooked, despite its significant disease burden. Long COVID presents an immediate and significant addition to the existing disease burden.

The chronic underfunding of post-infection disease research for decades now means the hundreds of thousands of Australians with Long COVID also have very few treatment options, and face years of chronic disability. But this isn't just about ME/CFS and Long COVID. Australia needs to prioritise understanding post-infection disease so that we are better prepared for the wave of post-infection that will inevitably follow the next pandemic. Up-to-date statistics are essential to enable Australia's health and social care systems to support people with post-infection diseases like ME/CFS and Long COVID. Emerge Australia advocates for ME/CFS and Long COVID to be included as separate diseases in the next ABDS, and in all subsequent national health surveys. This inclusion was similarly recommended for ME/CFS to the NHMRC in 2019.[23]

Long COVID also offers the opportunity of a large cohort of people with a known, infectious cause. More money is being poured into researching this post-infection disease than we have ever witnessed. Because the overlap of symptoms, signs and general features of individual post-infection diseases suggests the involvement of shared pathological pathways, it is possible that common diagnostic markers, or even a unified etiological model, might be established.[24]

For this reason, Emerge Australia advocates a collaborative approach to research into post-infection disease, to ensure that progress made in one post-infection condition translate to others.

A 10th NHPA for post-infection disease will ensure all Australians receive safe and equitable care, whether they are one of the new Long COVID patients, or whether they have been living with post-infection disease for many years. Similarly, support services and healthcare must be equitably provided to all people with post-infection disease.

1. Australian Government. 'Communicable Diseases Intelligence: COVID-19 Australia: Epidemiology Report 66', Department of Health and Aged Care, Canberra, vol 46. Available at: https://www1.health.gov.au/internet/main/publishing.nsf/Content/C50CAE02452A48A7CA2587320081F7BF/$File/covid_19_australia_epidemiology_report_66_reporting_period_ending_25_september_2022.pdf.
2. Australian Institute of Health and Welfare. (2022). 'Health conditions, disability & deaths' Australian Government. Available at: https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths (accessed 2 November 2022).
3. Australian Institute of Health and Welfare and Commonwealth Department of Health and Family Services, (1997). 'First report on National Health Priority Areas 1996'. Commonwealth of Australia, Canberra, ACT. Available at https://www.aihw.gov.au/getmedia/11b6bbee-cfcf-4af0-9d32-d303e0d7ee3b/frnhpa96.pdf.aspx?inline=true.
4. Ayoubkhani, D, et al. (2021). 'Technical article: Updated estimates of the prevalence of post-acute symptoms among people with coronavirus (COVID-19) in the UK: 26 April 2020 to 1 August 2021' Office for National Statistics. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/technicalarticleupdatedestimatesoftheprevalenceofpostacutesymptomsamongpeoplewithcoronaviruscovid19intheuk/26april2020to1august2021#approach-1-.
5. Bjornevik, K, Cortese, M, Healy, B, et al. (2022). "Longitudinal analysis reveals high prevalence of Epstein-Barr virus associated with multiple sclerosis" Science 375:6578. pp 296-301.
6. Choutka, J., Jansari, V., Hornig, M. et al. (2022) 'Unexplained post-acute infection syndromes.' Nat Med 28, 911–923. https://doi.org/10.1038/s41591-022-01810-6.
7. Close, S., et al. (2020). 'The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort' Frontiers in Public Health, 8.
8. Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine. (2015). 'Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness' National Academies Press (US).
9. Dewar, J. (2000). "The National Health Priority Areas Initiative" Current Issues Brief 18 1999-2000. Available at: https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/CIB/cib9900/2000CIB18#areview.
10. Fluge, Ø., Tronstad, K. and Mella, O. (2021). 'Pathomechanisms and possible interventions in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)', The Journal of Clinical Investigation,
11. Hensher, M & Angeles, MR. (2021). 'Potential scale of Long COVID cases from the Omicron wave in Australia: Summer 2021-2022.' Institute for Health Transformation, Deakin University, Melbourne. Available at: https://iht.deakin.edu.au/wp-content/uploads/sites/153/2022/02/Long-COVID-Omicron-briefing-paper-IHT-02-2022.pdf(accessed 2 November 2022).
12. Jason, L. et al. (1999). 'A community-based study of Chronic Fatigue Syndrome' Arch Int Med, 159.
13. Komaroff, A. and Bateman, L. (2021). 'Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?' Frontiers in Medicine, 7.
14. Komaroff, L. & Lipkin, W. (2021). 'Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome' Trends in molecular medicine, 27:9.
15. The Lancet. (2022). 'Long COVID: An opportunity to focus on post-acute infection syndromes' The Lancet Regional Health - Europe, Volume 22.

16. Lorusso, L. et al. (2009). 'Immunological aspects of chronic fatigue syndrome' Autoimmun Rev, 8.
17. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee. (2019). 'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Officer' Australian Government. Available at https://www.nhmrc.gov.au/about us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer.
18. Soriano, J., et al. (2021). 'A clinical case definition of postCOVID-19 condition by a Delphi consensus' The Lancet Infectious Diseases. Available at: https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition Clinical_case_definition-2021.1.