emerge
australia

Urgent recommendations to improve care for people with ME/CFS and long COVID

> *“Health should not be seen as a cost to the health system; it needs to be seen as an investment.”*
>
> – Anne Wilson,
> CEO, Emerge Australia

Open Medicine Foundation® Australia

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Foreword

Emerge Australia, the national patient organisation representing Australians with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Open Medicine Foundation Australia, and key stakeholders call on the Federal Government to urgently implement recommendation 8 of the House of Representatives inquiry into long COVID and repeated COVID infections published on 24 April 2023.

The inquiry recommended that “funding be made available for ME/CFS research and patient support and that this funding should be allocated in consultation with peak bodies for ME/CFS and with note of the recommendations of the ME/CFS Advisory Committee’s 2019 report to the National Health and Medical Research Council”.

In its response the Government said it “supports in-principle the recommendation to support Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research and patient supports”.

In this white paper we ask the Federal Government, in implementing recommendation 8, to:

1) fund the development of new ME/CFS clinical guidelines
2) increase investment into clinical education about ME/CFS
3) expand telehealth access and services, and
4) allocate $50 million to ME/CFS research.

These recommendations were discussed at a round table event held in Australian Parliament House on 27 March 2024. We thank the people living with ME/CFS, their carers, organisations, researchers, health practitioners and Members of Parliament who participated.

If these recommendations are implemented, they will significantly improve the lives of those with ME/CFS and long COVID. In addition, they will deliver savings to the Australian economy. A significant federal government funding increase into ME/CFS would provide this. To date, this has been sorely lacking.

Australia’s 250,000 people with ME/CFS need hope. Together, we will change the lives of people living with ME/CFS.

Anne Wilson

Anne Wilson, CEO

Emerge Australia

Bill Ranken

William Ranken, Board Chairman

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Executive summary

Emerge Australia represents 250,000 Australians living with ME/CFS, providing them, their family and/or carers with assistance through information, clinical education, advocacy, patient support and research. [1,2] Emerge Australia also supports the growing number of people who experience long COVID – 14 to 18% of all COVID infections – a number only expected to increase with future COVID infections.[3]

There are striking overlaps between ME/CFS and long COVID, with up to 45% of people with long COVID meeting the diagnostic criteria for ME/CFS. This is no surprise: long COVID is the latest in a long line of post-acute infection syndromes (PAIS). The majority of people with ME/CFS also experience the disease after an infection. Recovery from ME/CFS is rare, with less than 10% reporting recovery to pre-illness functioning. [4,5,6]

The long COVID inquiry received many submissions from people living with ME/CFS. Its work shone a light on the suffering of people living with ME/CFS, who have been invisible to the health system for too long. Given the Government's commitment to addressing health inequities for women, it is important to note that women are significantly more likely to be affected by these conditions. 75% of people living with ME/CFS are women[7] and women are more susceptible to long COVID than men.[8]

The core feature of ME/CFS, and those with long COVID who meet the diagnostic criteria for ME/CFS, is post exertional malaise (PEM). PEM is a worsening of symptoms, such as fatigue, pain and cognitive impairment, following physical or mental effort. It can be highly disabling, leaving people with ME/CFS unable to work or study. In the absence of a diagnostic test, people with ME/CFS experience the stigma of living with an invisible illness whose core feature, PEM, is also not fully understood.

Australians living with ME/CFS face unique barriers to healthcare access and support, including stigma and discrimination, and difficulties attending face-to-face consultations. Outdated clinical guidelines undermine the safety and quality of patient care.

> *“It's heart breaking to me when I see ME/CFS patients today in 2024 still struggling to get access to that accurate information and not being warned. It's sad that we still face stigma and disbelief and that we so often are still harmed by medical providers who just don't understand the condition.”*
>
> – Simone Eyssens, person living with severe ME/CFS,
> former psychologist, Research Director, Emerge Australia

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[1] L. Jason, et al (1999). 'A community-based study of Chronic Fatigue Syndrome' *Arch Int Med*, 159.

[2] L. Lorusso, et al (2009). 'Immunological aspects of chronic fatigue syndrome' *Autoimmun Rev, 8*.

[3] M. Woldegiorgis, et al (2024). "Long COVID in a highly vaccinated but largely unexposed Australian population following the 2022 SARS-CoV-2 Omicron wave: a cross-sectional survey". *MJA, 220:6.*

[4] International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (2014). 'Chronic Fatigue Syndrome Myalgic Encephalomyelitis Primer for Clinical Practitioners' available at https://www.massmecfs.org/images/pdf/Primer_2014.pdf.

[5] J. Baraniuk (2017). 'Chronic Fatigue Syndrome: BMJ Best Practice guideline' *BMJ*.

[6] L. Jason, et al (2011). 'A natural history study of chronic fatigue syndrome' *Rehabilitation Psychology*, 56:1.

[7] 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).

[8] J Cohen and Y van der Meulen Rodgers (2023). An intersectional analysis of long COVID prevalence. *Int J Equity Health*, 22:261.

The final report of the House of Representatives committee inquiry into long COVID, Sick and tired: Casting a long shadow, was published on 24 April 2023.

At recommendation 8 the inquiry recommended that “funding be made available for ME/CFS research and patient support and that this funding should be allocated in consultation with peak bodies for ME/CFS and with note of the recommendations of the ME/CFS Advisory Committee’s 2019 report to the National Health and Medical Research Council”.

The National Health and Medical Research Council established the ME/CFS Advisory Committee to advise the then NHMRC CEO Professor Anne Kelso on current needs for clinical guidance and research on ME/CFS.

The Committee’s report was finalised in April 2019 and included the following recommendations: [9]

1) build ME/CFS research quantity and capacity in Australia, encouraging community collaboration and translatable research.
2) improve ME/CFS health services research.
3) develop health advice, including updating clinical guidelines and improving clinician awareness of ME/CFS.

Emerge Australia, supported by Open Medicine Foundation Australia, hosted a roundtable at Australian Parliament House, 27 March 2024, to discuss the urgent needs of Australians with ME/CFS in the context of recommendation 8 of the House of Representatives inquiry into long COVID and repeated COVID infections.

The voices of people with lived experience of ME/CFS and their family and/or carers must be heard in research and policy discussions. Presentations at the roundtable were made by academic researchers, politicians, people with lived experience of ME/CFS, and family carers.

From these presentations and discussions, four recommendations were made:

1) fund the development of new ME/CFS clinical guidelines
2) increase investment into clinical education about ME/CFS
3) expand telehealth access and services, and
4) allocate $50 million to ME/CFS research.

This white paper expands on each of these recommendations, providing an overview of roundtable discussions and supporting evidence. In addition to this white paper, further evidence can be found in Emerge Australia’s State of the Nation: Because people with ME/CFS matter report, attached.

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[9] 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.

Recommendations

1. Fund the development of new ME/CFS clinical guidelines

Australia's ME/CFS clinical guidelines have not been updated since 2002. They are out of date. Contemporary evidence shows that ME/CFS is not temporary and treatable, but the current guidelines characterise it by the symptom of fatigue (rather than PEM) and state that it is treatable with exercise and cognitive behaviour therapy. [10,11,12]

> *"Because it's not a functional illness, we can't treat it as a functional illness, in using psychological approaches. That's bad science."*
>
> – Professor David Putrino, Director of Rehabilitation Innovation, Icahn School of Medicine, Mount Sinai, New York

Comparable countries, like the USA and UK, have updated their clinical guidance to move away from this outdated paradigm.

It is critical that the Government provides funding so that Australia's ME/CFS clinical guidelines are updated. This will ensure people with ME/CFS have access to the best possible care, based on current understanding of the disease and latest evidence. At present, out-of-date guidance can cause harm and impede peoples' access to necessary supports like NDIS and Disability Support Pension.

The National Health and Medical Research Council's (NHMRC) former CEO Professor Anne Kelso supported the recommendation made by the NHMRC ME/CFS Advisory Committee Report 2019 to update and revise the guidelines.[13] To date, no funds have been forthcoming to enable this work to commence.

In seeking funds for the development of new clinical guidelines, it is recommended that these become living guidelines, updated by experienced Australian guideline developers and a committee of clinicians, researchers, patients and carers as new evidence comes to light.

The MAGICApp, the online guideline development, collaboration and publication tool used extensively by a number of Australian guideline developers in accordance with NHMRC criteria, will assist with keeping information up to date and easily accessible.

We also recommend that Government awards funding for a communication campaign targeting GPs and other health professionals to inform them that the 2002 guidelines are out-of-date and the information they provide is inappropriate and may cause harm. Although not an ideal situation, while the Australian

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[10] Centers for Disease Control and Prevention. (2021, April 28). Clinical care for patients with ME/CFS. https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/index.html.

[11] L. Bateman et al (2021). "Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management." Mayo Clinic Proceedings, 96(11), 2861-2878.

[12] National Institute for Health and Care Excellence. (2021, October). "Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management." https://www.nice.org.uk/guidance/ng206.

[13] A. Kelso (2019), 'CEO Response – open letter to stakeholders' available at https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer#download (accessed 15 April 2024).

guidelines are being updated, providers should be directed to the (UK) National Institute for Health and Care Excellence (NICE) guidelines for ME/CFS diagnosis and management, updated and published in 2021. [14]

> *“These outdated guidelines not only impact the quality and the safety of medical care that patients receive, but also our ability to access things like the NDIS.”*
>
> – Simone Eyssens, person living with severe ME/CFS,
> former psychologist, Research Director, Emerge Australia

Roundtable discussion

The roundtable discussion heard that as long as GPs and clinicians refer to these guidelines, potentially harmful and inappropriate management of people with ME/CFS will continue. People living with ME/CFS will continue to be mistreated and experience stigma and disbelief from health professionals, loved ones, the general public and government support systems.

The central issue with the guidelines is the outdated understanding about post exertional malaise or PEM. PEM is not treatable with exercise (graded exercise therapy or GET) and cognitive behavioural therapy (CBT), as Australia’s current clinical guidelines suggest. There are no evidence-based treatments for ME/CFS.

The roundtable heard that the cost of not updating the guidelines is the ongoing harm people with ME/CFS may experience through outdated treatments, which affects access to supports. In order to qualify for supports like the Disability Support Pension and NDIS, people with ME/CFS are required to undergo CBT and GET. This is because these treatments are recommended in Australia’s outdated clinical guidelines. Many people with ME/CFS are not willing to undergo these treatments and risk worsening their symptoms, and therefore unable to meet application requirements.

As noted previously, the NHMRC’s former CEO Professor Anne Kelso supported the ME/CFS Advisory Committee’s recommendation to update and replace the outdated guidelines.

Professor Kelso recommended that the NHMRC develop clinical guidance on ME/CFS, working collaboratively with healthcare providers and people with ME/CFS.

> *“If ever there’s a time for revised guidelines, the time is now.”*
>
> – Dr Mark Donohoe, GP President ACNEM, Founder, Director, Mosman Integrative Medicine

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[14] Available at https://www.nice.org.uk/guidance/ng206.

2. Increased investment into clinical education about ME/CFS

Increased investment into education of doctors and allied health professionals to improve diagnosis and support for people with ME/CFS will improve peoples' health and wellbeing, as well as reduce the burden of disease on the economy and health system.

Greater investment in clinical education, co-designed with patients and underpinned by updated clinical guidelines, is required to improve health outcomes for people living with ME/CFS. Increased clinical education is essential to helping people with ME/CFS because:

- **rates of diagnosis are low.** An estimated 85-90% of people living with ME/CFS are undiagnosed, and for those who do get a diagnosis, it often takes years. [15,16,17] Without a diagnosis, symptoms can worsen due to incorrect, or no, management of the disease.
- **people with ME/CFS have complex health needs**, and with a number of comorbidities, are often known as "heartsink" [18] patients. While there are no evidence-based treatments, healthcare providers can help people with ME/CFS though steps like teaching pacing and facilitating access to other supports like NDIS/DSP. Pacing is an evidence-based strategy that research has shown can increase a person with ME/CFS's energy envelope and allow functional improvement and greater autonomy with ADL's. [19,20,21,22,23] It is a skill that can be learnt and have long term benefits with a very low side effect profile. Pacing can also reduce the frequency of crashes with PEM. Emerge Australia teaches patients about pacing, and supports GPs and other health professionals to learn learning about the pacing strategy.
- **we need to make healthcare safe.** Many people with ME/CFS are made worse because of harmful treatments offered by healthcare providers who don't know enough about ME/CFS.

In addition to the above, whilst we recognise this is not the responsibility of government, clinical training in ME/CFS should be incorporated into undergraduate and postgraduate degrees for healthcare workers, and workforce education. This will increase awareness, understanding and safe, non-judgemental health and work environments for people with ME/CFS.

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[15] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.

[16] M. Reyes, et al (2003). 'Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas' *Arch Intern Med*, 163.

[17] L. Jason, et al (1999). 'A community-based study of Chronic Fatigue Syndrome' *Arch Int Med*, 159.

[18] Patients who "exasperate, defeat and overwhelm their doctors by their behaviour". This term was coined by TC O'Dowd (1988). "Five years of heartsink patients in general practice." *BMJ* 297:528–30.

[19] J. Nijs, I. Van Eupen, J. Vandecouter, et al. (2009). Can Pacing self-management modify physical behavior and symptom severity in Chronic Fatigue Syndrome? A case series. *JRRD* 46(7): 985–996.

[20] LA Jason, M Brown, A Brown (2013). Energy Conservation/Envelope Theory Interventions to Help Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Fatigue*. Jan 14;1(1- 2):27-42. Epub 2012 Aug 8.

[21] LA Jason, M Benton (2009). The impact of energy modulation on physical functioning and fatigue and severity among patients with ME/CFS. *Patient Educ Couns*;77(2):237–41.

[22] EM Goudsmit, et al (2011). Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: a consensus document. Disability and Rehabilitation.

[23] EM Goudsmit, S Howes (2008). Pacing: A strategy to improve energy management in chronic fatigue syndrome. Health Psychology Update. 17(1):46–52.

Ongoing and inclusive collaboration with the Royal Australian College of General Practitioners and Royal Australasian College of Physicians is required to effect the changes needed.

> *“We need to educate clinicians. We need to support education so that when a doctor sees someone with ME/CFS, they do not run for their script pad to get them out of the room.”*
>
> – Dr Mark Donohoe, GP President ACNEM, Founder, Director, Mosman Integrative Medicine

Roundtable discussion

The roundtable discussion heard how people with lived experience of ME/CFS as a patient or carer were often met with stigma and/or healthcare providers who had limited knowledge of ME/CFS. Similar evidence was also provided during the inquiry into long COVID and repeated COVID infections.

In addition to the disabling physical impact on her husband, wife and carer, Tori Sommer, said the lack of validation significantly impacted them both, socially and emotionally.

> *“I turned on myself in the absence of recognition.”*
>
> – Tori Sommer, wife and carer of her husband who lives with ME/CFS

Ms Sommer said recognition of ME/CFS and other post-acute infection syndromes has “somewhat improved” since COVID, but still has a long way to go.

The roundtable discussed the need for clinical training at all education levels (undergraduate, postgraduate and continuing professional development), and that people with ME/CFS should be involved in developing training materials.

3. Expand telehealth access and services

Telehealth opens up healthcare to all people with ME/CFS, especially those who are most unwell. This is due to PEM, the core feature of ME/CFS. An estimated 25% of people living with ME/CFS are housebound or bedbound. For them, travelling to a clinic for face-to-face appointments is often not possible because of the PEM they will experience afterwards. The effort needed to get to a clinic may require days or weeks of recovery. For these very sick people, the introduction of Medicare rebates for telehealth services made healthcare accessible for the first time.

Many people with ME/CFS have since lost access to healthcare with the eligibility for Medicare rebates for telehealth services requiring a face-to-face appointment in the previous 12 months. This makes it impossible for the most unwell people to access these services.

We call on the government to expand the exceptions to this requirement to include those living with ME/CFS whose health would be negatively impacted by attending a clinic. The decision of whether a patient needs to be seen face-to-face should be made by the doctor and patient, based on the clinical needs of the patient.

Similarly, we call on the Medicare Benefits Review Advisory Committee (MRAC) to reverse its 2023 recommendation to remove initial non-GP telehealth consultations from the MBS. ME/CFS and long COVID are complex multi-system conditions. People living with these conditions often have to see multiple specialists. Each appointment can take them days or weeks to recover from. A telehealth service, if the specialist deems it appropriate, allows them to receive healthcare without overtaxing their already taxed body.

> “*We shouldn’t have to feel worse in order to access healthcare that’s supposed to help us feel better.*”
>
> – Simone Eyssens, person living with severe ME/CFS,
> former psychologist, Research Director, Emerge Australia

There are insufficient patient support services tailored to the specific and unique needs of people with ME/CFS in Australia. As discussed in the previous section, most healthcare providers do not know enough about the condition to provide the type of information and care these often-complex patients require.

Expanded patient-centric telehealth services that specifically respond to the needs of people with ME/CFS will overcome some of the barriers they experience accessing healthcare, evidence-based information, and integrated non-clinical support.

Funding the expansion of telehealth services for people with ME/CFS will increase the ability of organisations like Emerge Australia to support people living with ME/CFS via optimal care pathways. Health professionals like nurses, physiotherapists, exercise physiologists, dieticians, occupational therapists and psychologists can provide critical support with symptom management. Similarly, specialists including cardiologists, gastroenterologists and rheumatologists can help with symptoms of ME/CFS and long COVID and common comorbid conditions, like postural orthostatic tachycardia syndrome, irritable bowel syndrome and fibromyalgia.

Emerge Australia’s national telehealth support and information service currently provides nursing and social work support to Australians with ME/CFS and long COVID and plays a complementary role in delivering broader Australia-wide telehealth. This service helps people to overcome some of the barriers in accessing healthcare, evidence-based information, and integrated non-clinical support.

> *“This is a group of people for whom we need to rethink telehealth and be accessible as doctors and practitioners across the country and if we can’t do that, we have not cared for them. We’re not listening to what the disability is.”*
>
> – Dr Mark Donohoe, GP President ACNEM,
> Founder, Director, Mosman Integrative Medicine

Roundtable discussion

The roundtable discussion heard that the MBS requirement for initial non-GP consultations (and subsequent 12-month follow-ups) to be in-person rather than through telehealth placed a significant burden on many people with ME/CFS.

In addition to accessing a GP via telehealth, people with ME/CFS can also benefit greatly from accessing informed allied health support. Emerge Australia’s national telehealth service, for example, offers support from a registered nurse and social worker. The roundtable heard due to demand from people living with ME/CFS and long COVID, this service is at capacity.

4. Allocate $50 million to ME/CFS research

ME/CFS has existed for decades, possibly centuries, [24] and yet we still don't know its cause, have no diagnostic test or effective treatments. The pandemic showed how much progress can be made in a short period of time with dedicated research funding.

Research funding in Australia for ME/CFS has been grossly inadequate over many decades. Government research funding for ME/CFS is insignificant by comparison with funding of other chronic diseases of similar complexity, prevalence and level of disability experienced. Australia also compares very poorly with other countries in funding research into ME/CFS (and long COVID) as well as in guideline development and medical education.

The inquiry into long COVID highlighted the necessity for increased research funding to build a foundation of knowledge to impact policy and the lives of Australians with long COVID. This inquiry led to a $50 million Medical Research Future Fund (MRFF) for long COVID, correctly identifying the role funding plays in initiating a research field and building a foundation of knowledge. This comes alongside $20 million in funding already provided by the Australian government through the MRFF and NHMRC bringing the total to a commendable $70m.

Long COVID is characterised as a post-acute infection syndrome triggered by the SARS-CoV-2 virus but it's not unique; other types of pathogens (viruses and bacteria) that infect us can produce a post-acute infection syndrome. If symptoms of fatigue, brain fog and PEM exist for a period of more than 6 months then these people will meet an ME/CFS diagnosis. This phenomenon has existed for as long as we've been infected by pathogens and was defined as ME/CFS over 35 years ago. In the past 20+ years, the Australian government has supported less than $7m of research on ME/CFS. The NIH in America has funded $200m in that same time-period for ME/CFS and yet they recognise ME/CFS as having the lowest funding-to-DALY ratio of all diseases (DALY = Disability Adjusted Life Year). [25]

A lack of funding globally has led to a lack of knowledge in the field of ME/CFS and ultimately people have suffered in the past decades, and they continue to suffer now. Had we invested more into ME/CFS research prior to the pandemic then long COVID would not be a problem of the same magnitude. Furthermore, future pandemics may not be closely associated to SARS-CoV-2, they are more likely to be closely associated with one of the many other viruses or bacteria that result in ME/CFS. By not investing in research to understand ME/CFS we are destined to continue to make the same mistakes.

> *“ME/CFS is three times more common in females and is the literal poster child of stigmatisation and historical underfunding.”*
>
> – Dr Christopher Armstrong, PhD, Director, Melbourne ME/CFS Collaboration (Open Medicine Foundation Australia)

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[24] L. Komaroff & W. Lipkin. (2021). 'Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome.' Trends in Molecular Medicine, 27(9), 895-906.

[25] A Mirin (2021). Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health. *Journal of Women's Health*, 30:7.

We urge the Government to commit $50 million to translational research to improve health and wellbeing outcomes for people with ME/CFS.

ME/CFS research should prioritise strengthening the evidence base and using innovative solutions to help accelerate our understanding of the condition and make progress towards a diagnostic test and effective treatments. Research should be inclusive and reflective of the population of people with ME/CFS, including patients with different levels of disease severity.

It should be an imperative that researchers commit to open and transparent knowledge-sharing and that the research is a collaboration between scientists and clinicians, and codesigned with patients and their carers.

Knowledge from ME/CFS research, as well as common comorbid conditions, and the emerging field of long COVID should be shared between researchers and stakeholders to ensure any overlaps across the diseases are well understood.

Roundtable discussion

The roundtable heard that the Federal Government has provided $4.7 million for ME/CFS research since 2019 ($3.3 million through the NHMRC's Targeted Calls for Research Scheme and $1.27 million through Ideas Grants).

The scale of this investment is negligible compared with that for similar diseases, including long COVID, Parkinson's Disease and Multiple Sclerosis, noting the Government's pledge to fund $50 million for research into long COVID over five years.

While ME/CFS shares many symptoms and pathophysiology with long COVID, ME/CFS deserves dedicated funding for research to help these people

5. Additional calls to action

We urge the Department of Health and Aged Care to embed post-acute infection syndromes (PAIS) into the refreshed National Strategic Framework for Chronic Conditions. This will give a voice to all the linked PIDs, such as ME/CFS and long COVID, and will assist with providing focus and a basis for future funding.

A national Post-Acute Infection Syndrome Strategy will deliver economies of scale and savings to the health system in the medium and long term, avoid duplication of effort, and ensure Australia is prepared for the next pandemic.

The AusME registry was established as part of the Emerge Australia/La Trobe University Biobank, funded by the Mason Foundation. The registry collects data from individuals who are 12 years and older with long COVID and/or ME/CFS, and healthy controls. It is an invaluable resource for understanding post-acute infection syndromes. This data needs to be considered as part of the work of the Australian Centre for Disease Control.

Government funding of the AusME registry would allow Emerge Australia and the tertiary institutions who utilise this registry to ensure inclusion in the Australian Institute of Health and Welfare (AIHW) data set for future burden of disease studies. ME/CFS has been excluded from the AIHW's chronic burden of disease study since 2003. This impacts the availability of quality data on the prevalence and disease burden of ME/CFS in Australia. It also impacts policy decisions, rendering an already invisible disease even more invisible. ME/CFS incidence and prevalence data needs to be collected and reported on in the Australian Institute of Health and Welfare's chronic burden of disease study.

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