acnem submission to the Parliamentary Inquiry into Long COVID and Repeated COVID Infections

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December 2, 2022

Firstly, we thank the Minister for initiating this important inquiry into Long COVID and thank the Members for their work on this inquiry. We appreciate the two-week extension granted to our college to complete this response to the Terms of Reference.

acnem has been continuously delivering medical education and training to Australian doctors for 40 years. Our current membership exceeds 1,000 healthcare practitioners, of which the large majority are medical practitioners.

The College has considerable experience in healthcare practitioner training and in the identification and management of post-infectious illness, including ME/CFS. The clinical similarities between ME/CFS and long COVID are now widely acknowledged.

acnem stands ready to play our part in reducing the incidence, severity and duration of long COVID illness in Australia, using the skills and experience gained from decades of ME/CFS prevention, diagnosis, treatment, management and social justice. The College has also developed instruments for diagnosis assessment of individuals suffering Long COVID.

The College's goal is to train a broad range of healthcare providers to help reduce the number, severity, duration and impact on quality of life of Australians suffering long COVID.

In addition, we wish to argue for inclusion of Australians suffering long COVID-like illness following vaccination in the population addressed by this Inquiry. These cases are clinically indistinguishable from the cases following infection with SARS-CoV-2, but are excluded from the current inquiry by the requirement that long COVID must follow identifiable COVID-19 infection.

Our submission addresses only long COVID rather than repeated COVID-19 infections. We address only terms of reference numbers 2, 3 and 6.

We trust our contribution will help inform the Inquiry Members about ways we can improve the care and reduce the illness and disability of long COVID sufferers in Australia.

Yours sincerely,

Dr Mark Donohoe

acnem President (on behalf of **acnem** Board)

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Acronyms, Initialisms and Abbreviations used in this document

The term “long COVID” (LC) refers to the condition and health problems also described as Post-acute sequelae of COVID-19 (PASC), Post COVID-19 condition (PCC)

ME/CFS myalgic encephalomyelitis/chronic fatigue syndrome

acnem Australasian College of Nutritional & Environmental Medicine

Preamble

acnem practitioners have worked closely with the ME/CFS community to develop patient-centered approaches and effective treatment for a wide variety of the clinical presentations of long Covid. We would recommend the Human Health Services + program of the United States government published in November 2022, as the preferable model with which to proceed in the care of patients with a long Covid.

Large numbers of healthcare practitioners need to be urgently trained in the symptomatic and deeper care of the 300,000+ Australians, currently suffering long Covid. This has more than double the size of the post viral community of ME/CFS, which was to be around 250,000 Australians.

acnem proposes to work with partners to undertake training of doctors and other healthcare professionals in the recognition, classification, management, support, and treatment of long Covid, by addressing the components of long Covid, in an evidence-informed manner.

The long-term relationship between **acnem**, its member healthcare practitioners, and Australians suffering post-viral illness has been established over decades. **acnem** stands ready to recruit and train sufficient healthcare practitioners to meet the demand for care of a growing numbers of Australians affected by long Covid in evidence-informed fashion.

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Specific responses to terms of reference

2. **The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections**;

In **acnem's** experience, long COVID is not a single definable medical condition or disease. It is an umbrella term used to aggregate a complex group of symptoms leading to prolonged suffering and disability for a subset of Australians following COVID-19 infection.

Long COVID currently does not have an agreed case definition, making clear diagnosis difficult for primary healthcare practitioners. This is a problem that urgently needs agreement and resolution. It was a problem that dogged the ME/CFS field for decades, leading to poor research and ineffective interventions such as cognitive behavioural therapy and graded exercise therapy. The lessons learned in the ME/CFS community need to be used to prevent such wasted and potentially harmful interventions and outcomes in the long COVID community.

At **acnem**, we oppose any simplistic binary diagnostic event occurring at an arbitrary time following COVID-19 diagnosis. We propose (and intend to use) a progressive case definition for symptoms persisting after infection as follows:

TIME	**NOMENCLATURE**
Weeks 1 to 4	acute COVID-19
Weeks 5 to 8	long COVID at risk (LCAR)
Weeks 9 to 12	early long COVID (ELC)
After week 12	long COVID (LC)

The purpose of this is to help define those at risk of progression to each subsequent stage using the best available evidence, and to focus on interventions that may prevent progression to long COVID at each stage of the 3 preceding months.

Long COVID comprises a number of separate but linked symptom clusters, and these can be distinguished to facilitate prevention and treatment.

Our experience is that early and appropriate simple low-cost interventions, including a focus on diet and nutrition, sleep, movement and exercise, a healthy personal environment, and management of the stresses associated with the illness significantly reduces the risk of progression to the subsequent stages. Early intervention in these areas is a key to preventing progression.

Our College has created an algorithmic instrument to facilitate diagnosis and severity assessment following acute COVID based on recent internationally agreed criteria. We have also drawn on our clinical experience in the ME/CFS area. The instrument can be used not only for diagnosis, but also for assessment of the severity and impact on quality of life of the sufferers.

The instrument can also aid in identifying the principal components of illness subtypes contributing to long COVID as an aid to clinical decision-making.

We have identified those subdivisions from work we have done in the ME/CFS area, namely:

- dysautonomia
- autoimmunity
- mitochondrial impairement
- persistent inflammation, including mast cell activation and endotheliitis
- persistent COVID-19 infection, including gut persistence
- Co-infections
- biopsychosocial issues and stress, exacerbating and prolonging the initial infection

We are willing to make the instrument available to healthcare practitioners after validation and clinical testing by our College's members. Our ME/CFS experience is that this ability to measure and re-measure after intervention will provide a basis for research based on practitioner feedback.

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In our experience, long Covid-like symptoms occur commonly amongst our practitioners' patients following vaccination, principally following mRNA vaccines. Those patients' symptoms are indistinguishable from long Covid following COVID-19 infection, and are found more commonly in people with heightened (as opposed to suppressed) immune responses, including people suffering ME/CFS, Allergies, sensitivity reactions and patients with previous vaccine adverse reactions.

We believe that this group of people, who have suffered as a result of participation in the vaccination program in Australia, should be included in any and all recommendations of the Inquiry. In all public health programs, risk and benefit of intervention are unequally distributed, and idiosyncratic adverse events resulting in long COVID-like outcomes need to be cared for within any program developed for long COVID care.

It is our experience that those suffering long COVID-like illness following vaccination tended towards the younger age categories (typically 20 to 50 year olds) rather than in the older population over 65. There seems to be little sex bias in this group. Most had none of the known comorbidities associated with hospitalisation or death from COVID-19.

acnem recommends an active survey be undertaken to discover the number of Australians so affected, their demographics, and whether previous medical conditions can be identified that could predict those more likely to suffer these reactions. This could inform doctors and ATAGI on the matter of risk for specific subgroups. Our experience, and experience from New Zealand, suggest that people suffering ME/CFS or other post-infectious illness may be among those at risk.

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3. **Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia**;

The factors leading risk of progression to long COVID appear to be:

- severity of initial infection (asymptomatic cases) < 1%
- community acquired and not hospitalised cases 5% to 8%,
- hospitalised ± ICU cases 30%.

We propose that research in the field of long COVID is best carried out with active involvement of those suffering the illness and their primary healthcare providers, not only medical practitioners.

We would support the processes proposed by the **US Human Health Services health+ Long COVID** program of "human centered design" which can be found at:

https://www.hhs.gov/sites/default/files/healthplus-long-covid-report.pdf

Research needs to be directed towards benefit for the sufferers, and we would propose that the Inquiry adopt the research priorities currently decided by the US NIH RECOVER program:

"Through RECOVER study questionnaires, surveys, and discussions with people who have Long COVID, these were considered most burdensome, most important to address, and the priorities for trial protocols under development. The symptom clusters include:"

- *Viral persistence: When the COVID-19 virus stays in some people's bodies.*
- *Autonomic dysfunction: Changes in ability to regulate heart rate, body temperature, breathing, digestion, and sensation.*
- *Sleep disturbances: Changes to sleep patterns or ability to sleep.*
- *Cognitive Dysfunction: Trouble thinking clearly or brain fog.*
- *Exercise intolerance/fatigue: Changes in a person's activity and/or energy level.*

https://recovercovid.org/docs/RECOVER.Clinical.Trials.Announcement.10.31.22.2.pdf

Based on our College's 2022 long COVID Symposium, Long COVID Symposium (Practitioner ONLY) - acnem we would suggest the addition of three additional areas of research with good evidence to at least a contribution to the long COVID experience, namely:

1. Autoimmunity and autoimmune exacerbation
2. Persistent co-infection/inflammation - EBV, mould, allergy, vector borne illness
3. Mitochondrial function and metabolic syndrome

6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

These are described above and draw on the US proposals for research priorities and the involvement of the affected long COVID community and their chosen primary care practitioners in all aspects of research.

We propose a breaking down of the "headline" term "long COVID" into more clinically relevant subdivisions which correspond to the clinical approaches developed in the ME/CFS framework for the past 30 plus years by **acnem**.

We propose that **acnem's** diagnostic and classifying instrument be supported in development, clinically validated, and deployed to standardize and enhance the capacity of healthcare practitioners to diagnose and classify the components of long COVID. We propose that support be provided to **acnem** to deliver a healthcare practitioner training program, based on the best practice for an evidence-supported preventive, diagnostic, treatment and social justice approaches to long COVID.

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