

The following submission seeks to address Terms of Reference 1 and 3:

1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;

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;

I am writing to highlight to the Committee the significant crossover in symptoms and treatments between long COVID and those suffering chronic side effects from COVID vaccinations.

For the record, prior to my injury I was (and remain) pro-vaccination, and I still support COVID-19 vaccination; it is just unfortunate that I am part of a small proportion of people vaccinated for COVID that subsequently suffer 'long COVID-like' symptoms.

I won't dwell on my personal experience; in short, after my second COVID vaccination I began experiencing significant neuropathic pain in my arms and legs, together with significant post-exertion fatigue. This has had a major impact on my work and home life; I went from being a fit, very active and busy professional to leading a slow and sheltered life, where my energy and activities are seriously limited and my quality of life is poor.

While I am lucky to have an excellent GP, in the ensuing 18 months I have been on a merry-go-round of testing, specialist visits and trialling various treatments; I have had to organise all of this myself, in spite of lengthy waiting lists for specialist visits (6 to 8 months is normal). While Medicare has subsidised some costs, I remain out of pocket many thousands of dollars (not counting lost income during this period); I shudder to think the impact this condition has on people unable to self-fund their care as I have.

A general physician specialising in "hard cases" recently diagnosed me with 'long COVID-like symptoms', though he was not able to provide any treatments beyond what I had already identified myself. While some medications (in particular low dose naltrexone for fatigue) have provided a degree of respite, I still have no sense of when or even if I will recover.

I cannot find the words to describe my frustration that there is no organised or coordinated support for a person in my position – other than my GP's well-intended efforts (given she has no training or experience with this), I have been completely on my own to address a complex and debilitating condition. What little useful support I have received has come from a disparate set of online support groups in Australia and the USA, set up by people suffering these effects because no other support is available.

While I believe and appreciate that adverse reactions to COVID vaccines have been rare, the sheer scale of the vaccination program means that even a tiny adverse reaction rate will mean many thousands of people are suffering – with all the human and economic impact that entails.

I can understand that the Commonwealth wishes to encourage vaccination and would not want questions or doubts around side effects or efficacy to impact this; at the same time, burying heads in the sand and avoiding what might be a delicate discussion among medical professionals and with the community simply delays the inevitable and prolongs the suffering of people in my position.

Through my GP I followed the official process and made an adverse reaction report to my State Health Department (which contributes to TGA data), and had a telehealth consultation with a specialist immunologist – who found that there was (at that stage at least) insufficient data that COVID vaccines might have these effects. I note that Australia has no proactive monitoring of *chronic* adverse vaccine reactions (as opposed to *acute* reactions, immediately after vaccination); by that I mean nobody in Australia is reaching out to a representative sample of vaccinated Australians to see if there are any ongoing side effects – which to me is a significant potential blind spot.

I respectfully recommend the Committee:

- Consider or at least explore the *possibility* that ‘post vaccine syndrome’ exists, is related to long COVID, and specifically that it shares many ‘long COVID-like’ symptoms
- Encourage the TGA and Ausvaxsafety to formally and proactively investigate and report on the incidence of ‘post vaccine syndrome’ (and for them to not rely solely on reactive and inconsistent self-reporting by patients)
- Support funding for academic research into links between long COVID and post-vaccine syndrome, and potential treatments for both
- Provide a single entry point at a State or national level to the healthcare system for people suffering from long COVID and post-vaccination syndrome, where patients can access multi-disciplinary clinics and care management plans that focus on case management and recovery
- Provide a single, national information website resource where patients, families and medical practitioners can access information about long COVID, and access the latest research, clinical guidelines (given these are evolving quickly internationally and in Australia) and treatments

References:

- <https://www.science.org/content/article/rare-cases-coronavirus-vaccines-may-cause-long-covid-symptoms>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8979721/> Autoimmune post-COVID vaccine syndromes
- <https://www.2gb.com/teenagers-harrowing-journey-after-covid-vaccine-side-effect/>
- <https://www.news.com.au/lifestyle/health/health-problems/outright-lying-australian-scientist-hits-out-at-tga-after-lifechanging-covid-vaccine-injury/news-story/c57a554e4f7b6750e8ae6ff2db6c9514>
- <https://converse.org.au/> An Australian non-profit organisation in Australia run by and for people who have suffered a significant adverse reaction following their COVID-19 vaccination
- <https://react19.org/> USA non-profit supporting people suffering from long-term COVID-19 vaccine effects