

Vaccines, Long Vaccine Syndrome, and Long Covid

A submission by **CO**VERSE Ltd to the Australian Parliament Inquiry into Long Covid and Repeated Covid Infections

For questions about COVERSE visit coverse.org.au

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Term of Reference Addressed in this Submission

- 1. The patient experience in Australia of Long Covid and those with 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 those with repeated Covid infections in Australia;
- 4. The health, social, educational and economic impacts in Australia on individuals who develop Long Covid and/or have repeated Covid infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;
- 5. The impact of Long Covid and those with repeated Covid infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and
- 6. Best practice responses regarding the prevention, diagnosis and treatment of Long Covid and those with repeated Covid infections, both in Australia and internationally.

1. Executive Summary

COVID-19 vaccines are an essential aspect of the discussion of Long Covid and repeat Covid infection for four key reasons:

- 1. Vaccine risks, as well as benefits, must be openly discussed to ensure that trust in public health and vaccines is not undermined.
- 2. There is a *significant* overlap in the range of symptoms seen in Long Covid and the serious ongoing symptoms caused by COVID-19 vaccine adverse reactions.
- 3. Understanding the illnesses caused by COVID-19 vaccines is essential for isolating and mapping complications of Long Covid.
- 4. People who have suffered significant COVID-19 vaccine injuries are at a greater risk of severe complications, including Long Covid, if infected or reinfected with Covid.

Our submission focuses on COVID-19 vaccine Serious Adverse Events (SAE) and what we call "Long Vaccine Syndrome" *alongside* Long Covid. We explain the scientific and policy basis for addressing these conditions together.

We believe that urgent reforms to the Australian Government's pharmacovigilance efforts and management of adverse events are critical to ensuring the integrity of, and confidence in, vaccination programs and government public health measures.

There are many pressing issues facing the current parliament. As the challenges of social justice and equity issues, economic issues, environmental issues, and geopolitical issues come to a head, how we treat our own in times of crisis is a mark of our identity.

After heeding the call by our governments to step-up and get vaccinated for the good of our community, Australian citizens and residents suffering a COVID-19 vaccine injury have faced ongoing derision, gaslighting, and censorship, while suffering from oppressive health disabilities with zero support.

The extent to which our politicians and governments have almost completely turned their backs on the victims of COVID-19 vaccine harm is a stain upon our democracy and our enviable government-funded public health system. This situation does not bode well for future public health crises, and is a tragedy of significant proportion.

We are calling on the Parliament of Australia to urgently address this injustice. Our lives and livelihoods depend upon the integrity of this government to right the wrongs that have been inflicted upon this group of Australian citizens who have suffered so greatly for their civic contributions.

2. Recommendations

This submission details a series of issues that lead to the following recommendations:

1	Acknowledge the international and emerging research on COVID-19 vaccine injuries and Long Vaccine Syndrome.
2	Instruct doctors to fully comply with the reporting of all Adverse Events Following Immunisation (AEFI), irrespective of whether they are 100% certain the conditions are connected to the vaccine.
3	Accept COVID-19 vaccine-injured Australians into all Long Covid Clinics, regardless of whether they have had a COVID-19 infection or not.
4	 Provide Australian doctors and specialists with comprehensive education and training opportunities to: Access and follow COVID-19 vaccine Serious Adverse Event (SAE) medical research. Recognise COVID-19 vaccine-caused illnesses. Deliver frontline treatment protocols for these adverse events in line with leading-edge international innovations.
5	Encourage all Australian research projects concerning Long Covid to include COVID-19 vaccine injuries.
6	Accelerate all of the above by pursuing collaborations with leading patient-led organisations and medical research undertakings already addressing COVID-19 vaccine reactions internationally (see Attachment A).
7	 Overhaul the COVID-19 vaccine claims scheme to: Allow for claims against all injuries caused by the COVID-19 vaccines. Remove the hospitalisation requirement. Readjust the lost income test to adequately account for financial losses suffered by non-salaried workers (e.g. business owners who may not be able to demonstrate lost income). Remove the requirement that patients must have accrued minimum losses/costs of \$1,000.
8	Conduct an independent inquiry into vaccine approvals and pharmacovigilance processes of responsible government agencies, regarding the minimisation of, and disinterest in, serious adverse reactions.
9	Conduct an independent inquiry into potential collusion between government officials and media actors (including social media companies). Issues to assess include suppression of reasonable, scientific medical opinions and censorship of now-proven scientific facts about possible adverse vaccine outcomes that ran counter to the prevailing public health messaging strategies.
10	Conduct an independent inquiry into health profession regulators, who bullied and censored doctors who were attempting to raise concerns about vaccine safety and patient risk. This should focus not just on the improper regulation of doctors but on the abandonment of patients as a result of these measures.

3. About **CO**VERSE

COVERSE Ltd is the only non-profit organisation in Australia run by and for people who have suffered a significant adverse reaction following their COVID-19 vaccinations.

The organisation was founded by a group of Australian professionals¹ who have had medically recognised, life-changing serious adverse reactions to COVID-19 vaccines but do not qualify for the Government's COVID-19 vaccine claims scheme.

We represent a larger group of genuinely injured and ill Australians suffering from serious adverse reactions to COVID-19 vaccinations. We estimate the number of Australian residents suffering significant ongoing adverse reactions to be in the many thousands.²

COVERSE advocates against government neglect and medical abandonment of the COVID-19 vaccine-injured through good science, proactive medical industry engagement, inclusive public policy, and honourable political discourse.

We work voluntarily for all COVID-19 vaccine injured Australians. We also provide patients and health professionals with new and emerging information about COVID-19 vaccine injuries and leading-edge insights on how to treat them, based on peer-reviewed science and overseas studies. We provide this information due to the fundamental absence of Australian Government diagnostic and medical guides being provided for our conditions in any form whatsoever.

4. Introduction and Context

The COVID-19 vaccination program is the largest and most accelerated adult vaccination program in global history, undertaken during intersecting political crises and advanced, non-transparent, developments in the biomedical and ICT industries.

Australian public health authorities implemented this unprecedented vaccination campaign in an attempt to alleviate pressure on public health facilities and improve patient and public health outcomes in the midst of a pandemic. In all cases, the vaccines utilised were brand new products with no long-term safety data.³

Australia was in a novel situation at the commencement of the global vaccine rollouts, in so far as our border closures and domestic lockdowns prevented a majority of Australians from being infected prior to being vaccinated. This unique situation provided significant clarity around causation with regard to illnesses resulting from serious adverse reactions to COVID-19 vaccines, as distinct from COVID-19 itself. However, the Australian Government had no national medical plan for addressing the diagnostic or treatment needs of those injured by these vaccines, who all rolled up their sleeves for the public good.

Drug regulators typically demand very high standards of safety outcomes for vaccines, with serious adverse events being extremely rare, typically in the order of 1-in-1,000,000 to 1-in-100,000 individuals.⁴ However, for the COVID-19 vaccines we are observing a significantly larger rate of adverse events than we might expect, perhaps as much as 100× greater.⁵ Hence COVID-19 vaccines appear to be significantly more likely to cause serious and other adverse reactions compared with existing vaccines used throughout the general population.

¹ For more information about **CO**VERSE see the About and FAQ sections of our website: https://coverse.org.au/ ² Estimate based on the number of patients in our online support groups, and the far larger group of patients who are not part of any support groups.

³ [Haseltine2020] https://wapo.st/3AlhzCK

⁴ [DOHAC2020] https://doi.org/10.33321/cdi.2022.46.47

⁵ [Montano2022] https://doi.org/10.3389/fpubh.2021.756633

When a person first experiences significant issues following their COVID-19 vaccinations it is reasonable that they seek and expect medical care. It is also reasonable that, should they not receive proper medical attention, especially where vaccinations have been mandated, they could call a government hotline and be told of other routes to public assistance. Following proper medical attention, it would be reasonable also that health information on COVID-19 vaccine reactions — what to expect and what appropriate treatments to seek — might be given to them if they were confirmed to be a reaction case. None of this happens in Australia.

Despite thousands of peer-reviewed scientific papers and case studies that address COVID-19 vaccine reactions,⁶ only extremely limited medical guidelines have emerged for Australian GPs or other specialists to aid doctors or patients with the diagnosis or treatment of serious complications caused by the COVID-19 vaccines. Even while Long Covid research and education becomes prioritised by doctors and patients, there is little to address COVID-19 vaccine sufferers at all.

We assert the scientific and public health rationality of our submission, following the publication of the article "Serious adverse events of special interest following mRNA COVID-19 vaccination in randomised trials in adults" in the journal *Vaccine*⁷ (and subsequent open letter in the *British Medical Journal*),⁸ the position statement by OzSAGE on the importance of managing COVID-19 vaccine adverse events,⁹ and the release of raw data from the CDC (in the USA) from their V-Safe surveillance app showing alarming rates of reactions and hospitalisation.¹⁰ Almost two years into the vaccine rollout, it is not scientific or responsible that the Australian Government continues to provide official information that misinforms the Australian public about the safety and risks of the COVID-19 vaccines and the degree of real ongoing harm they have caused in the community.

4.1. Data for All Australians

It is reasonable to expect that Australian citizens receive Government updates on COVID-19 vaccine reactions that reflect the severity and duration of COVID-19 vaccine illnesses. This data is not collected,¹¹ thus is not available to Australian Government decision-makers.

COVID-19 vaccine-injured Australians receive zero follow-up investigation of their case after having their cases reported to pharmacovigilance authorities. There is no evidence among the COVID-19 vaccine-injured in Australia of the Government's claims that it investigates or tracks any serious adverse events cases beyond one initial phone call (which seems aimed at merely confirming the victim's identity and the veracity of their initial reaction).

For this reason, **CO**VERSE questions the claim that COVID-19 vaccine-injuries are 'self-limiting', as the Government has collected *no ongoing data* with which to make this claim.

⁶ for example, https://react19.org/1250-covid-vaccine-reports

⁷ [Fraiman2022] https://doi.org/10.1016/j.vaccine.2022.08.036

⁸ [Doshi2022] https://www.bmj.com/content/378/bmj.o1731/rr-0

⁹ [OzSAGE2022] https://bit.ly/3X1fXrw

¹⁰ [ICAN2022] https://www.icandecide.org/v-safe-data

¹¹ While pharmacovigilance agencies are required to accept and analyse reports of adverse reactions following immunisation (AEFI) they are not compelled to track these cases to determine ongoing and long-term impacts. The only way this information is gathered is via voluntary follow-up reports from patients and/or their doctors.

4.2. The Real Scope of Serious COVID-19 Vaccine Injuries

Despite claims of COVID-19 vaccine products to be both safe and effective, a diverse list of life-changing adverse reactions emerged during the clinical trials and the global rollout that have not been acknowledged by drug regulators.¹²

While some of these adverse reactions (such as thrombosis, myocarditis and pericarditis) have since been acknowledged by governments, there remain a large number of people suffering from a clear constellation of other adverse reaction illnesses that have not been recognised by drug regulators or governments, and who receive no assisted treatment or compensation.

Typically, an adverse reaction to a COVID-19 vaccine begins in the first hours or days following vaccination.¹³ However, some reactions may occur within minutes, and others can have a more delayed onset, with some confirmed cases not emerging until 3 months after vaccination¹⁴ (**CO**VERSE has suspicion of some cases emerging at up to 6 months post vaccination).

Following the acute phase of a serious COVID-19 vaccine injury, "Long Vaccine Syndrome" is the name being given to conditions of patients whose serious adverse reactions develop into multi-system illnesses with waves of sequelae, and no known end-point or duration.

Common and chronic ongoing symptoms of Long Vaccine Syndrome are similar to Long Covid, and include:

- brain fog
- extreme fatigue
- memory loss
- tinnitus
- headaches
- blurred vision
- chest pain
- abnormal heart rate
- myo/pericarditis

- shortness of breath
- circulatory issues
- blood pressure changes
- hair loss
- numbness
- tingling / burning
- internal tremors
- muscle twitching
- vascular bulging

- joint pain
- gastric issues
- food sensitivities
- menstrual issues
- rashes
- bruising
- reactivated diseases
- chronic pain
- organ dysfunction

The scientific link between Long Vaccine Syndrome and Long Covid is based on research that suggests that some (although clearly not all) Long Covid sufferers have the spike protein of the SAR-CoV-2 virus at the source of their problems.¹⁵ This same protein is the antigen used in all of the COVID-19 vaccines currently available in Australia.

An expanded description of Long Vaccine Syndrome is included in Attachment B, and early data from **CO**VERSE's patient symptom survey is presented in Attachment C.

While there is evidence that Long Vaccine Syndrome chronic reactions, affecting multiple organs in the body, require frontline proactive treatment to alleviate them (as COVID-19 does), our injured members immediately come up against barriers to this.

For example, it is never stated in the media (or by the Government), that a significant percentage of individuals afflicted with acknowledged vaccine reactions such as myocarditis are also suffering ongoing and complex Long Vaccine Syndrome.

¹² [Fraiman2022] https://doi.org/10.1016/j.vaccine.2022.08.036

¹³ https://www.cdc.gov/coronavirus/2019-ncov/vaccines/expect/after.html

¹⁴ [2GB2022] https://www.2gb.com/teenagers-harrowing-journey-after-covid-vaccine-side-effect

¹⁵ [Schieffer] https://doi.org/10.3389/fcvm.2022.992686

Based on the health challenges being faced by members in our patient support groups, **CO**VERSE estimates that as many as two thirds of those afflicted with myocarditis or pericarditis from their vaccinations fall into this category, which is in stark contrast to government messaging that claims these conditions are mostly mild and resolve quickly. Across our community, this is simply not the case; furthermore, no research body in Australia is studying this chronically ill community of Australians.

Our data suggests that those people suffering from Long Vaccine Syndrome typically suffer for many months (6+) before seeing any improvement at all, and most have yet to make a full recovery. This also is in dramatic contrast to public health messaging around vaccine safety, which never relays the seriousness or longevity of symptoms being experienced by those whose reactions are not "mild" and not "short-lived".

The negative impacts that these vaccine products have had on an unknown but likely large number of Australians is not currently estimable, while the *almost total lack of support* that many people suffering adverse reactions in Australia have had to face is totally unendurable and politically unsustainable. Internationally, patient groups are continuing to lose members to suicide; our only recent incorporation prevents us from having suicide statistics for Australia.

Our submission therefore draws attention to the systemic inadequacies that must be addressed to ensure these people, alongside Long Covid sufferers, can get timely and effective diagnostics and treatments. The submission will further look at some of the research connecting these two conditions, and make the case for including vaccine-injured Australians in Long Covid treatment and research programs.

4.3. Reaction Frequency, Data Distortion and Censorship

The nature of COVID-19 — its emergence as a disease with no prior degree of immunity in human populations, its highly infectious nature, and initially significant rates of serious complications and death — led to the development, rollout and uptake of new vaccines in record time.

Despite considerable public messaging that no safety protocols were skipped,¹⁶ the rapid development of these products in the midst of this pandemic did indeed give rise to various safety and other protocols being undermined or pragmatically deprioritised, due to a multitude of factors,¹⁷ including political pressure.¹⁸

It is typical in a non-emergency approval process for as many as half of all adverse reactions to not be identified until a product enters the marketplace, sometimes not for several years. It is thus understandable that in the face of the rapid development process for COVID-19 vaccines, coupled with the limitations and compression of clinical trials, that important safety signals were missed and went unacknowledged and unreported. However, with thorough long-term research of side-effects after the emergency approval, it is important to acknowledge these injuries and take necessary action.

In September 2022, an independent reanalysis of the combined public data from Pfizer and Moderna's clinical trials demonstrated that the rate of occurrence of serious adverse events was not rare, and may be greater than 1-in-1,000.¹⁹

This is in dramatic contradiction to the claimed safety of these vaccines, with the public being repeatedly told that these vaccines went through all the same tests as more familiar vaccines on the family immunisation schedule, and had been declared equally as "safe and effective". This is just not correct.

¹⁶ [Khorshid2021] https://bit.ly/3Aj3zJN

¹⁷ [Prasad2022] https://ssrn.com/abstract=4276828

¹⁸ [Diamond2021] https://wapo.st/3TKix2h

¹⁹ [Fraiman2022] https://doi.org/10.1016/j.vaccine.2022.08.036

Since the introduction of these products, public health authorities have continued to make strong claims around their safety, particularly denying that they exhibited any number of worrying properties that were raised from time-to-time by members of the medical establishment or public. However, one by one, many of the safety and efficacy claims have turned out to be, at the very least, premature.

Some of the safety and efficacy claims that are now refuted by reputable peer-reviewed studies include: mRNA stays at the injection site;²⁰ mRNA is short-lived in the body;²¹ the spike protein is short-lived in the body;²² the spike protein alone cannot cause any harm;²³ the vaccines do not affect reproductive health;²⁴ breast-feeding mothers cannot pass the vaccine to their babies,²⁵ and; vaccines prevent transmission.²⁶

Both scientific logic and common sense allow us to accept that the rapid introduction of such a product will reveal new evidence over time. Scientific literature now has significant numbers of findings and case studies of adverse reactions to these vaccine products that were not (and in most instances are still not) acknowledged by government authorities.

5. Patient Experience, Poor Treatment, and Abandonment of the Vaccine-Injured

Thanks to the consistent messaging from governments and media that (a) severe vaccine reactions are extremely rare, and (b) that anyone who says otherwise are misinformed anti-vaxxers, most of the vaccine-injured people in Australia have faced derision from public figures and unconscionable gaslighting and bullying by doctors, work colleagues, friends, and even from family. It is not rare among our members for intimate relationships to end and friendships and support structures to break down as we and our families confront this paucity of public recognition. For many of us, despite our best efforts to stay connected and request help, other vaccine-injured people are our main source of support, resources and hope.

This type of response towards people who are suffering a significant adverse reaction to their vaccinations is the most inappropriate and horrendous way to treat people who got vaccinated for the benefit of the society they are a part of. It is also hugely discriminatory and goes against all public health principles that vaccinated citizens committed to.

In addition to the following detail about the overall patient experience, we have attached to our submission a number of mainstream news articles covering the experiences of several individuals.

5.1. The Patient Experience

The complex condition of Long Vaccine Syndrome, like Long Covid, consists of a larger cluster of symptoms that varies from person to person.

Individuals can suffer varying degrees of disability on account of these symptoms, ranging from minor annoyances that do little to interrupt daily life, to significant impairment resulting in the inability to function on even a basic level, for weeks, months or years.

²⁰ [Di2022] https://doi.org/10.1007/s11095-022-03166-5

²¹ [Röltgen2022] https://doi.org/10.1016/j.cell.2022.01.018

²² [Cosentino2022] https://doi.org/10.3390/ijms231810881 & [Cristoni2022] https://doi.org/10.5281/zenodo.5831816

[&]amp; [Patterson2022] https://doi.org/10.21203/rs.3.rs-1844677/v1

²³ [Lin2022] https://www.mmri.edu/2022/08/02/revealing-covids-impact-on-the-heart

²⁴ [Edelman2022] https://doi.org/10.1136/bmjmed-2022-000297

²⁵ [Hanna2022] https://doi.org/10.1001/jamapediatrics.2022.3581

²⁶ [Boucau2022] https://doi.org/10.1056/NEJMc2202092

These disabilities resulting directly from COVID-19 vaccines, meant to keep people safe from the impairments caused by Covid itself, are not at all recognised by the Australian Government.

Not unlike Long Covid, currently, there is a lack of appropriate tests and singular diagnostic frameworks available in Australia that can be used to identify the extent and specificity of such suffering. Internationally, organisations and institutes do pioneer diagnostic tests and treatments that are unavailable in Australia. Examples include cytokine testing,²⁷ specialised antibody testing,²⁸ biopsy analysis for Small Fibre Neuropathy,²⁹ and specialised microscopy for observing micro-clotting.³⁰

After an initial period of self-advocacy in which the patient must work quite hard to be believed regarding their symptoms, the additional barrier to diagnosis is that the syndrome rarely displays any findings in standard diagnostic tests — most available serology testing is failing to find explanations for the symptoms, and various scans rarely indicate any injury (including in many instances of myocarditis and pericarditis).

We note, however, that through the use of highly-specialised processes, researchers at Yale University have observed microclots through a microscope,³¹ and the National Institutes of Health (USA) have observed immune system damage.³²

Given that this diagnostic hurdle is similar for Long Covid, **CO**VERSE advises that Long Vaccine Syndrome patients should be treated with the same degree of investigative enthusiasm, ethical sensitivity, and concern given to Long Covid patients. Except in rare cases, this is simply not happening.

Currently, in Australia, doctors work to the assumption that there are no reliable treatment options for Long Vaccine Syndrome, and furthermore that our symptoms might improve without intervention. This is unfortunate given that important international doctor-patient collaborations and lab projects do exist that are experimenting with protocols and treatment combinations that are showing promising outcomes and improvements in our health.

Vaccine-injured patients in Australia, without access to such specialised facilities or frontline treatments, have taken to self-experimentation out of their own pockets with a wide range of treatments, including pharmaceuticals, nutraceutical supplements, physical therapies, and other approaches.

Finally, it is worth emphasising that despite Long Vaccine Syndrome conditions not being recognised by the Australian Government, similar conditions were also experienced by participants during the clinical trials (but not identified by the pharmaceutical companies in their peer-reviewed trial results publications) of Pfizer³³ and AstraZeneca,³⁴ and likely others.

5.2. Medical Issues

Typically, unless a patient is displaying clear clinical symptoms and associated biomarkers of a familiar life-threatening condition (e.g. a large blood clot or heart attack showing up in ED imaging and pathology),

²⁷ https://incelldx.com

²⁸ https://www.celltrend.de

²⁹ The Neurology Laboratory at the Brain and Mind Centre, University of Sydney, had planned to introduce the capability to undertake Small Fibre Neuropathy analysis from biopsies, however this has been placed on hold indefinitely. https://www.sydney.edu.au/brain-mind/our-clinics/clinical-service-partners/neurology-lab.html ³⁰ [Grobbelaar2021] https://doi.org/10.1042/BSR20210611

³¹ https://twitter.com/VirusesImmunity/status/1589762087597019137

³² [Safavi2022] httpd://doi.org/10.1101/2022.05.16.22274439

³³ e.g. [GiangPaunon2022] https://fxn.ws/3hFVOH9 & [Healy2022] https://davidhealy.org/disappeared-in-argentina

³⁴ e.g. [CouzinFrankel2022] https://doi.org/10.1126/science.ada0394

they will most frequently receive a dismissive attitude from doctors, who will instruct them to take painkillers or simply rest.

Scientific literature has meanwhile emerged to show that many of the curiously negative biomarkers that appear in the preliminary investigations of serious Long Covid conditions are also missing in Long Vaccine Syndrome patients. For example, troponin may not be elevated in patients later proven via cardiac MRI to have heart inflammation or scarring, and D-dimer may not be elevated (or just go unchecked) in patients that are later proven to have blood clots from their COVID-19 vaccination — both are real situations that have been conveyed to us by multiple patients.

It is not at all uncommon among COVID-19 vaccine injury cases for a patient to be suspected of, or labelled with, a psychological disorder instead of receiving exhaustive diagnostic investigations.

Sadly, individuals in the initial reaction phase and Long Vaccine Syndrome phases of their illnesses are usually experiencing significant pain, cognitive dysfunction, motor skill issues, and many other disabilities. This makes their articulation of semi-novel and under-researched reaction symptoms even more difficult to translate to doctors who distrust their patient's assessment of dysfunction.

Some doctors take pains to explain to such patients that "coincidence is not causality" yet are making little or no effort to find any other cause — as if a patient simply mentioning a "vaccine reaction" is enough to assume that a patient is either lying, a hypochondriac, or suffering a psychological episode.

This tendency for patients to be treated as psychological cases by medical professionals leads many individuals to spend significant funds seeking a second, third, fourth and even fifth opinion before they find a practitioner who will undertake meaningful and thorough investigative tests, and/or refer the patient to appropriate specialists for further investigation.

This extremely challenging and alienating situation is facilitated and reinforced by continued public health messaging around the safety and efficacy of COVID-19 vaccines. If these messages were accompanied by instructions for patients and doctors to be on the lookout for new adverse reactions, then perhaps doctors would be less inclined to dismiss adverse reactions that have not been listed as acknowledged side effects.

While diagnosing these conditions is challenging in their own right, treatment is proving even more difficult. As with Long Covid, most treatments for COVID-19 vaccine injuries rely on addressing individual symptoms rather than the underlying pathologies.³⁵ However, there are a number of highly qualified groups who are actively pursuing a range of experimental treatment options with varying results, including some treatments that have been inexplicably banned for off-label use by regulators in Australia. Such groups include, but are not limited to, the Front Line COVID-19 Critical Care (FLCCC) Alliance,³⁶ University Hospital Marburg,³⁷ and IncelIDX.³⁸ A very small minority of Australians who can afford to access these do fly internationally to do so, given the total absence of comparable approaches available domestically.

5.3. Financial Issues

Whilst compassionate and helpful medical care has been difficult for the vaccine-injured to obtain, access to financial aid is virtually impossible.

³⁵ [Greenhalgh2022] https://doi.org/10.1136/bmj-2022-072117

³⁶ https://covid19criticalcare.com/treatment-protocols/i-recover

³⁷ https://www.ukgm.de/ugm_2/deu/umr_kar/51186.html

³⁸ https://www.covidlonghaulers.com

JobSeeker

The first government scheme they might access is JobSeeker, which has a provision to provide income support for people who are temporarily unable to undertake their normal work. However, the restrictions on this scheme (household income test, assets test, etc.) mean that many vaccine-injured are ineligible for such support, and for those who can access it only three months of payments are available.

Workers compensation

Some are "fortunate" enough to have been injured whilst being subject to a workplace vaccine mandate, which opens the possibility of workers compensation. However, even in these instances, many claims are being rejected on the basis that the patient's symptoms are not recognised by the TGA, or the medical specialist preferred by the employer will override previous diagnosis and symptom severity, to the benefit of the employer's case.

COVERSE's early patient survey data suggests that two thirds of such patients are having their worker's compensation claims denied, which severely undermines the rationale for these mandates — if employers are not prepared to stand by their workers when they get injured complying with these mandates, then those employers have no business imposing such mandates at all, and this includes the federal and state governments.

COVID-19 vaccine claims scheme

The previous federal government established the *COVID-19 vaccine claims scheme*, aimed at compensating people for their economic losses resulting from an adverse reaction. However, to date only a handful of claims have been granted — less than 2% of claims submitted.³⁹ While some workers received leave payments for self-isolating with Covid and made use of schemes such as JobKeeper, the vast majority of the COVID-19 vaccine injured have received zero financial assistance or recognition of hardship since the very beginning of the rollout.

Attachment D includes a patient letter to the Minister for Government Services that details typical bureaucratic challenges being faced by patients applying to this scheme.

Compare this with Thailand, which has paid out over 10,000 vaccine injury claims, representing more than 70% of submitted claims.⁴⁰

The government of Thailand has provided security for all Thai people receiving these vaccines by allowing claims for *all* vaccine injuries, not just those from a narrow list, and not just those requiring hospitalisation.

Furthermore, they pay out provisional claims quickly (within 5 days of application) regardless of ultimate determination of whether the vaccine was the cause of the injury.

Clearly the government of Thailand has given greater consideration into supporting its citizens who "took one for the team" than many other governments around the world, and by doing so has demonstrated its commitment to fostering trust in their public health institutions and policies through openness and transparency. The Thai people can feel secure, knowing that their government indeed does have their back if something goes wrong with their vaccinations.

³⁹ [Evans2022] https://bit.ly/3GhT2Cr

⁴⁰ [NHSO2022] https://bit.ly/3USdVYE

The Australian Government scheme suffers from multiple failings that ensure that the vast majority of vaccine-injured Australians cannot access it. This only serves to foster further distrust in government health messaging and in the government's motives.

The initial points of failure in the Government's treatment of the vaccine-injured and their financial compensation are (a) the requirement to have suffered one of only a very small and specific set of "approved" adverse reactions, and (b) to have been admitted to hospital as an in-patient.

The first of these requirements ensures that a large number of Australians whose lives are still in turmoil due to their vaccine complications are ineligible for compensation via the Government's scheme, even though they have medical reports that prove their conditions have been caused by their vaccinations.

The second requirement similarly excludes the majority of vaccine-injured patients who are suffering ongoing impairment and disablement due to the vaccine reactions but were never admitted to hospital.

It appears as though this scheme has been developed to minimise the numbers of eligible patients in order to improve the optics around how many Australians have been negatively impacted by these vaccines. However, it has achieved the exact opposite — it is causing many Australians to realise that their government cares little for them, and that the government is more interested in covering up these injuries rather than openly demonstrating compassion and support for *all* vaccine-injured citizens, and being transparent around the real risks associated with these products.

The third eligibility criteria for the vaccine claims scheme requires that patients must be able to demonstrate direct losses (e.g. loss of salary) and costs (e.g. medical costs) of at least \$1,000. This is prejudicial to low-income and unemployed people who rely solely on public health support yet still deserve compensation for the pain and suffering endured by themselves and their families.

For these patients, doctors fees have been paid for by Medicare, and many have not pursued further medication or therapies since either they cannot afford the additional expenses or they are not informed that any options exist. We do not yet have a confident idea of how many of these Australians have slipped through the cracks, and it will take a significant redirection in public health messaging to identify such cases and enable them to access the treatment and compensation they deserve.

Further to these eligibility and abandonment issues, the scheme asks applicants to provide evidence of their economic loss. This is a relatively easy task for employees, but is difficult for small business owners, freelancers, students or people on zero hour contracts who may not have been drawing a regular salary. In the case of small business operators already dealing with significant financial losses due to the pandemic, or who may have been growing a business and sustaining themselves from their savings whilst doing so, the current scheme simply fails to consider such adverse (yet common) situations at all.

The current scheme is wholly inadequate and inappropriate in every aspect. We urge the current government to revise every aspect of this scheme to be inclusive of *all* vaccine injuries.

Disability support

The final piece of the puzzle with regards to financial support for the vaccine-injured is recognition and support of new disabilities caused by the vaccines. At present there is no clear pathway for recognition of disability due to a vaccine injury, particularly Long Vaccine Syndrome, and we note that the situation is similar for Long Covid sufferers.

Whilst we are hopeful that all Long Vaccine Syndrome sufferers will heal and be able to resume their full and productive lives as before, we are mindful that in an environment where we are treated with derision by our

government such healing may never come. The government must actively develop pathways for these individuals to obtain recognition of their disability, and ways to access established disability support mechanisms such as the disability pension and the NDIS.

5.4. Exemptions for Mandated Workers

Amongst our vaccine-injured community are many professionals mandated to not only be vaccinated against Covid, but to remain up-to-date with their boosters. Even though they continue to suffer ill health on account of their vaccine injuries, current rules around exemptions have left many of them in a precarious situation — unable to obtain an exemption from getting further shots yet not being in a financial position to be able to walk away from their income.

There are a number of barriers for these workers to obtain an exemption:

- As with a significant number of COVID-19 vaccine-injured patients, many doctors have been unwilling to identify the patient's condition with the vaccinations, and so will not provide an exemption for them.
- In cases where doctors do recognise the vaccine reaction, many refuse to provide an exemption out of fear of attracting the ire of health profession regulators (discussed below in section 6.1).
- Even if patients are able to obtain an exemption from their doctor, this is too often being rejected by health authorities.
- For those with ongoing health challenges and have been able to successfully obtain an exemption, this is usually limited to a few months only, and it is very rare for them to successfully obtain further exemptions after their first one expires.

These workers are afraid of speaking to anyone in their workplaces, government or media about these challenges, out of fear of being bullied, sacked or simply not given any further hours (as has occurred in a number of instances), and many have been pressured into getting additional vaccinations which has caused their symptoms to worsen.

5.5. Silencing of the Vaccine-Injured

Perhaps the most insidious injustice being inflicted upon the vaccine-injured has been the silencing of their voices by the government, traditional media, and social media networks. Hardly a day goes by without a member of our community being locked out of their social media accounts for "breaches of community standards" (aka daring to share their very real story of pain and suffering on account of their vaccinations).

In the USA, it is emerging that government actors actively colluded with social media companies on which topics and even which individuals to censor in the high stakes discussion of Covid.⁴¹ Whilst it might make sense to silence individuals inciting violence, it is hard to swallow that people already suffering huge social and medical injustice simply on account of their adverse reaction are being denied a voice and labelled as "misinformation" or "anti-vaxxers" following vaccination. This is a clear sign that our governments and many of our media corporations are in fact working against their citizens.

Many in our community have reached out to Australian journalists with their stories. Whilst a number of journalists are compassionate towards these patients, and the stories of abject failure by our governments

⁴¹ [Klippenstein2022] https://theintercept.com/2022/10/31/social-media-disinformation-dhs

and public health authorities to support them, most have revealed that they are simply not allowed to run such stories.

At any other time, in any other circumstance, these stories would make for prime-time journalistic coverage: ordinary honest citizens suffering at the hands of an unsympathetic and powerful government.

The fact that these stories are being actively suppressed leads us to suspect that political forces may be pressuring media outlets (perhaps through threats of funding cuts or the removal of tax concessions) to ensure that our stories remain hidden from the public eye, or that financial incentives (e.g. advertising) from large foreign pharmaceutical corporations is perverting the news narrative in Australia.

6. Medical Regulatory and Pharmacovigilance Failure

The first thing to remind the committee of, with regards to the monitoring and identification of safety signals from any vaccine, is that failure of pharmaceutical companies and pharmacovigilance agencies to publicise details of any given side effect is not evidence that said side effect is not caused by the vaccine.

The second thing to be reminded of is that causality in any given patient case cannot be denied in the absence of proper investigations.

Acknowledging these important and basic logic precepts is important, as much of our public health apparatus has doggedly insisted that individuals' adverse reactions cannot be related to their vaccination because government drug safety agencies have not publicised relevant safety warnings and the patient presents no evidence of causality.

The mantra "coincidence does not imply causality" has been inappropriately used to try and convince people of the safety of vaccines. However, in the world of actual science (as opposed to "science by policy"), coincidence is a reason to suspect causality and provides justification for further investigation.

Of all of the Australians that **CO**VERSE has spoken with who are vaccine-injured, not a single one has been contacted by drug safety agencies for follow-up investigations.

This fact is worth repeating:

Pharmacovigilance agencies have not conducted any follow-up investigation (nor have any other public health agencies).

With this fact, how can we be expected to believe any public health declarations associated with or reliant upon these regulatory bodies and their data? Significant reform is needed here.

6.1. Reporting challenges

When patients first experience an adverse reaction, they will generally seek medical help for their symptoms. Even though these reactions often occur relatively soon after vaccination, it is rare for doctors to prepare and submit an adverse event report to the appropriate authorities.

The reasons for this — based on what our doctors tell us — fall under three primary categories:

• The doctor is not certain that the symptoms are caused by the vaccine. Ironically, doctors often dismiss symptoms that might indicate a vaccine reaction if these symptoms have not been identified and communicated by drug regulators. This creates a vicious cycle, where doctors hence don't submit

an AEFI (adverse event following immunisation) report, which leaves drug regulators without relevant data to identify an appropriate safety signal. Without this safety signal, they will not inform doctors of the potential adverse reactions, and without this information, doctors often dismiss symptoms as vaccine reactions because they haven't been told about them...

- The doctor does not have the time to dedicate towards writing an adverse event report. It will typically take a doctor between 15-30 minutes to prepare and submit an adverse event report. These reports are mandated by law in many jurisdictions, yet too many doctors prioritise their waiting patients over fulfilling their obligations to their vaccine-injured patients and state medical authorities.
- Doctors are afraid of repercussions from their employer or from health profession regulators if they
 are seen to be "undermining" public health messaging around vaccine safety by submitting AEFI
 reports. This fear has been successfully instilled into the medical community by heavy-handed
 punishment of any doctor who dared to publicly question the safety of these vaccines or any other
 public health measure connected with the pandemic. Us, the vaccine-injured, are suffering due to this
 approach by health profession regulators.

This situation leads to significant under-reporting of adverse reactions by doctors — a situation that should not be allowed to have occurred during the rollout of new products under emergency use authorisation. While we cannot say to what degree this problem exists, we are confident in saying that the degree of adverse reactions being experienced by the public is likely well more than 10× greater than what is being reported.

In very many cases, patients experiencing a COVID-19 vaccine injury will have a large cluster of symptoms, but their doctors will not have a diagnosis for them. When reports do get submitted to drug safety authorities (either from the doctor or the patient), these consist largely of symptoms and no diagnoses.

In the complex cases of Long Vaccine Syndrome this means that drug safety agencies are receiving a significant number of reports with a wide variety of symptom clusters with no diagnoses and hence no firm conclusions as to what the vaccines may have done to the patients. Pharmacovigilance systems are poorly equipped to deal with such complex and disjointed symptom clusters, and without any dedicated case-by-case analysis, including active case updates on diagnoses later attained, these systems clearly fail to identify safety signals.

Many amongst our community have tried, in vain, to educate drug regulators about this situation, and in every single instance the regulators have shown zero interest in understand the complexities of these patient experiences or how they might begin to account for them in their analysis, and have steadfastly refused to undertake broader follow-up investigations with patients in order to better understand the progression of these symptoms.

It is also worth noting that Australia's national drug regulator is almost completely funded by the pharmaceutical industry — presenting a clear conflict of interest when it comes to the safety of Australian patients.

6.2. Pharmacovigilance shortfalls

The pharmacovigilance system in Australia consists of two parts. Firstly, AusVaxSafety, which conducts surveys of people who have recently received vaccines. For the COVID-10 vaccines, this survey process was time-limited to six weeks, and we would also argue that the most severely impacted of patients would have

been unlikely to have been well enough to complete the surveys. Moreover, this survey limited responses to pre-defined categories of symptoms only.⁴²

The second part of Australia's pharmacovigilance system is the TGA's system of voluntary reporting. The TGA claims to be "actively monitoring" reports, however, this is a gross misrepresentation of what they actually do. Receiving voluntary reports and adding them to a database is most certainly not an "active" undertaking — it is a passive system that is not compelled to investigate anything. In fact, their own website states that even if they find a safety signal, they can simply choose to do nothing about it.⁴³

Compare this situation with that of Germany. Their pharmacovigilance system has established an *ongoing* survey, in addition to passive reporting. This system has identified a "chronic fatigue"- like safety signal, which the Germany Federal Ministry of Health has labelled "Post-Vac-Syndrom".⁴⁴ Moreover, German data indicates serious adverse events occurring at a rate of 0.3-per-1,000 doses (in the Australian context, where the majority of adults have had at least three shots, this translates to a rate of a little over 1-in-1,000 individuals).⁴⁵

Throughout 2021 and 2022, a number of patients wrote to the TGA with adverse event reports that detailed Long Covid-like symptoms stemming from their vaccinations. They argued that the TGA surely had enough data to identify this as a safety signal, and that by not alerting the public to this potential adverse event it was denying all future vaccine recipients the right to be fully informed (informed consent) of the potential risks.

As the vaccine booster programs began, our online support groups saw new people join — people who did not have any significant issues with their primary doses but developed Long Vaccine Syndrome and other issues upon having their boosters. When they discover that there are many Australians suffering similar symptoms, that the Government was notified (and warned) of this situation and that the Government subsequently did nothing to communicate the risks, these patients are understandably furious.

Further, doctors who were noticing these adverse reactions were actively discouraged from speaking out publicly, with health profession regulators threatening to suspend the registration of doctors who made any statements that might undermine the Government's immunisation rollout.

Moreover, as time progresses we learn worrying facts about the clinical trials of most of these vaccine products and can't help but conclude that drug regulators (in Australian and overseas) did not undertake a thorough analysis of the clinical trial data, and/or have been disinterested in pursuing accusations of:

- Clinical trial protocols not being adhered to;
- Clinical trial data being altered;
- Cases of serious adverse events being misreported;
- Cases of serious adverse events being excluded from data.

In November 2021, the British Medical Journal published the result of an investigation of reports from a whistleblower involved in Pfizer's clinical trial that the contract company she was employed with suffered from an alarming number of data integrity issues, failures to adhere to proper protocols, and even fraud.⁴⁶ These claims have appeared to have gone unanswered by the TGA.⁴⁷

In our view, the Australian Government has grossly failed the Australian public in its pharmacovigilance duties.

^{42 [}Deng2021] https://doi.org/10.5694/mja2.51619

⁴³ https://www.tga.gov.au/safety/safety/safety-monitoring-medicines/tga-safety-monitoring-medicines

⁴⁴ https://twitter.com/BMG_Bund/status/1540243408123478016

⁴⁵ [PEI] https://www.pei.de/EN/newsroom/dossier/coronavirus/coronavirus-content.html?cms_pos=6

⁴⁶ [Thacker2021] https://doi.org/10.1136/bmj.n2635

⁴⁷ [Chung2021a] https://bit.ly/3GiRhoy

7. Conclusion

Australian residents who have suffered an injury from their COVID-19 vaccinations have been abandoned by the governments and health authorities that pushed them all to get vaccinated and convinced them that these products were "safe & effective".

These Australians have been:

- Dismissed by the medical profession;
- Ignored by drug safety agencies;
- Derided by our politicians, and;
- Silenced by our media.

These Australians did everything that was asked of them, and for their pain and suffering they have been treated as sub-humans.

This situation is unbecoming of a compassionate nation and of a compassionate government.

Australians who are struggling with a vaccine-injury ought to be celebrated, and our governments and public health authorities should be clambering over themselves to help these public health casualties.

We call on this committee to immediately:

- Apologise, on behalf of the Australian Parliament, for having abandoned these people, and;
- Make a public commitment to dedicate all necessary resources to ensure these Australians get effective medical care and have access to appropriate financial compensation.

8. References

[2GB2022] 2GB 873AM. (2022). *Teenager's harrowing journey after COVID vaccine side effect*. https://www.2gb.com/teenagers-harrowing-journey-after-covid-vaccine-side-effect/

[Boucau2022] Boucau, J., Marino, C., Regan, J., Uddin, R., Choudhary, M.C., Flynn, J.P., Chen, G., Stuckwisch, A.M., Mathews, J., Liew, M.Y., Singh, A., Lipiner, T., Kittilson, A.,Melberg, M., Li, Y., Gilbert, R.F. Reynolds, Z., Iyer, S.L., Chamberlin, G.C., Vyas, T.D., Goldberg, M.B., Vyas, J.M., Li, J.Z., Lemieux, J.E., Siedner, M.K., Barczak, A.K. (2022). Duration of Shedding of Culturable Virus in SARS-CoV-2 Omicron (BA.1) Infection. *New England Journal of Medicine*, 387, 275-277. doi:10.1056/NEJMc2202092

[Chung2021a] Chung, F. (2021). TGA requests information from Pfizer after medical journal alleges contractor 'falsified' safety data. *news.com.au*. https://www.news.com.au/technology/science/human-body/tga-requests-information-from-pfizer-after-medical-jo urnal-alleges-contractor-falsified-safety-data/news-story/342806323e802035bb1d810e561977f4

[Chung2021b] Chung, F. (2021). 'Too busy': Are rare vaccine reactions being brushed off by doctors? news.com.au.

https://www.news.com.au/lifestyle/health/health-problems/too-busy-are-rare-vaccine-reactions-being-brushed-off -by-doctors/news-story/043bc0eadc5e15aa17a94ea6e3362130

[Chung2022a] Chung, F. (2022). 'They say it's stress': Sydney woman seeks answers to migraines and tinnitus, six months after Pfizer. *news.com.au*.

https://www.news.com.au/lifestyle/health/health-problems/they-say-its-stress-sydney-woman-seeks-answers-to-migraines-and-tinnitus-six-months-after-pfizer/news-story/03cb54afd06b6f785b762f9c1a15aa1b

[Chung2022b] Chung, F. (2022). 'Outright lying': Australian scientist hits out at TGA after 'life-changing' Covid vaccine injury. *news.com.au*.

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

[Chung2022c] Chung, F. (2022). Queensland teacher's life 'ruined' after severe reaction to Pfizer shot. *news.com.au*.

https://www.news.com.au/lifestyle/health/health-problems/queensland-teachers-life-ruined-after-severe-reaction-to-pfizer-shot/news-story/90b45f2b10d90552b1de906149d8950f

[Chung2022d] Chung, F. (2022). DJ who 'lost motor skills' after Moderna vaccine says doctors privately admitted link. news.com.au.

https://www.news.com.au/lifestyle/health/health-problems/dj-who-lost-motor-skills-after-moderna-vaccine-says-d octors-privately-admitted-link/news-story/23d4186d816aeb91b18691548963be12

- [Cosentino2022] Cosentino, M. & Marino, F. (2022). Understanding the Pharmacology of COVID-19 mRNA Vaccines: Playing Dice with the Spike? *International Journal of Molecular Sciences*, 23(18). doi:10.3390/ijms231810881
- [CouzinFrankel2022] Couzin-Frankel, J., Vogel, G. (2022). In rare cases, coronavirus vaccines may cause Long Covid–like symptoms. *Science*, 375(6579), 364-366. doi:10.1126/science.ada0536
- [Cristoni2022] Cristoni S., Brogna C., Frongillo A., Marino G., Montano L., & Piscopo M. (2022). Detection of recombinant spike protein in plasma from vaccinated against SARS-CoV-2 individuals. *Zenodo*. doi:10.5281/zenodo.5831816
- [Deng2021] Deng, L., Glover, C., Dymock, M., Pillsbury, A., Marsh, J.A., Quinn, H.E., Leeb, A., Cashman, P., Snelling, T.L., Wood, N., Macartney, K. (2021). The short term safety of COVID-19 vaccines in Australia: AusVaxSafety active surveillance, February – August 2021. *The Medical Journal of Australia*, 217(4), 195-202. doi:10.5694/mja2.51619
- [DOHAC2020] Australian Government, Department of Health and Aged Care. (2020). *Communicable Diseases Intelligence Surveillance of adverse events following immunisation in Australia annual report, 2020.* doi:10.33321/cdi.2022.46.47
- [Di2022] Di, J., Du, Z., Wu, K., Jin, S., Wang, X., Li, T., Xu, Y. (2022). Biodistribution and Non-linear Gene Expression of mRNA LNPs Affected by Delivery Route and Particle Size. *Pharmaceutical Research*, 39, 105-114. doi:10.1007/s11095-022-03166-5
- [Diamond2021] Diamond, D. (2021). House panel: Trump sought to pressure FDA on covid vaccines, treatment. *The Washington Post*, 24 August 2022. https://www.washingtonpost.com/health/2022/08/24/trump-fda-pressure-covid-vaccines-treatment/

[Doshi2022] Doshi, P. (2022). Open letter to the CEOs of Pfizer and Moderna. Rapid response to "Covid-19: Researchers face wait for patient level data from Pfizer and Moderna vaccine trials". *BMJ*. https://www.bmj.com/content/378/bmj.o1731/rr-0

- [Edelman2022] Edelman A., Boniface, E.R., Male V., Cameron, S.T., Benhar, E., Han, L., Matteson, K.A., Van Lamsweerde, A., Pearson, J.T., & Darney, B.G. (2022). Association between menstrual cycle length and covid-19 vaccination: global, retrospective cohort study of prospectively collected data. *BMJ Medicine*. doi:10.1136/bmjmed-2022-000297
- [Evans2022] Evans, J. (2022). The major problem with Covid-19 vaccine compensation claims. *news.com.au*. https://www.news.com.au/national/the-major-problem-with-covid19-vaccine-compensation-claims/news-story/39 b052c5ec6abd11ff933659d309a20f
- [Fraiman2022] Fraiman, J., Erviti, J., Jones, M., Greenland, S., Whelan, P., M. Kaplan, R.M., Doshi, P. (2022). Serious adverse events of special interest following mRNA COVID-19 vaccination in randomized trials in adults. *Vaccine*, 40(40), 5798-5805. doi:10.1016/j.vaccine.2022.08.036
- [GiangPaunon2022] Giang-Paunon, S. (2022). Mom details 12-year-old daughter's extreme reactions to COVID vaccine, says she's now in wheelchair. *Fox News*. https://www.foxnews.com/media/ohio-woman-daughter-covid-vaccine-reaction-wheelchair
- [Greenhalgh2022] Greenhalgh, T., Sivan, M., Delaney, B., Evans, R., Milne, R. (2022). Long covid an update for primary care. *BMJ*. doi:10.1136/bmj-2022-072117
- [Grobbelaar2021] Grobbelaar, L.M., Venter, C., Vlok, M., Ngoepe, M., Laubscher, G.J., Lourens, P.J., Steenkamp, J., Kell, D.B., Pretorius, E. (2021). SARS-CoV-2 spike protein S1 induces fibrin(ogen) resistant to fibrinolysis: implications for microclot formation in COVID-19. *Bioscience Reports*, *41*(8). doi:10.1042/BSR20210611
- [Hanna2022] Hanna, N., Heffes-Doon, A., Lin, X., De Mejia, C.M., Botros, B., Gurzenda, E., Nayak, A. (2022). Detection of Messenger RNA COVID-19 Vaccines in Human Breast Milk. JAMA Pediatrics. doi:10.1001/jamapediatrics.2022.3581
- [Haseltine2020] Haseltine, W. (2020). Beware of covid-19 vaccine trials designed to succeed from the start. The Washington Post. https://www.washingtonpost.com/opinions/2020/09/22/beware-covid-19-vaccine-trials-designed-succeed-start/
- [Healy2022] Healy, D. (2022). Disappeared in Argentina. *davilhealy.org*. https://davidhealy.org/disappeared-in-argentina/

2pi.html

- [ICAN2022] Informed Consent Action Network (ICAN). (2022). V-Safe Data. https://icandecide.org/v-safe-data/
- [Khorshid2021] Khorshid, O. (2021). Australia will get fast and safe vaccine rollout with help of GPs. Sydney Morning Herald. https://www.smh.com.au/national/australia-will-get-fast-and-safe-vaccine-rollout-with-help-of-gps-20210215-p57
- [Klippenstein2022] Klippenstein, K., Fang, L. (2022). Leaked Documents Outline DHS's Plans to Police Disinformation. *The Intercept*. https://theintercept.com/2022/10/31/social-media-disinformation-dhs/
- [Lin2022] Lin, Z., Kessinger, C., Sheldon, C., Negron, S., Xu, B., Pu, W.T., Lin, C. (2022). Revealing COVID's Impact on the Heart. https://www.mmri.edu/2022/08/02/revealing-covids-impact-on-the-heart/
- [Montano2022] Montano, D. (2022). Frequency and Associations of Adverse Reactions of COVID-19 Vaccines Reported to Pharmacovigilance Systems in the European Union and the United States. *Frontier in Public Health*, 9. doi:10.3389/fpubh.2021.756633

- [NHSO2022] National Health Security Office (Thailand). (2022). One billion baht paid to COVID-19 vaccine recipients experiencing side effects. https://eng.nhso.go.th/view/1/DescriptionNews/One-billion-baht-paid-to-COVID-19-vaccine-recipients-experienci ng-side-effects-/409/EN-US
- [OzSAGE2022] OzSAGE. (2022). Importance of COVID-19 vaccination & development of better systems for management of uncommon subsequent adverse events. https://ozsage.org/media_releases/importance-of-covid-19-vaccination-development-of-better-systems-for-mana gement-of-uncommon-subsequent-adverse-events/
- [Patterson2022] Patterson, B.K., Edgar B. Francisco, E.B., Yogendra, R., Long, E., Pise, A., Beaty, C.,Osgood, E., Bream, J., Kreimer, M., Heide, R.V., Guevara-Coto, J., Mora, R., Mora, J. (2022). SARS-CoV-2 S1 Protein Persistence in SARS-CoV-2 Negative Post-Vaccination Individuals with Long COVID/ PASC-Like Symptoms. preprint. doi:10.21203/rs.3.rs-1844677/v1
- [PEI] Paul-Ehrlich-Institut (Germany). *Safety of COVID-19 Vaccines*. https://www.pei.de/EN/newsroom/dossier/coronavirus/coronavirus-content.html?cms_pos=6
- [Prasad2022] Prasad, V. (2022). COVID-19 vaccines: history of the pandemic's great scientific success & flawed policy implementation. *SSRN*. https://ssrn.com/abstract=4276828
- [Röltgen2022] Röltgen, K., Nielsen, S.C.A., Silva, O., Younes, S.F., Zaslavsky, M., Costales, C., Yang, F., Wirz, O.F., Solis, D., Hoh, R.A., Wang, A., Arunachalam, P.S., Colburg, D., Zhao, S., Haraguchi, E., Lee, A.S., Shah, M.M., Manohar, M., Chang, I., Gao, F., Mallajosyula, V., Li, C., Liu, J., Shoura, M.J., Sindher, S.B., Parsons, E., Dashdorj, N.J., Dashdorj, N.D., Monroe, R., Serrano, G.E., Beach, T.G., Chinthrajah, R.S., Charville, G.W., Wilbur, J.L., Wohlstadter, J.N., Davis, M.M., Pulendran, B., Troxell, M. L., Sigal, G. B., Natkunam, Y., Pinsky, B. A., Nadeau, K. C., Boyd, S. D. (2022). Immune imprinting, breadth of variant recognition, and germinal center response in human SARS-CoV-2 infection and vaccination. *Cell*, *185*(6), 1025-1040. doi:10.1016/j.cell.2022.01.018
- [Safavi2022] Safavi, F., Gustafson, L., Walitt, B., Lehky, T., Dehbashi, S., Wiebold, A., Mina, Y., Shin, S., Pan, B., Polydefkis, M., Oaklander, A.L., Nath, A. (2022). Neuropathic symptoms with SARS-CoV-2 vaccination. *preprint*. doi:10.1101/2022.05.16.22274439
- [Schieffer] Schieffer, E., Schieffer, B. (2022). The rationale for the treatment of long-Covid symptoms A cardiologist's view. *Frontiers in Cardiovascular Medicine*, 9. doi:10.3389/fcvm.2022.992686
- [Thacker2021] Thacker, P.D. (2021). Covid-19: Researcher blows the whistle on data integrity issues in Pfizer's vaccine trial. *BMJ*. doi:10.1136/bmj.n2635
- [Trougakos2022] Trougakos, I.P., Terpos, E., Alexopoulos, H., Politou, M., Paraskevis, D., Scorilas, A., Kastritis, E., Andreakos, E., Dimopoulos, M.A. (2022). Adverse effects of COVID-19 mRNA vaccines: the spike hypothesis. *Trends in Molecular Medicine*, *28*(7), 542-554. doi:10.1016/j.molmed.2022.04.007

Attachment A: Studies and Support Organisations

A.1. Global studies into vaccine injuries

While there are a number of small and targeted studies happening in different research institutions around the world, currently there are only two major international studies that are considering the international community and that will produce statistically significant results:

- Yale University, *LISTEN Study* to understand Long Covid, post-vaccine injuries and the corresponding immune responses. https://www.kindred.hugo.health/research/listen-study
- Global Vaccine Data Network, *Genomics of COVID-19 Vaccine-Induced Adverse Events*. https://www.globalvaccinedatanetwork.org/genomics-covid-19-vaccine-induced-adverse-events

A.2. Notable patient support groups

There are a number of patient support groups who are involved with research efforts in their countries. The most prominent ones are:

- React19 (USA) https://react19.org
- UK CV Family (UK) https://www.ukcvfamily.org
- Post-Vac-Syndrom (Germany) https://nebenwirkungen-covid-impfung.org

Attachment B: Scientific Summary of Long Vaccine Syndrome

Long Vaccine Syndrome is likely a form of post-vaccine Long Covid-like sequelae that become chronic after being induced directly by the vaccine antigen or by side effects from the body's immune response or a combination of these causes (Choutka2022; Schieffer2022).

Similar to Long Covid, it is the body's ongoing immune response that primarily keeps the body reacting over many months, even when the originating causative factor (namely the vaccine) has exited the system (Choutka2022; Schieffer2022; Patterson2022; Patterson2021a; Patterson2021b). Unlike Long Covid, which may have lingering viral components and infectious disease damage as contributing factors, Long Vaccine Syndrome is primarily a response to the spike protein itself, sufficient to create an extraordinarily debilitating condition (Schieffer2022; Patterson2022).

A full scientific breakdown of pathology is beyond the scope of this submission, and while the exact mechanisms involved are still unclear, the scientific literature presents several potential pathologies that may operate individually or in combination, which we summarise in short below:

- Immune system dysregulation, antibody response and ongoing autoimmune reaction: Immune response to the vaccine and the introduction of the spike protein into humans may lead to severe immune dysregulation, miscalibration and autoimmune reactions. Antibodies, anti-idiotype antibodies, and autoantibodies (all various forms of spike protein reactive immune responses) can lead to autoimmune reactions that cause symptoms extremely similar to Long Covid (hence the overlap with Long Vaccine Syndrome) (Hohberger2021; Wallukat2021). This may be due to the distribution of the lipid nanoparticles throughout body systems leading to the autoreactivity of many tissues after injection into the deltoid and subsequent widespread vascular circulation. Once perfused through many tissues, possibly including within long-lived immune cells, the inflammatory and autoimmune reaction builds, often for many months, until reaching a critical feedback point and becoming a chronic debilitating condition (Merchant2022; Patterson2022; Patterson2021a; Patterson2021b).
- Microclots and microthrombosis: The immune response and spike protein introduction can cause the blood to become hypercoagulable (clots quickly) and filled with microclots that perfuse microvasculature, causing microthrombotic events, which may lead to small vessel/capillary inflammation/damage in peripheral tissues (Grobler2020; Kruger2022; Pretorius2022; Nunes2022). These clots may not be detectable via standard clotting tests, however, they have been observed using specialised laboratory techniques (Grobler2020; Pretorius2022; Nunes2022).
- Endothelial injury and microvasculitis: Along with hypercoagulable blood, the blood vessels themselves can become systematically inflamed, and injury to their lining can lead to leakage, inflammatory microclotting and tissue injury perfusing into peripheral tissues, muscles and nerves (Kruger2022; RenzPolster2022; Turner2022). This may also include damage and leakage to the blood-brain barrier, leading to hyperactive immune responses due to foreign body infiltration, leading to various autonomic, neuropathic, and peripheral nervous inflammatory disorders (brain fog, blood/heart rate dysfunction etc.) (RenzPolster2022; Turner2022).
- Hypoperfusion, reperfusion and ischemic injury: Starvation of peripheral, muscle, nervous, and brain tissues leads to damage due to lack of nutrients and gas exchange, reperfusion injury (when clots clear dynamically) with shifting blood makeup, and finally, ischemic injury (lack of blood flow) to the tissues in the process (Wirth2021; Lubell2022; Turner2022; Grobler2020; Grist2022). This can lead to disability in the form of the inability to move, think, process or act, as well as a measured and dramatic ability to exert in any fashion (chronic fatigue) (vanCampen2021b; Wirth2021). Fundamentally, it leads to the entire body being unable to process materials correctly, specifically in

the nervous system, connective tissue, and microvasculature, analogous to multiple system starvation such as lack of oxygen, energy or food.

- Chronic inflammation and mast cell activation syndrome (MCAS): Tissue damage in the endothelial system across multiple organ systems leads to an activated inflammasome, in addition to damage increasing the presence of mast cell reactions in connective tissues (Glynne2022; Patterson2022; Patterson2021b). This causes systemic reactions in the gut, vasculature, connective tissues, brain and nerves, leading to a wide variety of hard-to-source symptoms, which can be initiated by food, stress, internal reactions, histamines and movement (Schieffer2022). This chronic systemic inflammation interacts with autoreactivity leading to a permanent homeostatic equilibrium of chronic fatigue, similar to permanent flu.
- Post-exertional malaise: A common co-occurrence with the above and below pathologies is that of
 post-exertional malaise (Choutka2022; Joseph2021). This involves a marked reduction in capacity,
 and an increase in symptoms, post inflammation and stress-induced exertion (Joseph2021;
 deBoer2022). It is one of the most dangerous components of this disease, causing any action to put
 the patient into further suffering, and exercise, in any form, should never be recommended in patients
 that become worse with exertion (vanCampen2021a; Choutka2022).
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and mitochondrial injury: Ongoing inflammatory damage can lead to the development of long-term or permanent ME/CFS, as well as mitochondrial injury, all of which can lead to a permanent and ongoing disabling reduction in the quality of life, energy and ability to work in any capacity (bed/housebound due to reduced energy production) (Choutka2022; RenzPolster2022; deBoer2022; Nunes2022). Fundamentally once in a diseased and stressed state, it becomes difficult for the body to self-heal back into a healthy equilibrium as the ability to act globally is dramatically and permanently impaired without outside intervention (Choutka2022; RenzPolster2022).
- Autonomic dysfunction: Various nerve, endothelial and hyperadrenergic reactions due to post-vaccine and post-viral illnesses can cause the development of various blood pressure dysregulation disorders such as; postural orthostatic tachycardia syndrome (POTS, high standing heart rate with normal exertion), orthostatic hypotension (low standing blood pressure), or hypertension (high blood pressure), etc. (Li2014; vanCampen2022a). These disable the ability of patients to move, walk, stand or carry out normal tasks due to poor blood pressure regulation (Li2014; vanCampen2022b). This interacts with hypoperfusion and ischemic regulatory issues, combined with CFS across the board, leading to a full body system essentially starved of blood, oxygen, and energy when it needs it most, during movement and thought.
- Nerve and muscle damage: Peripheral nerves and muscle fibres can be damaged by the multiple above pathologies, leading to the development of neuropathy (including small fibre neuropathy (SFN), chronic inflammatory demyelinating polyradiculoneuropathy (CIDP), rapid idiopathic sudden sensorineural hearing loss and non-length dependent neuropathy), fibromyalgia and muscle damage, causing debilitating symptoms that drastically impair the ability of anyone to function due to severe pain and suffering (Safavi2022; Stefanou2022; Oaklander2022; Schelke2022). Full body pins-and-needles, internal electric shocks, limb weakness, paralysis, hearing loss and other pain/nervous system reactions without a source can come from this damage (Safavi2022; Stefanou2022; Oaklander2022; Stefanou2022; Oaklander2022; Stefanou2022; Stefa

• Genetic comorbidities, gender and vulnerable populations: Ehlers-Danlos Syndrome (EDS) and other connective tissue dysfunctions, as well as neurodivergent populations, are often cross-correlated with being vulnerable to post-vaccine and post-infection disorders (Monaco2022; Columbo2022; Golstein2021). Many with underlying comorbidities (such as CE/MFS) appear to be at greater risk, as are those with a history of viral/fungal infections that can become reactivated (such as Epstein–Barr virus (EBV), Lyme and shingles) due to the immune system damage caused by the vaccine, leading to chronic secondary infection (Choutka2022). Females generally have much stronger immune responses and are more likely to develop such an autoimmune syndrome, with patient-driven surveys suggesting that females may make up 60-80% of sufferers (Safavi2022).

B.1. References

- [Choutka2022] Choutka, J., Jansari, V., Hornig, M., & Iwasaki, A. (2022). Unexplained post-acute infection syndromes. *Nature Medicine*, *28*(5), 911-923. doi:10.1038/s41591-022-01810-6
- [Colombo2022] Colombo, J., Weintraub, M. I., Munoz, R., Verma, A., Ahmad, G., Kaczmarski, K., Santos, L., & DePace, N. L. (2022). Long COVID and the Autonomic Nervous System: The Journey from Dysautonomia to Therapeutic Neuro-Modulation through the Retrospective Analysis of 152 Patients. *NeuroSci*, 3(2), 300-310. doi:10.3390/neurosci3020021
- [deBoer2022] de Boer, E., Petrache, I., Goldstein, N. M., Olin, J. T., Keith, R. C., Modena, B., Mohning, M. P., Yunt, Z. X., San-Millán, I., & Swigris, J. J. (2022). Decreased Fatty Acid Oxidation and Altered Lactate Production during Exercise in Patients with Post-acute COVID-19 Syndrome. *American Journal of Respiratory and Critical Care Medicine*, 205(1), 126-129. doi:10.1164/rccm.202108-1903LE
- [Glynne2022] Glynne, P., Tahmasebi, N., Gant, V., & Gupta, R. (2022). Long COVID following mild SARS-CoV-2 infection: characteristic T cell alterations and response to antihistamines. *Journal of Investigative Medicine*, *70*(1), 61-67. doi:10.1136/jim-2021-002051
- [Goldstein2021] Goldstein, D. S. (2021). The possible association between COVID-19 and postural tachycardia syndrome [Review of The possible association between COVID-19 and postural tachycardia syndrome]. *Heart Rhythm*, *18*(4), 508-509. doi:10.1016/j.hrthm.2020.12.007
- [Grist2022] Grist, J. T., Collier, G. J., Walters, H., Kim, M., Chen, M., Abu Eid, G., Laws, A., Matthews, V., Jacob, K., Cross, S., Eves, A., Durant, M., Mcintyre, A., Thompson, R., Schulte, R. F., Raman, B., Robbins, P. A., Wild, J. M., Fraser, E., & Gleeson, F. (2022). Lung Abnormalities Depicted with Hyperpolarized Xenon MRI in Patients with Long COVID. *Radiology*. doi:10.1148/radiol.220069
- [Grobler2020] Grobler, C., Maphumulo, S. C., Grobbelaar, L. M., Bredenkamp, J. C., Laubscher, G. J., Lourens, P. J., Steenkamp, J., Kell, D. B., & Pretorius, E. (2020). Covid-19: The Rollercoaster of Fibrin(Ogen), D-Dimer, Von Willebrand Factor, P-Selectin and Their Interactions with Endothelial Cells, Platelets and Erythrocytes. International Journal of Molecular Sciences, 21(14). doi:10.3390/ijms21145168
- [Hohberger2021] Hohberger, B., Harrer, T., Mardin, C., Kruse, F., Hoffmanns, J., Rogge, L., Heltmann, F., Moritz, M., Szewczykowski, C., Schottenhamml, J., Kräter, M., Bergua, A., Zenkel, M., Gießl, A., Schlötzer-Schrehardt, U., Lämmer, R., Herrmann, M., Haberland, A., Göttel, P., Müller, J., Wallukat, G. (2021). Case Report: Neutralization of Autoantibodies Targeting G-Protein-Coupled Receptors Improves Capillary Impairment and Fatigue Symptoms After COVID-19 Infection. *Frontiers of Medicine*, *8*. doi:10.3389/fmed.2021.754667
- [Joseph2021] Joseph, P., Arevalo, C., Oliveira, R. K. F., Faria-Urbina, M., Felsenstein, D., Oaklander, A. L., & Systrom, D. M. (2021). Insights From Invasive Cardiopulmonary Exercise Testing of Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Chest*, 160(2), 642-651. doi:10.1016/j.chest.2021.01.082

- [Kruger2022] Kruger, A., Vlok, M., Turner, S., Venter, C., Laubscher, G. J., Kell, D. B., & Pretorius, E. (2022). Proteomics of fibrin amyloid microclots in long COVID/post-acute sequelae of COVID-19 (PASC) shows many entrapped pro-inflammatory molecules that may also contribute to a failed fibrinolytic system. *Cardiovascular Diabetology*, *21*(1), 190. doi:10.1186/s12933-022-01623-4
- [Li2014] Li, H., Yu, X., Liles, C., Khan, M., Vanderlinde-Wood, M., Galloway, A., Zillner, C., Benbrook, A., Reim, S., Collier, D., Hill, M. A., Raj, S. R., Okamoto, L. E., Cunningham, M. W., Aston, C. E., & Kem, D. C. (2014). Autoimmune basis for postural tachycardia syndrome. *Journal of the American Heart Association*, *3*(1). doi:10.1161/JAHA.113.000755
- [Lubell2022] Lubell, J. (2022). Letter: Could endothelial dysfunction and vascular damage contribute to pain, inflammation and post-exertional malaise in individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)? [Review of Letter: Could endothelial dysfunction and vascular damage contribute to pain, inflammation and post-exertional malaise in individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)?]. Journal of Translational Medicine, 20(1), 40. doi:10.1186/s12967-022-03244-7
- [Merchant2022] Merchant, H. (2022). Inadvertent injection of COVID-19 vaccine into deltoid muscle vasculature may result in vaccine distribution to distance tissues and consequent adverse reactions. *Postgraduate Medical Journal*, *98*(1161). doi:10.1136/postgradmedj-2021-141119
- [Monaco2022] Monaco, A., Choi, D., Uzun, S., Maitland, A., & Riley, B. (2022). Association of mast-cell-related conditions with hypermobile syndromes: a review of the literature. *Immunologic Research*, *70*(4), 419-431. doi:10.1007/s12026-022-09280-1
- [Nunes2022] Nunes, J. M., Kruger, A., Proal, A., Kell, D. B., & Pretorius, E. (2022). The Occurrence of Hyperactivated Platelets and Fibrinaloid Microclots in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). *Pharmaceuticals*, 15(8). doi:10.3390/ph15080931
- [Oaklander2022] Oaklander, A. L., Mills, A. J., Kelley, M., Toran, L. S., Smith, B., Dalakas, M. C., & Nath, A. (2022). Peripheral Neuropathy Evaluations of Patients With Prolonged Long COVID. *Neurology: Neuroimmunology & Neuroinflammation*, 9(3). doi:10.1212/NXI.00000000001146
- [Patterson2021a] Patterson, B. K., Guevara-Coto, J., Yogendra, R., Francisco, E. B., Long, E., Pise, A., Rodrigues, H., Parikh, P., Mora, J., & Mora-Rodríguez, R. A. (2021). Immune-Based Prediction of COVID-19 Severity and Chronicity Decoded Using Machine Learning. *Frontiers in Immunology*, *12*. doi:10.3389/fimmu.2021.700782
- [Patterson2021b] Patterson, B. K., Francisco, E. B., Yogendra, R., Long, E., Pise, A., Rodrigues, H., Hall, E., Herrera, M., Parikh, P., Guevara-Coto, J., Triche, T. J., Scott, P., Hekmati, S., Maglinte, D., Chang, X., Mora-Rodríguez, R. A., & Mora, J. (2021). Persistence of SARS CoV-2 S1 Protein in CD16+ Monocytes in Post-Acute Sequelae of COVID-19 (PASC) up to 15 Months Post-Infection. *Frontiers in Immunology*, *12*. doi:10.3389/fimmu.2021.746021
- [Patterson2022] Patterson, B. K., Francisco, E. B., Yogendra, R., Long, E., Pise, A., Beaty, C., Osgood, E., Bream, J., Kreimer, M., Heide, R. V., Guevara-Coto, J., Mora, R., & Mora, J. (2022). SARS-CoV-2 S1 protein persistence in SARS-CoV-2 negative post-vaccination individuals with long COVID/ PASC-like symptoms.preprint. doi:10.21203/rs.3.rs-1844677/v1
- [Pretorius2022] Pretorius, E., Venter, C., Laubscher, G. J., Kotze, M. J., Oladejo, S. O., Watson, L. R., Rajaratnam, K., Watson, B. W., & Kell, D. B. (2022). Prevalence of symptoms, comorbidities, fibrin amyloid microclots and platelet pathology in individuals with Long COVID/Post-Acute Sequelae of COVID-19 (PASC). *Cardiovascular Diabetology*, *21*(1), 148. doi:10.1186/s12933-022-01579-5

- [RenzPolster2022] Renz-Polster, H., Tremblay, M.-E., Bienzle, D., & Fischer, J. E. (2022). The Pathobiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: The Case for Neuroglial Failure. *Frontiers in Cellular Neuroscience*, 16. doi:10.3389/fncel.2022.888232
- [Safavi2022] Safavi, F., Gustafson, L., Walitt, B., Lehky, T., Dehbashi, S., Wiebold, A., Mina, Y., Shin, S., Pan, B., Polydefkis, M., Oaklander, A. L., & Nath, A. (2022). Neuropathic symptoms with SARS-CoV-2 vaccination. *preprint*. doi:10.1101/2022.05.16.22274439
- [Schelke2022] Schelke, M. W., Barcavage, S., Lampshire, E., & Brannagan, T. H., 3rd. (2022). Post-COVID-19 vaccine small-fiber neuropathy and tinnitus treated with plasma exchange. *Muscle & Nerve*, 66(4). doi:10.1002/mus.27696
- [Schieffer2022] Schieffer, E., & Schieffer, B. (2022). The rationale for the treatment of long-Covid symptoms A cardiologist's view. *Frontiers in Cardiovascular Medicine*, 9. doi:10.3389/fcvm.2022.992686
- [Stefanou2022] Stefanou, M.-I., Palaiodimou, L., Bakola, E., Smyrnis, N., Papadopoulou, M., Paraskevas, G. P., Rizos, E., Boutati, E., Grigoriadis, N., Krogias, C., Giannopoulos, S., Tsiodras, S., Gaga, M., & Tsivgoulis, G. (2022). Neurological manifestations of long-COVID syndrome: a narrative review. *Therapeutic Advances in Chronic Disease*, *13*. doi:10.1177/20406223221076890
- [Turner2022] Turner, S., Naidoo, C. A., Usher, T. J., Kruger, A., Venter, C., Laubscher, G. J., Asad Khan, M., Kell, D. B., & Pretorius, E. (2022). Increased levels of inflammatory molecules in blood of Long COVID patients point to thrombotic endotheliitis. *preprint*. doi:10.1101/2022.10.13.22281055
- [vanCampen2021a] van Campen, C. L. M. C., Rowe, P. C., & Visser, F. C. (2021). Deconditioning does not explain orthostatic intolerance in ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome). *Journal of Translational Medicine*, 19(1), 193. doi:10.1186/s12967-021-02819-0
- [vanCampen2021b] van Campen, C. L. M. C., Rowe, P. C., & Visser, F. C. (2021). Orthostatic Symptoms and Reductions in Cerebral Blood Flow in Long-Haul COVID-19 Patients: Similarities with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Medicina*, 58(1). doi:10.3390/medicina58010028
- [vanCampen2022a] van Campen, C. L. M. C., & Visser, F. C. (2022). Orthostatic Intolerance in Long-Haul COVID after SARS-CoV-2: A Case-Control Comparison with Post-EBV and Insidious-Onset Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. *Healthcare*, *10*(10). doi:10.3390/healthcare10102058
- [vanCampen2022b] van Campen, C. L. M. C., & Visser, F. C. (2022). Long-Haul COVID Patients: Prevalence of POTS Are Reduced but Cerebral Blood Flow Abnormalities Remain Abnormal with Longer Disease Duration. *Healthcare*, 10(10). doi:10.3390/healthcare10102105
- [Waheed2021] Waheed, W., Carey, M. E., Tandan, S. R., & Tandan, R. (2021). Post COVID-19 vaccine small fiber neuropathy. *Muscle & Nerve*, *64*(1). doi:10.1002/mus.27251
- [Wallukat2021] Wallukat, G., Hohberger, B., Wenzel, K., Fürst, J., Schulze-Rothe, S., Wallukat, A., Hönicke, A.-S., & Müller, J. (2021). Functional autoantibodies against G-protein coupled receptors in patients with persistent Long-COVID-19 symptoms. *Journal of Translational Autoimmunity*, *4*. doi:10.1016/j.jtauto.2021.100100
- [Wirth2021] Wirth, K. J., Scheibenbogen, C., & Paul, F. (2021). An attempt to explain the neurological symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Journal of Translational Medicine*, 19(1), 471. doi:10.1186/s12967-021-03143-3

Attachment C: early data from **CO**VERSE patient survey, indicating breadth and severity of symptoms

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Attachment D: Letter to the Minister for Government Services

(included with permission)

The Hon Bill Shorten MP Minister for the National Disability Insurance Scheme Minister for Government Services Parliament House CANBERRA ACT 2600

Dear Minister,

I am writing to you with nowhere else to turn. On August 17, 2021, I was adversely affected by the Covid-19 vaccine. I had swelling in my heart and brain, nerve damage, autoimmune damage, and was diagnosed with acute severe pericarditis.

It has been over a year since this happened, however unfortunately I am still battling these conditions. Moreover, I am aware of many people in the community who are suffering much worse than I am.

On February 17, 2022, I submitted a claim to the *COVID-19 Vaccine Claims Scheme*, and joined the many thousands of others who are a part of this process. Since then, there has been almost no communication from Services Australia into the status, update, and progression of this claim.

Despite submitting over 200 pages of evidence, I received a letter from Services Australia in May 2022 stating that I needed to provide more information. I was also given a phone number at this time. Upon speaking to a representative from Services Australia, I was told that I had to put the information I had already provided into a form that had just been created by Services Australia. They also mentioned that they sent this letter out to everyone who has made a claim as a "catchall statement."

On July 22, 2022, I received a notification in my MyGov inbox that my claim had "progressed" and had been referred to an external Medical Officer for consideration. I spoke to a representative of Services Australia who said that they had not heard anything from the external Medical Officer, and could not provide me with any further information.

Minister, I am writing to you because I would like some clarification and justification in some of the processes as part of the *COVID-19 Vaccine Claims Scheme*, namely:

- External Medical Officer Review

Is it true that the external Medical Officer that reviews the claims are representatives from the Therapeutic Goods Association (TGA)? What expectations have been put on the TGA to review these claims in a timely manner? What consultation and communication do they have with Services Australia with regards to this scheme? Will their findings and review be made available to the claimant?

- Scheme Timeframe

I note the COVID-19 Vaccine Claims Scheme website states the following: "We have implemented a claims scheme for people who suffer a moderate to severe impact following an adverse reaction to a TGA-approved COVID-19 vaccine.

We have done this to provide a simple, streamlined process to compensate eligible people, without the need for complex legal proceedings."

Minister, these words are the furthest thing from the truth. Submitting a claim within this scheme was an extraordinarily difficult procedure. I am aware of many other Australians who aren't able to submit a claim because the scheme is far too complex. I am also aware that the scheme's policy is almost identical to that of the Civil Liability Act, which would in turn make it the absolute definition of a 'complex legal proceeding.'

If this matter was taken up as part of a common legal proceeding, there would be reviews, hearings, and constant correspondence to determine an outcome. Through the *COVID-19 Vaccine Claims Scheme*, such actions and mediums of communication are non-existent. This is putting a serious amount of stress on Australians who are already battling health and stress conditions – to no fault of their own. Minister, I wish to inform you that as a result of the abhorrent communication to claimants, many claimants will have no choice but to withdraw their claim (or not submit one in the first place), and instead take this matter to court in what will be an absolute stain on the Australian government.

Can you please provide clarification on what Services Australia means by stating the *COVID-19 Vaccine Claims Scheme* is a "simple, streamlined, process" in light of the information you have received in this letter?

- Review of Policy

Minister, since my submission in February 2022, the *COVID-19 Vaccine Claims Scheme* policy has changed to now not include providing a percentage calculation of pain and suffering.

It appears there are two major, high-level factors to assessing the claim:

- 1. 'Was the patient's harm caused by the Covid-19 Vaccine?'
- 'What is the appropriate pain and suffering calculation pertinent to the claimant?'

Through the policy and also in the timeframe of my claim review, it is clear that these are the two major factors.

In this sense, could you please explain how it is fair that claimants need to wait for this process to take place? It should be a simple, streamlined process to determine if the harm was caused by the Covid-19 vaccine, given the amount of evidence that has to be provided before submitting a claim.

From there, the scheme should allow a reimbursement to the claimant of their out-of-pocket medical expenses and past lost earnings <u>at the very least</u>. The government could also then make it much easier for claimants to access

Centrelink and other funding support networks while they wait for the legal process of the scheme to take place.

The response to whether the patient's harm was caused by the Covid-19 vaccine should not – in my case – be taking upwards of 8 months to determine. On many of my phone calls to Services Australia in this matter, they have blamed staffing issues and lack of workforce to keep up with the volume of claim submissions.

In September 2021, the scheme opened a 'notice of intent to make a claim' where people could notify the department that they were going to make a claim. The scheme then opened 3 months later in December 2021. Senate hearings and media reports showed that 10,000 Australians had registered their intent to make a claim. How then could the government not have been prepared with the appropriate staffing and training for something they knew was going to have 10,000 submissions?

I understand that when my claim has been reviewed by the TGA, that it will then be referred to an external legal panel to determine the value of my reimbursement.

Can you please inform me on what corporations/associations/companies are a part of this legal panel? If not, please justify how you won't release this information despite it being of necessary importance to the Australian public.

For future claimants, will you consider changing the policy to allow some form of immediate accessibility to funds upon determination that the claimant's harm was caused by the vaccine?

Finally, Minister, all I really want is for someone to talk to me like a human being. The content of this claim is my information – it's my personal, medical harm – it's my life that has been ruined – it's my condition that will significantly impact the rest of my life. I can't stand constantly being told that no one can give me any information, or provide anything to help my situation. I, along with many thousands of other Australians, have been beyond let down by this whole process. It has caused an extraordinary amount of stress to what is already a horrible situation.

I don't imagine you will consider responding to this letter. As disappointingly expectant as that is, this is more to document my process in dealing with the Australian Government, and will come in handy in the future. The Australian Government has failed me. The Australian Government has failed Australians. In the spirit of all Australians and what we represent, I just want someone to put a hand on my shoulder and say: "Sorry to hear what you've gone through, mate."

Let that be you if you want to restore this Australian's faith in his country.

Sincerely,

