COVERSE response to questions on notice for the Australian Senate inquiry into terms of reference for a *COVID-19 Royal Commission*

26 February 2023

COVERSE thanks the Senate Legal and Constitutional Affairs Committee for inviting us to attend the first public hearing of this inquiry and to provide further information to assist the Committee's deliberations. We were represented by co-founders Rachel O'Reilly (MA) and Rado Faletič (PhD).[1]

This document responds to specific questions on notice and provides additional contextual information and evidence towards the questions that were put to us during the hearing. We hope this additional effort is helpful.

As summarised in our opening statement, **CO**VERSE exists since 2022 because neither the Federal Government nor any State & Territory Governments are adequately addressing the very real scientific and ongoing public health issues of Covid vaccine reactions, nor providing any support for the vast majority of people suffering. The political consequences of this abandonment are multiple, evidencing a clear democratic deficit and declining public perception of truth in politics, which we see affecting citizen's trust in all major political parties and harming the uptake rates unfortunately for *all* vaccines.

Contextualising our concerns from a scientific perspective

COVERSE is both a patient-led and science-led organisation. Before we were established — noting that Australia's vaccine rollout lagged behind other Western countries — injured members of our Australian community were entirely dependent on private social media networks and the English language patient advocacy organisation React19 in the USA to understand their health problems,[2] medical doctors' interpretations of such, to make sense of emerging patient and treatment outcomes surveys[3] and

---

[1] Rachel O'Reilly is a writer, researcher, international artist and educator with an MA in Media and Culture from the University of Amsterdam. Her academic expertise is on neoliberal governance, cultural politics, populism and climate change. Her PhD research (suspended due to illness) addresses legal and media struggles around fossil fuels, corporate impunity and water futures in the rollout of unconventional gas mining in North Australia. She toured her first feature documentary internationally in 2020 www.infractionsdocumentary.net

Dr Rado Faletič is a consultant in the area of international scientific collaborations, and co-founder of boutique consulting firm Montroix Pty Ltd. He earned a BSc (Hons) in mathematics and a PhD for his research into the 3D visualisation of hypersonic air flows, both from The Australian National University. Rado has spent his career working across multilateral projects involving Australian scientists and institutions in areas such as computing, climate change, natural resources, infectious diseases, science policy, and more.

[2] It was not uncommon for injured Australians to sign up to global video calls hosted by React19 with special guest doctors in the early days, and for some of us this was the only medical expertise we had access to, and the only connection to other Australians suffering. The extreme paucity of information resulting from global media censorship and Australian medical industry censorship of everything to do with Covid vaccine reactions is explained at length in our public response to the *Exposure Draft Communications Legislation Amendment (Combatting Misinformation and Disinformation) Bill 2023*.
media.coverse.org.au/documents/submissions/ACMA%20misinformation%20bill%202023-08.pdf

[3] See, for example:

- react19.org/science-and-research/lit-reviews-and-surveys/react19-patient-led-research-persistent-symptoms-survey-1
- react19.org/science-and-research/lit-reviews-and-surveys/persistent-neurological-symptoms-patient-survey
- react19.org/research-studies-surveys/covid-vaccine-long-haul-survey-harriet-carroll-phd-kevin-deans-phd

peer-reviewed medical literature.[4] There are currently over 3,580+ peer reviewed medical journal articles regarding Covid vaccine reactions, yet no Australian medical research organisation studies or communicates this peer reviewed literature to our community, nor to our GPs. There are no professional, diagnostic or regulatory incentives for GPs to develop any expertise in this area. The ongoing absence of Australian diagnostic and treatment guidelines - out of step with international initiatives - results in our *ongoing* medical abandonment.

Today, in dialogue with our multiple international partners, **CO**VERSE aggregates Australian patient data via custom-built surveys from our community in order to gauge ongoing symptoms and medical diagnoses. We use our data to: map broader reaction trends, understand the real duration of specific post-vaccine conditions, identify what treatment routes our community is taking for these (with and without medical supervision), and assess broader political, legal, and economic barriers that the Covid vaccine-injured continue to experience. We also keep informed of international diagnostic work-up guidelines[5] and treatment guidelines being authored by doctor-patient collaborations in this space, in the absence of such important guidelines being put out by Australian medical groups for Australian GPs and/or their patients' self-advocacy needs.[6] As a patient- and science-led charity, we do not and cannot give medical advice.

COVERSE is at the forefront of patient-led research in this space and have already formally contributed data and expertise to:

- The Yale Listen Study (**L**isten to **I**mmune, **S**ymptom and **T**reatment **E**xperiences **N**ow), run by Yale University in the USA, takes seriously the productive role of online patient communities in granting agency to people with Long Covid and post-vaccine adverse events. It explores these patients' corresponding immune responses by collecting information about symptoms and medical history, including blood and saliva samples from some participants. medicine.yale.edu/ycci/listen-study

- 'Online Survey on COVID-19 Vaccine Adverse Events' run by the University of Maryland (USA) & React19 (in collaboration with **CO**VERSE and 11 other national advocacy groups). This is a first-ever IRB-approved patient-led research collaborative being driven by and for the science-led needs of vaccine injured groups, with the explicit aim of educating the global medical community and vaccine-injured patients. The resulting data, and subsequent peer-reviewed publications, will help to inform quality needs-driven future research in this area. www.react19.org/study

COVERSE is part of an international coalition of ~20 similar national patient-led organisations,[7] sharing and discussing latest peer-reviewed research, medical advancements, and advocacy efforts. This global community of volunteers includes qualified injured researchers and medical doctors.

We draw the Senate's attention to the continued relevance of our first public submission to the *Inquiry into Long COVID and Repeated COVID Infections (2022-2023)* including 'Attachment B: Scientific Summary of Long Vaccine Syndrome'.[8] Based on the emergent scientific literature, 'Long Vaccine Syndrome' or 'Post-vac 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. Similar if not identical 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 likely exited the system, with the spike protein being one common agent.[9] While the exact mechanisms involved are still being discussed in the scientific community, the scientific literature presents several potential pathologies that may operate individually or in combination 1) immune system dysregulation, antibody response and ongoing autoimmune reaction, 2) microclots and microthrombosis, 3) endothelial

[4] see react19.org/science-and-research/published-science-database
[5] e.g. react19.org/for-providers/provider-resources/diagnostic-workup-guide
[6] To our knowledge, the Australia College for Emergency Medicine (ACEM) has put out diagnostic guides for myocarditis/pericarditis and thrombosis with thrombocytopenia syndrome (TTS) — these are only short guides. Compare to footnote 5. acem.org.au/Content-Sources/Advancing-Emergency-Medicine/COVID-19/Resources
[7] see react19.org/get-involved/international-coalition
[8] media.coverse.org.au/documents/long-covid-inquiry/516%20-%20COVERSE.pdf
[9] for example see doi:10.3390/biomedicines11082287

injury and microvasculitis, 4) hypoperfusion, reperfusion and ischemic injury, 5) chronic inflammation and mast cell activation syndrome (MCAS), 6) post-exertional malaise, 7) myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and mitochondrial injury, 8) autonomic dysfunction, 9) nerve and muscle damage 10), genetic comorbidities, gender and vulnerable populations (e.g. EDS, ADHD, post-viral illness, females, etc).[10]

The more recent research paper 'Characterising long COVID-like COVID-19 vaccine reactions' by UKCVFamily's patient-led collaboration with scholars from the NHS-funded Long Covid Scientific Consultancy (LCSC) Cardiff University, San Diego State University, University of Kent, Hamburg University, and Oxford University - similarly maps what a research framework looks like for Covid vaccine reactions when that framework is patient-led and initiated.[11] Beyond the above example patient collaborations, globally significant research of most relevance to our patient communities in the Long Vaccine (+/Long Covid) space include studies on Long Vaccine conditions and experimental treatments at Marburg University, Germany,[12] on micro-clots and amyloid clots and treatments by Pretorius and Bell,[13] on immune/inflammatory responses and treatments by Patterson,[14] on dysautonomia and rehabilitation by Putrino,[15] and on the genomics and risk factors of COVID-19 vaccine-induced adverse events by Carlton at the University of British Columbia.[16]

This brief summary of the most current state of the science is important to assist in the contextualization of our answers to questions on notice for the Australian context. The state of the science frames our concerns as patients — that while the global acceptance of Long COVID-like vaccine reactions is steadily rising, both in scientific mainstream media and in research, patients across the world still find themselves in an evidence void, whereby clinicians are unclear about how to investigate or treat patients.[17] Australia stands out in fact for having no medical research organisation or researcher collaborations studying the peer-reviewed scientific literature of Covid vaccine reactions against our community's ongoing medical conditions — not in the immediate aftermath of our reactions, nor over time.

Not proactively studying or monitoring vaccine reactions

According to the Australian Government's management of the Covid vaccine rollout, the Therapeutic Goods Administration (TGA) is tasked with *passively* collecting data regarding our initial reactions and symptoms. The TGA website states that "The TGA closely monitors reports of possible side effects to the COVID-19 vaccines". This is extremely misleading to our political representatives and to the public, as the TGA does not "monitor" our community of patients, not qualitatively or quantitatively. The TGA only advises people to consult their GPs for ongoing medical examination and advice.

The cost to the public health system of our ongoing, roundabout pursuit of (and denial of) informed care is incalculably high, impacting also disability budgets and services. The personal economic cost of such information deficits and 'trial and error' treatment approaches creates an ever increasing debt burden for our already abandoned and disempowered community, harmed by a government-approved product and set of pandemic policies.

COVERSE are planning to release a report in the first half of 2024, with an analysis of the data we have collected directly from our Australian patient community, in the hopes that it will be of use to patients, doctors, researchers, and public health policy-makers.

Our initial written submission to this current inquiry included a number of footnoted references that the Committee may wish to re-examine in greater detail, as these references contain additional information and evidence for some of our concerns. Our other public submissions are similarly referenced, and we would

[10] media.coverse.org.au/documents/long-covid-inquiry/516%20-%20COVERSE.pdf
[11] doi:10.5281/zenodo.10582006
[12] "Post-vac syndrome — the forgotten COVID victims", www.dw.com/en/post-vac-syndrome-the-forgotten-covid-victims/a-65051748
[13] doi:10.1186/s12933-021-01359-7 & doi:10.1042/bcj20220016
[14] doi:10.3389/fimmu.2021.746021 & doi:10.3389/fmed.2023.1122529
[15] doi:10.1101/2023.11.09.23298266
[16] www.globalvaccinedatanetwork.org/ourwork/genomics-covid-19-vaccine-related-adverse-events
[17] doi:10.5281/zenodo.10582006

particularly encourage the Committee to examine the references provided in our submissions to Parliament's *Inquiry into Long Covid and Repeat Covid Infections*[18] (submission #516) and our submission in response to the *Exposure Draft Communications Legislation Amendment (Combatting Misinformation and Disinformation) Bill 2023*[19] (submission 31795) — copies are attached.

In response to specific requests from the Committee for further information, we include the following information:

Covid-19 Vaccine Claims Scheme listed conditions

The Government's compensation scheme for injuries sustained from the Covid-19 vaccines is complex, and difficult to navigate for injured Australians, with no administrative or legal support to assist with the preparation of claims. We made a very simple summary of the scheme's narrowness during our appearance before the Committee. The main issue, as the scheme currently stands, is that it fails to recognise or provide support for the vast majority (we estimate from our own data, 95-99%) of Australians who have suffered serious harms from these products.

Part of the problem lies in the significant under-reporting of adverse reactions and the failure of global pharmacovigilance agencies to identify major safety signals despite their own data. For example, in early 2023 a freedom of information request for data from the CDC in the USA revealed 770 different potential safety signals for the Covid vaccines, of which more than 500 constituted larger safety signals than myocarditis and pericarditis - which are both recognised by governments around the world.[20] The Australian Government's compensation scheme's compensable list of conditions relies on the TGA itself nominating specific medical conditions connected with the vaccines. However if the TGA doesn't actively or ongoingly monitor registered reaction patients - as we assert it does not - but instead allocates such responsibility to GPs (who on the whole do not file either initial or additional reports about the progress of our illnesses and diagnoses to the TGA), it continues to perplex the Covid vaccine-injured community how the TGA could or should be tasked with refining or reforming the list of recognised reaction conditions. Both the initial list, and the current updated version of the list, has very little relation to the scope, breadth or seriousness of reaction conditions represented by our patient community, and by earliest pharmacovigilance and post-marketing safety data.[21]

COVERSE wishes to insist also on numerous other serious inherent flaws in the scheme's design. Already mentioned during the first hearing for this inquiry is the fact that the scheme requires patients to have been hospitalised (i.e. admitted as an *in-patient*, rather than simply attending hospital emergency). This arbitrary requirement immediately excludes many Australians, even those who continue to suffer very serious disability on account of TGA-recognised reactions such as myocarditis. Then there is the issue that some diagnoses are recognised as risks for one vaccine product and not the others, even though throughout our patient community almost all of these conditions are being caused by all of the Covid vaccines to different degrees.

A related design issue is a problematic disconnect between the rates of reaction types and severity. For example, you may have experienced a medical condition so rare that only a handful of people in the world have that condition as a result of their vaccinations. Such rare cases receive attention in the medical literature precisely and rightly because they attract scientific interest and need further understanding. However, such a unique and rare serious condition would never make it onto the Government's list of compensable conditions, despite the medical and scientific evidence being able to demonstrate that it was likely caused by vaccination in each of those cases. People who experience such serious but rare medical conditions resulting from a therapeutic good with no long term safety data available in the beginning, will

---

[18] www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/LongandrepeatedCOVID

[19] www.infrastructure.gov.au/have-your-say/new-acma-powers-combat-misinformation-and-disinformation

[20] Note: surprisingly this information was not reported in mainstream press, as far as we know, nor was this data, or its analysis, published by the CDC in any peer reviewed scientific journal. However, others have attempted to explain the data, such as: researchrebel.substack.com/p/cdc-finally-released-its-vaers-safety

[21] e.g. Pfizer's *Cumulative Analysis of Post-authorization Adverse Event Reports of PF-07302048 (BNT162B2) received through 28 February 2021*. phmpt.org/wp-content/uploads/2022/04/reissue_5.3.6-postmarketing-experience.pdf

never be able to be compensated by a scheme that limits eligibility to conditions nominated on a very poorly updated shortlist.

The narrow list of compensable conditions in Australia currently are:[22]

- AstraZeneca:
    - Anaphylactic reaction
    - Capillary leak syndrome
    - Cerebral Venous Sinus Thrombosis (CVST) without Thrombocytopenia
    - Guillain Barre Syndrome (GBS)
    - Thrombosis with Thrombocytopenia Syndrome
    - Thrombocytopenia, including immune Thrombocytopenia
    - Transverse Myelitis.
- Pfizer/Biontech, Moderna or Novavax:
    - Anaphylactic reaction
    - Erythema Multiforme (Major)
    - Myocarditis
    - Pericarditis
- injury from the physical act of being vaccinated, such as SIRVA (shoulder injury related to vaccine administration)

We mentioned in session a (non-comprehensive) list of conditions that feature heavily in the global support groups (some conditions at rates significantly greater than any that are recognised by the TGA) and medical literature, but are not recognised by the Government's claims scheme:

- vaccine-induced ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)
- POTS (Postural Orthostatic Tachycardia Syndrome)
- tachycardia
- MCAS (Mast Cell Activation Syndrome)
- dysautonomia
- autoimmune conditions
- costochondritis
- ventricular dysfunction
- cardiac arrest
- stroke
- tinnitus
- vertigo
- menstrual and fertility issues
- thyroid disorders and more.

NOTE: We emphasised this list of serious uncompensated conditions is not comprehensive, and we argue that the deliberate limitation of the eligibility criteria has been inappropriately utilised by the Government to misinform the Australian public about the scope and severity of harms Australians have experienced from the Covid vaccines. On 18 September 2022 the Minister for Government Services is represented as claiming, with regards to the number of compensated claims, that "the figures showed the vaccines were overwhelmingly safe".[23] Clearly, in fact, the *vast majority of serious reactions* have not been compensated and will never be under the current scheme design.

COVERSE would be very happy to organise permissions for the Senate to access a short list of exemplary cases from our community where a claim has either a) been rejected despite clear medically confirmed evidence of severe injury linked to the Covid vaccines by doctors, or b) been deemed ineligible despite seriousness, sheerly due to the narrowness of the current scheme. This would give Senators a strong

[22] "Which conditions are eligible", www.servicesaustralia.gov.au/who-can-get-support-under-covid-19-vaccine-claims-scheme?context=55953#whichconditions

[23] "Less than 50 payments made for adverse reactions to covid vaccines", www.smh.com.au/politics/federal/less-than-50-payments-made-for-adverse-reactions-to-covid-19-vaccines-20220915-p5bigu.html

appreciation on the precise scale and scope of administrative injustices experienced by our community in the aftermath of the injustice of their vaccine-caused illness.

Comparison of international vaccine compensation schemes

Globally, the range of government programs that provide compensation for people who have suffered harms from the Covid-19 vaccines is extremely diverse. Some schemes have very narrow eligibility criteria that list very specific medical conditions, and others are broadly open in recognition that the biological response to vaccines is as diverse as humanity.

The University of Oxford's Faculty of Law has established the *COVID-19 Vaccine No-Fault Compensation Schemes Project*, which documents all public compensation schemes globally and provides detail of eligibility criteria. We would stress, however, that this project does not attempt to analyse the accessibility of these schemes, or whether they are fit-for-purpose. Our discussions with international counterparts suggests that these schemes are largely failing to support the majority of impacted people, with the shortcomings falling into three main categories: too narrow eligibility criteria, inadequate financial support for recipients, and lack of medical support for identifying vaccine injuries.

Full details of the project can be found via its website at:
www.law.ox.ac.uk/no-fault-compensation-schemes-covid-19-vaccines

The Committee may also find it helpful to listen to public testimony from the second meeting of the US National Academies "Review of Relevant Literature Regarding Adverse Events Associated with Vaccines" for insights as to emerging conditions being experienced by patients though not yet recognised by US compensation programs (and certainly not by the Australian program):
www.nationalacademies.org/event/03-27-2023/review-of-relevant-literature-regarding-adverse-events-associated-with-vaccines-meeting-2

It is our position that government compensation schemes should not limit compensation to conditions provided on a bureaucratic list, as doing so is guaranteed to exclude a significant number of patients who must then attempt to obtain compensation via the courts if they have the financial means to do so. Appropriate medical assessments by the patient's own treating physicians should suffice in determining if a patient's condition was caused by their vaccinations, even if they might be the only person in the world who experienced a particular condition from their vaccinations.

Pharmacovigilance concerns & Covid vaccine class action

As discussed in our submission and during the hearing, we have grave concerns about the way that government regulatory and pharmacovigilance authorities have dealt with the Covid vaccines and the adverse reactions being caused by them.

Whilst our insight into these problems are primarily around the patient experiences (which can confirm that affected patients are almost entirely not being investigated or followed-up by appropriate authorities, and are certainly not being studied by authorities nominally charged with the task according to existent governance arrangements), others have documented a range of specific concerns regarding regulatory failures. We note in particular the Statement of Claims made in the currently running class action against the Government and its officials, which provides detailed examination of the situation and the issues that should be of concern to Parliament.

These Statement of Claims can be downloaded from the class action website at:
www.covidvaxclassaction.com.au
and we provide a copy attached to this response (downloaded 13 February 2024), which includes a 3-page summary of the claims made in the action.

We particularly draw the Committee's attention to paragraphs 188 (page 499) and 211 (page 552), which summarise the scale of reports being received by the TGA and its failure to adequately address this unprecedented number of serious adverse events.

Our organisation is not aware of any patients, suffering a serious Covid vaccine reaction, who have been investigated by the TGA. This lack of investigation is a part of every patient's story, and highlights one of the reasons why a Royal Commission is necessary in order to explore this, and other, pharmacovigilance shortcomings despite constant reassurances from Government.

If the Government adequately compensated vaccine-injured Australians, quickly, for any and all conditions attributed by medical specialists in individual patient cases, then there would be no need for class actions or any other type of legal recourse. Sadly, the Government's inadequacies, failures and strategic blunders have made legal actions against it an urgent necessity.

Individual stories of vaccine injury

Our two board members who appeared before the Committee have previously documented various aspects of their vaccine injuries.

We attach Rachel O'Reilly's letter (redacted to protect privacy of some named individuals) to her MP, Mr Graham Perrett (Moreton), and we request that this letter be considered confidential by the Committee, and not be made public, as it contains personal medical information.

Also attached is a copy of Dr Rado Faletič's speech at a public event in mid-2023 in which he details aspects of his reaction, along with a copy of a news media interview with him from mid-2022.