

Personal submission on the exposure draft bill:

Communications Legislation Amendment (Combatting Misinformation and Disinformation) Bill 2023

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Introduction

I am writing to express my extreme concerns regarding the draft misinformation and disinformation bill.

I am an older woman who has experienced a severe adverse reaction to the AstraZeneca COVID-19 vaccine on 19 May 2021. On that date, my life suddenly became coded as 'disinformation' by Australian government and social media policies, and I still live with the dire consequences of the censorship of my medically confirmed vaccine-induced illnesses to this day. I have been diagnosed with a range of injuries affecting all my body systems. These injuries shut down my life as I knew it and, 26 months after the injury, I have still not fully recovered. I have not been able to undertake paid work for that entire period and will not be able to do so in the foreseeable future.

I am fully aware that misinformation and disinformation, broadly speaking, and in very particular instances can have negative consequences for the community, and therefore I do understand some of the well-meaning sentiments with which this legislation has been written.

However, I am also too well aware that the current practices of censorship are quite literally disabling, indebting and abandoning my fellow Australians. Over the last two years, censorship carried out by the media, educational institutions, social media and digital platforms in response to government Covid policies have already caused me severe and continuing harm as I attempt to obtain proper compensation, medical information and care, treatment and peer support as a vaccine-injured Australian.

Due to the censorship of emerging peer-reviewed scientific research and legitimate investigative journalism on Covid vaccine harms, I have been impeded in my efforts to find medical help and treatment. Furthermore, false claims provided to me by the Government and medical community (for example that our reactions are 'self-limiting' or not severe) have hindered proactive action by my treating physicians and have been, therefore, damaging to public health.

Perhaps most alarmingly, in the context of receiving such limited assistance from the Australian government and medical establishments, I have even been prevented from sharing my personal story. This has interfered with my ability to gain emotional and peer support from my social networks, because of social media censorship, again under the spurious claim that my personal story would be damaging to public health.

The increase of, and normalisation of these powers, and the provision of additional reserve powers, will not protect me and other vaccine-injured Australians from harm. The bill is intended to protect me and people like me, but it will instead increase our vulnerability and harm our health, which is in direct contradiction to the purpose of the bill.

Examples of harm I have received:

1. Inability to get a diagnosis or treatment and, therefore, being abandoned to deal alone with severe pain and disability.
2. Having to visit multiple medical providers only to be ridiculed, judged and sometimes insulted, and turned away without help.
3. Having to impose terribly on my partner for support, and witness his distress and horror at what was happening to me and the lack of medical or other help available.
4. Complete lack of information available on government websites, and outright lies.

5. Complete lack of financial or practical support to help me find, navigate and access medical treatment.
6. Terrible and untreated symptoms – terrible whole body pain, loss of cognitive capacity, dementia, loss of senses (especially vision and hearing), loss of balance and ability to walk unaided, so many other injuries and symptoms.
7. Terrible psychosocial losses – loss of capacity to work, to engage socially and in my community, loss of ability to contribute to society, loss of professional position and esteem, total loss of agency. Worst of all, loss of being able to be a wife and mother.
8. Huge financial loss – loss of income-earning capacity and enormous injury-related costs.

Initial injury

Australia's rollout lagged behind the rest of the world and I should therefore have been able to access experiences and data from elsewhere. So when I initially reacted to my Covid vaccination, it was shocking to find a total lack of information on government and public health websites, web searches and social media on what to do if you had a serious reaction, or what the array of symptoms being experienced could be.

Eventually was not able to locate a support group because I live in a regional town. However, months into my reaction, I discovered a community of researchers on Twitter and COVERSE which enabled me to inform myself about emerging knowledge. This significant and traumatic delay in accessing useful information about a life-destroying set of very serious symptoms meant a delay also in finding appropriate medical treatment. This, in turn, further delayed starting treatment for the worst of my symptoms. Had I been able to start this treatment soon, I may have had a better outcome with perhaps fewer long-term harms and the continuing disablement I have experienced.

Uninformed medical staff

When I sought medical treatment, medical staff had no access to meaningful guidelines about my illness and were unaware of how to identify my symptoms as a Covid vaccine injury. Several told me it was nothing and not to worry about it. Their catastrophic ignorance was (and remains) directly due to the censorship of any public discussion of Covid vaccine adverse reactions. I found one GP (then, after I moved to a new town, I eventually found another one) who was able to recognise my vaccine reaction as a serious issue. But, due to their having no access to information about how to effectively treat my injuries, it has been guess work among us to work it out as best we could. I still don't have an explanation for many of my terrifying ongoing symptoms and injuries and, therefore, no pathway to treatment.

To be clear, protocols for the treatment of Covid vaccine injuries were being developed by doctors and researchers around the world at this time. However, they were not being developed in Australia (and there are still no public, national, accessible guidelines for GPs or patients about how to identify or treat medically recognised Covid vaccine reaction outcomes).

In my case, the first step was to identify and treat neurological pain that was so extreme I was confined to the house and unable to do anything for myself other than the most basic of self-care. Even that left me in agony and tears, and exhausted. The combination of high doses of pregabalin and amitriptyline that was needed to control the pain left me with medication-induced dementia. As a professor of science, I'll let you think about how that affected me. The latest horrific finding, discovered from a brain MRI ordered to investigate continuing problems with balance and

coordination, is that I have abnormalities in my brain consistent with possible early MS. I have to wait six months, now, until the MRI can be repeated to look for changes in my brain structure. Again, I'll let you think about how that feels.

Other symptoms, such as sudden unexplained adrenalin surges, sudden unexplained breathlessness and problems with vision and hearing, have still not been addressed and I remain living with significant disabilities. I have not worked full-time since May 2021 and was only able to resume a few hours a week earlier this year. Early treatment could have enabled me to recover more quickly, reducing the long-term harm and enabling me to resume a more normal life, including my important research. Censorship of vital new information and scientific break-throughs got in the way of this.

Throughout my efforts to obtain medical assistance for my injuries, I have had to pay for every consultation (including abusive and ignorant ones), diagnostic test and medication. It has cost me thousands of dollars – this in the context of being unable to work.

Lack of government funded medical research

Trying to find evidence-based treatment protocols from Australian research is impossible because government-funded institutions will not conduct research into vaccine injury for fear of losing credibility (and funding) by being labelled as misinformation. The atmosphere of censorship that has been allowed to develop in Australia, because of the gagging of public debate around anything to do with Covid vaccine harms, has had a direct effect on our scientific community, stifling our ability to objectively investigate and examine adverse outcomes from Covid vaccines.

For myself and my treating medical professionals, this has meant we have had no assistance from the Australian research community as we have sought to find evidence-based treatment options. Treating my neurological pain was the result of a hit-and-miss process – itself traumatic – and it did not address the underlying causal problem. This has prolonged my suffering and worsened the long-term impact on my health.

Trying to find support groups once injured

There are no government support groups, therapies or rehabilitation, or even any treatment plans. I had to find these or – more often – work these things out myself. Again, this has been incredibly difficult because of the censorship on social media. People must talk in code about their vaccine injury, making suitable support groups very difficult to find. In many instances, these groups have been shut down by social media companies for the perverse reason that discussion of very real and incredibly debilitating vaccine reactions was somehow of harm to the community.

There have been, of course, no government attempts to provide information or support for the loved ones of vaccine-injured Australians like me. Again, I'll leave it to you to think about how it feels for my husband, children and friends reduced from a highly-functioning woman and senior research academic leading a full and engaged life to a person with dementia.

Government misinformation

Since critical public discussion of the Covid vaccines was censored, and only the official “safe & effective” messaging was allowed to be shared online, known and potential risks of these vaccines were suppressed, even though many were identified long before governments officially recognised them. (Today, there are still many acknowledged adverse reactions that our governments have not

told the public about through their official channels.) Covid vaccine injuries numbers and rates by state/territory and federally have never been collected, collated or published. We are literally invisible and voiceless.

This environment led me to believe that the vaccine would be safe for me and that the public health system would look after me if something adverse happened. This has turned out not to be the case. The exact opposite has been true. Australian governments, along with social media actors, are still perpetuating misinformation about the real risks associated with these vaccines. I'm very strongly pro-vaccine but these lies are leading to more Australians becoming seriously injured by them.

Censorship of all messaging other than official government claims of vaccine safety is directly responsible for my decision to get vaccinated, and for my inability to find the treatment and medical and psychosocial support I need. This has caused me significant harm, including traumatic stress. The government and social media organisations must take responsibility for this harm. Any and all efforts that seek to ensure that this environment continues will only ensure that more Australians will be harmed as a direct result of this official misinformation.

Conclusion & Recommendations

As previously stated, I am a vaccine-injured Australian and a scientist. I am absolutely NOT interested in receiving or sharing misinformation or disinformation. But the government controlled and tightly defined parameters about 'acceptable' Covid vaccine information has reduced the flow of information and support to nothing. As a result, I have been abandoned and left to fend for myself.

The provision of the Covid-19 Vaccine Claims Scheme demonstrates the Government's acknowledgement of at least a tiny fraction of the serious and long-term adverse consequences of Covid vaccination. We are clever enough to work out how to share needed information about vaccine injuries while still promoting population vaccination – a goal I strongly support.

If a situation such as my own, and that of other vaccine-injured Australians, can occur within the current legislative and industry frameworks, surely this is a red flag that current public health information is inadequate.

Further tightening of this legislation is only going to increase the numbers of innocent and unintended victims of Covid vaccines. Indeed, this will apply to *any* important issue that authorities and consensus groups determine they don't want discussed in public.

It is my recommendation that all efforts (including this bill) that serve to censor or hide unpopular views be abandoned. Even if governments and consensus positions don't like the facts, they are still the facts.