

Personal submission on the exposure draft bill:

Communications Legislation Amendment (Combatting Misinformation and Disinformation) Bill 2023

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Date: 17 August 2023

Introduction

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

I am a [REDACTED]-year-old female who has experienced a severe adverse reaction to the [REDACTED] COVID-19 vaccine on [REDACTED]. 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 vaccine induced pericarditis, lung hyperinflammation, Functional Neurological Disorder, POTs, Dysautonomia, dysarthria, aphasia, ataxia, paraesthesia, chronic headache and migraine, and I am still undergoing testing to try to determine root causes for a number of other symptoms I experience on a daily basis that impact my life to such an extent that I am no longer able to work, drive or care for my family.

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 extreme and ongoing 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 prevented from finding medical help and treatment. Furthermore, false claims provided to me by the Government and medical community (for example that our reactions are 'self-limiting') 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, and from gaining mental 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, as the bill is intended. 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:

Initial injury

When I initially reacted to my Covid vaccination, despite Australia's rollout lagging behind the rest of the world, and thus ought to have been able to access experiences and data from elsewhere, 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.

My vaccine reaction was when Australia first reopened, the Omicron wave had hit, hospitals were overflowing with people, there were no RATs available to test for Covid and people could wait in line all day for a PCR and then wait another 2-3 days to get test results. I was hit with such a sudden and unexpected array of symptoms after my booster vaccine that I really had no idea what was happening to me. I went through all the government information about reactions to vaccines and covid and could not find any information that related to the symptoms I was experiencing. I searched online for other sources of information about my symptoms, desperately trying to find out why I was suddenly so unwell and whether I should be going to the hospital – when the media was reporting to stay away from hospitals unless you were seriously unwell. I could not find any information to assist me.

It was not until 5 months after my initial onset of symptoms, after I had spent 6 weeks in hospital, that I found medical support online. I was only able to find this because a friend of mine, whose wife had long covid, was told in code by her doctor about this support. Watching a video from this group for the first time just made me cry and cry. I saw a woman, who was also vaccine injured, who had the same speech issues that I now have, and then I saw a doctor who apologised and with tears in his eyes said that he was so sorry that they had not been able to do more to prevent this from happening to us. The protocols I was then able to access from this group of doctors helped me to gain a better direction for what to do with my ongoing recovery. It also enabled me to start to see that what I was experiencing was not a mild or moderate illness, and I was not going to be getting better any time soon. I had to start preparing myself for a long battle with rehabilitation and adjustment of my life. To this day I am left to ponder if I had been given access to these treatment protocols sooner, would my long-term outcome have been better?

Uninformed medical staff

When medical treatment was sought, due to the censorship of any public discussion of Covid vaccine adverse reactions, medical staff had no access to meaningful guidelines about my illness. In my 7 hospital presentations and 3 admissions, my condition has always been recognised as an adverse reaction to the covid vaccine, but the doctors I encountered were completely unaware of how to treat my case. I was told many times while in hospital emergency that they are seeing lots of vaccine cases, but they also told me that the research they have is only on young males, so they could not explain why I, as a middle-aged woman, was experiencing such a serious, multifaceted and long-lasting response. Even now, 20 months on, as I

continue to try to access treatment for my ongoing and chronic symptoms, the doctors and specialists that I see do not know how to diagnose or treat me. My body demonstrates symptoms that traditional testing methods do not recognise, and when treatments are attempted for my symptoms, the reactions that I have are unexpected and unusual for what would normally be seen.

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, if doctors could easily access testing for spike protein, or microclotting, mast cell activation syndrome or functional MRI, then some of my ongoing issues may be able to be identified, and the treatments that are being developed implemented. Early treatment could have enabled me to recover more quickly, reducing the long-term harm. Censorship of important cutting-edge information got in the way of this.

Lack of government funded medical research

Trying to find treatment protocols that are based on research coming out of Australia 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 their 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. Like many vaccine injured patients, research into multi-organ inflammatory response, would have given my treating professionals some understanding of why my body continued to flare acutely, over the course of a number of months. If there had been research into this phenomenon, then doctors could have better responded by reducing this inflammation, which could have prevented the long-term impact of chronic inflammation and reaction that I now experience.

Trying to find support groups once injured

There are no government support groups, therapies or rehabilitation or even treatment plans. I had to find these things myself, but again this has been incredibly difficult to find because of the censorship on social media. People must talk in code about their vaccine injury, and support groups are therefore very difficult to find, and in many instances 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.

It was 4 months after my initial onset of symptoms that I was eventually told about an online support group by my chiropractor. Reading the stories of other people who had experiences that aligned with my own brought me immense comfort and stopped me from feeling so alone and isolated. I was told about other groups by my homeopath about 9 months into my illness. These groups have become my anchor. They offer me understanding, advice, hope, care and support. I do not know that I would have survived with my mental health intact if I had not found these groups. I have been involved in the disability community as an ally and advocate for 25 years and I knew that these groups must exist. I knew their value. I knew their purpose. I also knew that for other disability groups all it takes is to type in the name of the disability into the search engine and you will find an array of support options. That this has been denied to the vaccine injured because of the false premise that these support groups would harm the community has caused immense harm. I personally know people who have been close to suicide because they were unable to find any supports.

Trying to talk to family and friends about what has happened on social media and being censored

Personal posts to family and friends, sharing news of what has happened to me, why I was no longer working, why I had been in hospital, why I was no longer able to go out socially, were censored – either taken down or shadow-banned. I regularly find that my posts, or the posts of my vaccine-injured friends, are missing or the comments have been removed. Despite my story, and the similar stories of many thousands of other Australians, being factual, social media and other media actors (including government representatives) sought to silence my voice and the facts of my situation, causing further harm and a significant amount of distress to myself and my family.

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 (and today, there are still many acknowledged adverse reactions that our governments have not told the public about through its official channels).

This environment led me to believe that the vaccine would be safe for me, and that I would be well looked after if something adverse happened. This has turned out not to be the case, and the government along with social media actors are still perpetuating misinformation about the real risks associated with these vaccines 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, which has caused me significant harm. The government and social media organisations must take responsibility for this harm, and 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. I am not interested in receiving or sharing misinformation or disinformation, but within the current framework of government controlled and tightly defined parameters regarding Covid vaccine information, 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 small fraction of the serious and long-term adverse consequences of Covid vaccination.

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 further tightening of this legislation is only going to create more innocent and unintended victims, not only on this issue but on *any* 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, regardless of perceived basis in fact or consensus positions, be abandoned.