

Dear Petition Committee,

I want to start this response by thanking the Petition Committee for giving me the chance to respond. I would also thank Jeremy Miles for acknowledging the following in his response, *"Regrettably, a small number of those vaccinated may experience adverse effects that are more severe, persist or have lasting effect."* It is the first acknowledgment from a Welsh Government Minister acknowledging that some do have persistent adverse effects to the covid vaccine.

Background

I was diagnosed with Post Covid Vaccine Sequelae (PCVS) by a NHS Consultant in June 2022 (1). This was 15 months after the first AstraZeneca Covid vaccine in March 2021. I had an adverse reaction to the the first Covid vaccine. My GP at the time didn't know if these symptoms were due to my pre-existing diabetes, the start of fibromyalgia, or something autoimmune. I was advised to have the second AstraZeneca, within hours I had a relapse in symptoms - I have a timeline of appointments, I also kept a diary of daily symptoms due to my decline in remembering.

If there was better awareness to what Jeremy Miles has said in his response, *"regrettably a small number of those vaccinated may experience adverse effects that are more severe, persist or have lasting effect"*, I would have hopefully had been advised by the GP not to have the second Covid vaccine. If I had known what might have happened, I wouldn't have had the second AstraZeneca. There is still not enough awareness by health care professionals that these adverse effects can happen.

Being diabetic, I was classed as vulnerable, 1 of a group of 6 priority groups for the rollout of the covid vaccine. The Covid vaccine was supposed to protect me, to keep me safe in the job that I enjoyed. In 2021 I had difficulty in accessing healthcare, often being told to call back as there wasn't any appointments even though eg I explained that I was experiencing a new onset of pins and needles in my feet, legs, hands & arms or numbness in my foot.

In June 2021 one GP told me over the telephone *"your bloods are fine, you've been examined twice, graded exercises will help you"*.

This was an appointment for a new leg pain that I was experiencing and an increase/ relapse in other symptoms. The GP had never met me before, hadn't taken my activity history, eg that I'd walk my dog every day. The GP eventually agreed to an appointment, to just examine my leg, *"to put my mind at rest"*. I was examined and given a change of medication and a fit note for my employer.

It was not until August 2021 that I was eventually referred for a lumbosacral spine MRI & also a referral to Orthopedics for the pins and needles that had started in March 2021. I went private in October when we found out that Orthopedics were seeing Urgent 2020, I was Routine 2021, there were long waiting lists and I was extremely concerned regarding the pain and the symptoms. In January 2022 at the second Private Orthopedics appointment, the Consultant said *"I'd symptoms that needed ruling out"* & referred me to a Private Neurologist. In February 2022, Neurologist diagnosed, *"unexplained neurological symptoms in the aftermath of a covid vaccine"*.

He wrote in the clinic report *"This has been quite a common situation over the course of the last year, and I have seen numerous individuals with difficult to explain symptoms which arose around that time."*(3)

Some in the NHS were not accepting of the diagnosis. Being told I would *"need to challenge the Neurologist diagnosis"*. That *"chasing a diagnosis could harm my mental health"*.

It wasn't until later that year, 15 months after the first Covid vaccine in June 2022 I was eventually diagnosed with PCVS by a Long Covid NHS Consultant in the neighbouring health board. I will always be truly grateful to this hospital team.

There needs to be better awareness that some regrettably will suffer from adverse reactions, so healthcare professionals are aware that they know where to refer us to, so patients get seen sooner, we get the right tests, to get adequate treatment. The right tests, the right treatment, in the right place at the right time.

Patient information leaflet

Not once were we given the information that *"a small number of those vaccinated may experience adverse effects that are more severe, persist or have lasting effect"*

The patient information leaflets did not state that some may experience adverse effects that are more severe, persist or have lasting effect. (4)

We were constantly told the covid vaccines were safe and effective.

"Protect yourself, your loved ones, to keep Wales safe" was the message from Welsh Government

Patients need all the available information, so we can make an informed decision regarding any possible risks. Much more is known now (5a,5b) compared to what information was provided in 2021 (4)

Despite having a diagnosis of PCVS there is currently no adequate treatment, no cure, just medication to try to dampen down the symptoms, the medication then comes with their own side effects

There needs to be more research, to find the tests that we need to find out why we have reacted the way we have.

Due to the way that my symptoms were dismissed by some, the stress of the way I'd been treated by some in the NHS, I've also had a relapse in my mental health.

There's many with 'Vaccine Injuries' who are now suffering from their mental health. Some have been suicidal because of the way our symptoms have been dismissed by some, the lack of treatment and inadequate support. (6a,6b)

I have had counselling for loss and adjustment, but no amount of counselling will take away what I have been through, the changes to my life, the way I have been treated by some, the lack of adequate treatment and support .

In May 2023 I was ill health retired at the age of 52. The independent registered medical practitioner states *"It is my opinion that Mrs Butler has significant physical, mental and sensory impairments that are likely to be long term and she is unlikely to recover to a level where she would be able to work again."* (7)

The response from Jeremy Miles does not address what the petition is calling for

"I call for better awareness and an appropriate pathway for diagnosis and treatment for those experiencing such debilitating side effects."

"There needs to be more research into symptoms and illnesses that results from vaccination with improved diagnosis and treatment, specialist clinics or clinicians which can provide appropriate treatment"

Without a pathway for diagnostic tests, there currently for many of us no diagnostic tests in the NHS or we are not meeting guidelines to be referred for further testing to find out why we have reacted the way we have, to get us well again. For many of us the tests that we have had are coming back as satisfactory, then there is no further testing done with the NHS because our results are satisfactory.

Some people are then going private, they are being offered further testing and then they are finding that there is something causing their ill health because of the Covid vaccine.

With no diagnostic pathway, how will we understand as to why we have had an adverse reaction to the covid vaccine, for us to receive adequate treatment but also to also stop what has happened to us from happening to others in the future.

By not providing adequate diagnostic testing, an adequate treatment pathway, I feel the lack of treatment and inadequate support will cause further hesitancy with the current vaccines and any future vaccines that might be needed in the future.

I'm now too scared to have any further Covid vaccines, I have declined further Covid vaccines eg boosters because I'm too scared after what I have been through. Our loved ones are witnessing what we are going through.

The public needs trust in the vaccines but also, they need to know if they do regrettably suffer an adverse reaction, that everything will be done to get them well again or they will be able to access adequate support.

If a medical procedure was to go wrong, the NHS would do what they could, to put things right. Why are we not getting the treatment that we need, to try to reverse these adverse reactions?

The Adferiad (Recovery) program/ Post Covid Recovery

The Adferiad (Recovery) program/ Post Covid Recovery is not a diagnostic pathway

October 2023 formal response from the CEO of ABUHB states:

"The Post Covid Recovery Team offers a personalised rehabilitative programme when medical diagnostic pathways have been completed. "

"However, the team is not able to make a diagnosis of vaccine related harm as this is not a diagnostic service"

"The team works with people to understand the impact of their symptoms and offers individualised support to help them to manage and live with their concerns" (8)

Early 2024 I started physiotherapy; I explained that I experienced Post-Exertional Malaise (PEM). After an assessment, a graded approach was used and through a series of seated and standing exercises with the aim to help me move little and often around the home (9).

After the physiotherapist assessment and the start of these exercises, I had a relapse in the fatigue (PEM) . Physiotherapy was stopped. I'm still not back to my baseline pre physiotherapy.

Long Covid physio websites state the following regarding Post-Exertional Malaise (PEM): "Fatigue experienced by people living with Long COVID can be experienced alongside post-exertion symptoms exacerbation. [Exercise](#) (10a) is not recommended as a rehabilitation intervention for people experiencing [fatigue](#) (10b) and [post-exertional symptoms exacerbation](#) (10c)

Yet graded exercises were given to me as rehabilitation

There needs to be better awareness of how these symptoms affect the patients, how these symptoms can be better managed to stop further relapses. The patients needed to be listened to, after all we live with these symptoms, we know how these symptoms affect us.

In 2021 some of my symptoms were dismissed by the NHS eg the flicking of my hand, whilst loss of the feeling of hunger was blamed on anxiety. One GP raised their voice at me, accusing me of not pushing up with my one leg. I later found out my one leg 'doesn't always do as it's told'.

Some of my experience of the NHS after suffering with the adverse reactions (11) (12)

I have gone from being active, two part time jobs, gardening, diy, walking my dog to now being reliant on my loved ones. Due to the pain and fatigue, I now use an electric wheelchair outside of the home. I was told by the Council OT that I wouldn't meet the criteria for a Disability Facility Grant because my husband is working. In December 2023 we had to self-fund a wet room costing £8,000, I now have the independence to shower.

Please will you consider my petition calling for a pathway for adverse reactions, to bring awareness to everyone in the NHS. To create a pathway for the diagnosis and treatment of adverse reactions to the covid vaccine, to get us well again. To stop patients from going through what we have faced since 2021?

I get so anxious attending medical appointments, I now carry the diagnosis clinic letter with me, just in case my symptoms or diagnosis are ever dismissed. I'm not the only one in Wales who has suffered from adverse reactions, I'm not the only one who has not had adequate treatment or support. I'm not the only one in the UK who have suffered from an adverse reaction to a covid vaccine.

I'm a member of UKCV Family(13) (14) a support group for those who are adversely affected by the covid vaccine.

Vaccine Damage Payment Scheme (VDPS)

Quote "Vaccine Damage Payments are not a compensation scheme. You can still take legal action to claim compensation, even if you get a [Vaccine Damage Payment](#)." (15)

By not having a diagnostic pathway we cannot provide the epidemiological evidence that the VDPS is saying that is needed. Despite having a NHS diagnosis of Post Covid Vaccine Sequelae a reaction after my first, a relapse in symptoms on my second. The VDPS acknowledging a temporal relationship between receiving the vaccine and becoming ill, my application for the VDPS on balance of probability has been declined. (16)

The VDPS do not examine you, you do not even get to discuss your symptoms or the onset of side effects and how it's affected your life etc

The VDPS state there's no epidemiological evidence, which is difficult because there's currently no tests to find out why I've reacted the way I have.

By not having a diagnostic pathway, we are being stopped from providing the evidence that is needed to successfully claim the VDPS

If you can prove causation, you then have to pass the 60% disablement

They use an outdated assessment, which doesn't cover so many of the symptoms that the vaccine injured are experiencing eg Neurological , Postural tachycardia syndrome (PoTS), Mast Cell Activation Syndrome (MCAS) , Post-Exertional Malaise (PEM) etc If you lose your limb it's awarded but eg not if neurological symptoms giving you problems with walking it's not listed (17)

Guidance the medical assessor uses for the Vaccine Damage Payment Scheme (18)

"Independent medical assessors use resources to support their assessment, including, but not limited to, some or all of the following:

- Vaccine Damage Payment Scheme - [Principles of Medical Assessment Guidance \(Word: 336KB\)](#)
- Medicines and Healthcare products Regulatory Agency (MHRA) data, including [Yellow Card](#) information on suspected safety concerns involving a healthcare product
- Vaccine product information and updates
- The Green Book - a reference material produced by the UK Health Security Agency and used by healthcare professionals in the UK. The Green Book brings together all documents relating to immunisation against infectious diseases. Visit [immunisation against infectious disease: the green book front cover and contents page - GOV.UK](#) for more details
- Detailed guidance on disablement assessments relating to Schedule 2 of [The Social Security \(General Benefit\) Regulations 1982 \(legislation.gov.uk\)](#), which have been developed by the Department of Work and Pensions (DWP)
- [World Health Organization \(WHO\)](#) documents
- Established and accepted medical epidemiological research papers

- Past tribunal decisions and case law"

In the Principles of Medical Assessment Guidance

Item 3 , Medical Assessment, General Principles (19)

Quote "Clinical diagnosis should normally be accepted without a need to review. "

The diagnosis by my NHS Consultant was dismissed by the VDPS

Freedom of information ref 02351 ref Vaccine Damage Payment Scheme awarded

As of October 31st 2024 (20).

Currently, **16,824** claims have been received by the Vaccine Damage Payment Scheme (VDPS)

8,806 claimants have been notified of an outcome.

7,748 claims have been rejected, and a further 716 did not meet the criteria for medical assessment,

8,208 claims were unsuccessful because the independent medical assessor recommended that, on the balance of probabilities, the vaccine did not cause the disability in question (causation).

406 claims were unsuccessful because, although the claims met the criteria for causation, the independent medical assessor recommended that the vaccine has not caused severe disablement.

70 claims where an award outcome has been communicated were made on behalf of someone who has died.

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Acknowledge

Whilst I acknowledge that the MHRA Yellow card, the Vaccine Damage Payment Scheme is out of the scope of the Welsh Government. I've responded because Jeremy Miles explains about them in his response

Wes Streeting meets members from VIBUK

Recently some members of VIBUK (another vaccine injured and bereaved group) had a meeting with Health Secretary Wes Streeting to make their case for a reform of the Vaccine Damages Payment Scheme (VDPS). <https://www.leighday.co.uk/news/news/2024-news/vaccine-tragedy-campaigners-hopes-raised-by-meeting-with-wes-streeting/>

MHRA Yellow card reporting

Updating your yellow card is extremely challenging. In an email to Eluned Morgan April 2022 I'd explained how challenging this was. (21)

I've been in contact several times to the MHRA yellow card. I've had to chase up replies. I have even challenged them on why I wasn't asked any further questions, after I'd sent them information regarding being diagnosed by a Neurologist with unexplained neurological symptoms in the aftermath of a covid vaccine.

I was then sent several questions regarding my health, tests etc. When I'd updated them again, this time ref the Post Covid Vaccine Sequelae diagnosis, all they asked was for the clinic report. Since last contact made in early 2023, no one has been in contact with me. It's always been me contacting them. I have now given up on trying to keep them updated.

To the best of my knowledge no medical professional has submitted a yellow card for me. I've got copies of my emails to and from the MHRA Yellow card as evidence as how difficult it is to update. I've also requested a copy of my yellow card report (22)

As of 2nd January 2025 Yellow Card reports (23)

AstraZeneca Yellow card reports of adverse reactions ...

Total number of reports of suspected ADRs 249,496

Total number of suspected adverse reactions 885,374

Total number of suspected ADRs which were serious 193,388

Total number of reports of suspected ADRs with a fatal outcome 1,468

Question : If any other medication has over 1,000 suspected ADRs with a fatal outcome , would that medication be recalled?

Consideration

Please kindly take into consideration that due to health problems with fatigue, brain fog etc that any requests for further information may take me time to put together. Therefore, if you request further information, I might have to kindly request a reasonable adjustment in the timescale due to the current disabilities I'm facing.

Example - I'd received a very similar worded response from Jeremy Miles dated 21st November 2024 (24) and I'd already had been putting together a response since then, as the wording to both response are very similar and I'd most of the response written out ready, I am able to make this deadline . If I hadn't, I might not have completed this detailed response in just the 7 days' notice given for the 13th of January deadline.

I'm sorry this is more than the recommended 4 A4 pages, there is so much information to include. I've never done anything like this before and I hope the referencing is acceptable. I would also appreciate that items 1,3,7,8,9,16,22, are not published on the Senedd website because these are my personal medical information

References - links and also files attached

1. Post COVID Vaccine Sequelae diagnosis clinic letters x 2 PDFs
2. <https://www.gov.uk/government/publications/covid-19-vaccination-care-home-and-healthcare-settings-posters/covid-19-vaccination-first-phase-priority-groups>
3. Neurologist clinic report
4. AstraZeneca Patient information leaflets from March & May 2021
- 5a. <https://www.gov.uk/government/publications/regulatory-approval-of-covid-19-vaccine-astrazeneca/information-for-uk-recipients-on-covid-19-vaccine-astrazeneca>
- 5b. <https://www.astrazeneca.com/content/dam/azcovid/pdf/malta/en-epil-AZD1222.pdf>
- 6a. <https://news.sky.com/story/family-of-man-who-took-own-life-after-covid-jab-complications-call-for-action-on-government-compensation-13217959>
- 6b. <https://www.scottishdailyexpress.co.uk/news/scottish-news/scotlands-vaccine-injured-feel-abandoned-29951760>
7. Independent Registered Medical Practitioner ill health retirement assessment report
8. CEO response ABUHB - with paragraph ref long covid recovery
9. Physiotherapy clinical letter - evidence of the graded approach to exercise
- 10a. <https://longcovid.physio/exercise>
- 10b. <https://longcovid.physio/fatigue>
- 10c. <https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf>
11. <https://business.senedd.wales/documents/s138458/CC11%20-%20Alison%20Butler.pdf>
12. Every story matters - my experience of healthcare after the covid vaccine
13. UKCV family information pack & charity announcement
14. <https://www.ukcvfamily.org>
15. <https://www.gov.uk/vaccine-damage-payment>
16. VDPS report
17. <https://www.legislation.gov.uk/ukxi/1982/1408/schedule/2>
18. <https://www.nhsbsa.nhs.uk/vaccine-damage-payment-scheme-vdps-claim-process>
19. <https://www.nhsbsa.nhs.uk/sites/default/files/2024-11/Principles%20of%20medical%20assessment%20%28Nov%2024%29.docx>
20. <https://opendata.nhsbsa.net/dataset/foi-02351>
21. Email to Eluned Morgan and reply
22. Alison Butler Yellow card report
23. <https://yellowcard.mhra.gov.uk/idaps/CHADOX1%20NCOV-19>
24. Response from Jeremy Miles dated November 2024

Further links

Covid Inquiry Module 4 Vaccines and Therapeutics

[https://www.hudgellsolicitors.co.uk/news/public-inquiry/groups-give-covid-19-public-inquiry-evidence-of-vaccine-illness-and-lost-lives?](https://www.hudgellsolicitors.co.uk/news/public-inquiry/groups-give-covid-19-public-inquiry-evidence-of-vaccine-illness-and-lost-lives?_gl=1*ur3acm*_up*MQ.*_ga*MTM1OTUwMTQxMC4xNzZl5ODYz*_ga_DVD8DVXRF*MTczNjMyOTg2Mi4xLjAuMTczNjMyOTg2Mi4wLjAuMA..)

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Preliminary hearing 13 September 2023

Pages 85-105

<https://covid19.public-inquiry.uk/wp-content/uploads/2023/09/13194707/C-19-Inquiry-13-September-23-Module-4-prelim.pdf>

Preliminary hearing 22 May 2024 Transcript

Pages 69-88

<https://covid19.public-inquiry.uk/wp-content/uploads/2024/05/23094440/C-19-Inquiry-Mod-4-prelim-22-May-2024-amended.pdf>