

**IN THE UK COVID-19 INQUIRY**  
**BEFORE BARONESS HEATHER HALLETT**

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**MODULE 4 CLOSING WRITTEN SUBMISSIONS**  
**ON BEHALF OF**  
**VACCINE INJURED AND BEREAVED UK (VIBUK),**  
**UKCV FAMILY AND THE SCOTTISH VACCINE INJURY GROUP**

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**INTRODUCTION**

1. These closing submissions are written on behalf of the Scottish Vaccine Injury Group, the UKCV Family and the Vaccine Injured and Bereaved (VIBUK). Collectively they are referred to as the Covid Vaccine Adverse Reaction and Bereaved.
2. The UKCV Family is the largest group in the UK supporting and advocating for those who have lost a loved one or suffered a life changing adverse reaction to a Covid-19 vaccination. The group is run entirely by volunteers, all of whom are vaccine-injured or bereaved themselves. They are focused on the needs of UK based patients, providing help and advocacy, and actively raising awareness amongst the British healthcare system, media and government.
3. Vaccine Injured and Bereaved UK (VIBUK) is a group of individuals and families who have either been severely injured or bereaved as a direct and confirmed result of receiving a Covid-19 vaccine in the UK. The primary causes of these injuries and deaths are Vaccine-Induced Thrombotic Thrombocytopenia (VITT), Vaccine-Induced Vasculitis, Stroke, Cerebral Venous Sinus Thrombosis (CVST) and Guillain-Barre Syndrome (GBS). They are campaigning for the government to reform the Vaccine Damage Payment Scheme (VDPS) because it is inadequate and inefficient. They also run a support group, offering support, guidance and raising awareness of vaccine injury and bereavement.
4. The Scottish Vaccine Injury Group is a rapidly growing community of Scottish individuals who have either experienced adverse reactions to or who have been bereaved by Covid-19 vaccines. In a small number of instances, carers have joined the group on behalf of relatives who are too sick to participate. The group currently has over 600 members and has core participant status in the Scottish Public Inquiry.

5. The thousands of people that these groups represent pose what is an uncomfortable truth for many; that vaccine injury and death are part of the pandemic story. These are men, women and children who were otherwise healthy who followed public health advice and voluntarily attended to receive their vaccine. They include doctors, healthcare professionals, carers and parents who accepted the vaccine thinking not only of themselves but their patients and those that they care for. They are real people, with real experiences of vaccine injury or bereavement.
6. This Inquiry provides a vital opportunity to reflect on the decisions made during the Covid-19 pandemic - both what was done well and what must be improved for the future. One of the most critical areas requiring scrutiny is how those who suffered harm following vaccination were identified and treated. We remind the Inquiry that over 100,000 people signed a parliamentary petition calling for a dedicated Inquiry into the safety of the Covid-19 vaccines.<sup>1 2</sup> This reflects the significant public concern about this issue, yet the Inquiry's scope and lines of questioning have not adequately addressed it, and important questions remain unanswered.
7. As the Vaccine Adverse Reaction and Bereaved have long made clear, the scale of vaccine injury and bereavement cannot be ignored. Yet, despite this, many witness statements failed to mention vaccine injury and death, and the Inquiry did not question those omissions. The absence of discussion does not erase the reality of harm, nor does it relieve the Inquiry of its duty to investigate the full impact of the pandemic response.
8. Our submissions will focus on two key objectives:
  - i. Ensuring justice and redress for those who have suffered vaccine injury or bereavement.
  - ii. Establishing a meaningful safety net for vaccine injury before the next pandemic - one that provides clear pathways for reporting, support, and financial assistance, rather than leaving individuals to navigate a system that was never designed for them.
9. It is acknowledged that during a public health emergency, governments must act to secure vaccines and build public confidence. The Inquiry has heard from Dame Kate

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<sup>1</sup> UK Government and Parliament, *Petition: Open a Public Inquiry into Covid-19 Vaccine Safety*, 2022. Available at: <https://petition.parliament.uk/archived/petitions/602171>

<sup>2</sup> *Witness Statement of Charlet Crichton on behalf of UKCV Family*, 2024, [INQ000474462], p. 247, para. 506.

Bingham and Lord Sharma that the Government did just that - moving at speed to procure vaccines and provide financial indemnities for pharmaceutical companies. This meant that if an individual, including those we represent, sought to take legal action, the pharmaceutical companies would not bear the financial burden.

10. But this raises a fundamental question: while pharmaceutical companies were shielded from financial loss, where was the equivalent protection for those who suffered harm as a result of the vaccines?
11. Those injured were left to bear the consequences of their injury or bereavement alone, without an even remotely comparable safety net to ensure they received the support and treatment they needed. They also faced not only financial hardship, but mental distress, and the indignity of being overlooked and unrecognised.
12. A well-functioning public health system must not only focus on harm prevention but also ensure that, when harm occurs, there are clear pathways for treatment and support. Yet the evidence has revealed significant gaps in how vaccine-related risks were communicated, how those affected were able to report concerns, and what support was available once a report of an injury was made.
13. In our submission, the Inquiry should ask the following three questions in order to assess the adequacy of the pandemic response in relation to vaccines:
  - i. Was the public given the full and timely information needed to make an informed decision about taking the vaccine?
  - ii. When people experienced serious harm or bereavement due to the vaccine, was there a clear and accessible system for them to report their case?
  - iii. Once they reported, did they receive the compassion, medical support, financial redress, and recognition they deserved?
14. These are not unreasonable or unexpected questions. Any fair and functional public health system should have clear answers to them. Ensuring people are properly informed, have access to a straightforward reporting system, and receive meaningful support when things go wrong is not just a matter of fairness - it is fundamental to public trust.
15. Failures in these areas have left the vaccine injured and bereaved feeling abandoned, fighting not only the physical and mental consequences of vaccine injury or bereavement

but the compounding impact of struggling with a system that was never built with them in mind.

16. This Inquiry provides an opportunity to put things right - not just for those already affected, but for the future. If trust in public health is to be maintained, all people must have confidence that when things go wrong, they will be treated with fairness, dignity, and respect.
17. Four key areas have emerged from the evidence as particularly significant:
  - i. Public health communications - ensuring risk information is clear, accurate, timely, and allows people to make truly informed choices.
  - ii. The Yellow Card system - improving vaccine safety reporting so concerns are properly recorded, monitored, and acted upon and that people feel safe and able to come forward if they suspect they have experienced an adverse reaction.
  - iii. The Vaccine Damage Payment Scheme (VDPS) - addressing the inadequacies in the existing system to ensure those affected receive fair and timely support and the development of a bespoke compensation scheme for immediate financial relief for those who have already suffered so much.
  - iv. Censorship - ensuring that people's experiences are not dismissed, ignored, or prematurely labelled as misinformation, when in reality they may contain critical safety signals.
18. While all four areas require urgent reform, the evidence makes clear that the need for change to the way that the vaccine injured and bereaved can access financial support and compensation, and the VDPS is particularly time-sensitive. The system, in its current form, is not fit for purpose and the need for immediate improvements is undeniable. For this reason, we urge the Chair to issue an interim report with urgent recommendations on VDPS reform, allowing necessary changes to be implemented without waiting for the Inquiry's final conclusions. We address this later in these submissions.
19. The steps we propose are practical, fair, and fully aligned with the principles of accountability and public confidence. This Inquiry must ensure that lessons are learned, and that future public health responses are built on a foundation of transparency, fairness, and meaningful support for those who accept risk but tragically suffer harm as a result.

## **SECTION 1: PUBLIC HEALTH COMMUNICATIONS**

20. A recurring issue throughout the evidence is that the Government prioritised centralised messaging control over transparency in its public communications on vaccine risks. While the aim may have been to maintain confidence in the rollout, the consequences for those who suffered harm have been severe and unacceptable.
21. In our submission, a deliberate choice was made by those at the heart of government, namely the DHSC and the OCMO as to how information was presented in a centralised and simple way, with the overriding emphasis in public messaging being that vaccines were "safe" at a population level. Information about potential risks was neither consistently included in that messaging nor adequately publicised by other means. We do not accept that the existence of a limited number of publicly accessible online peer review journal articles equated to adequate and accessible public information on emerging safety signals.
22. This culture permeated decision-making at all levels - including those in whom we invested our trust to keep us safe. Between 17 March and 7 April 2021, safety concerns regarding the AstraZeneca vaccine were known within the MHRA<sup>3</sup>/ OCMO<sup>4</sup>/ DHSC and the UKSHA<sup>5</sup> but were not immediately shared with the public due to concerns of how the information would be received if given over the Easter weekend. During this period, people therefore continued to receive the vaccine without being given full risk information - a failure that had tragic consequences. As Charlet Crichton of UKCV Family stated in her oral evidence, there were members of the group who were vaccinated during this period who suffered adverse reactions and died<sup>6</sup>.
23. In any other context, the notion of withholding critical safety information from the public would be unthinkable. Even in a pandemic, informed consent is not optional. The urgency of a public health response does not override the fundamental right of individuals to be fully informed of the known risks of any medical intervention they are consenting to.

## **SECTION 1: RECOMMENDATIONS**

24. We invite the Chair to make four key recommendations that will transform public health communication in future pandemics.

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<sup>3</sup> [INQ000408453/2]

<sup>4</sup> [INQ000421508/1]

<sup>5</sup> [INQ000416158/1-2]

<sup>6</sup> Charlet Crichton, [6/159/18-21].

25. First, there must be a single, trusted source of public health information. This platform must be dynamically updated with the latest evidence, easily accessible to the public, and presented in clear, non-technical language, with an option for individuals to access more detailed, technical information if they choose. Public health bodies must actively promote this resource to ensure that it becomes the go-to source for vaccine-related information.
26. Second, Patient Information Leaflets (PILs) must be modernised and improved. Professor Evans stated as follows in his evidence: *"I think it's very likely, and from my own experience very likely, that the majority of patients getting Covid vaccinations did not read a PIL."*<sup>7</sup> Ruth O'Rafferty stated: *"A lot of our members were not given a leaflet until after they'd received their vaccination which means they didn't really have informed consent"*.<sup>8</sup> Vaccines should not be administered until the patient has confirmed that they have read the PIL.
27. As Professor Evan's evidence made clear, static printed documents, simply put, are no longer sufficient [7/109/5-19] PILs must be integrated with digital resources to ensure information remains current and accessible. Every vaccine recipient should receive a printed summary of key risk information, designed for clarity and ease of reading, alongside a QR code or digital link directing them to an always up-to-date online resource with the latest safety information, reported side effects, and reporting mechanisms.
28. These resources must be available in multiple languages and accessible formats, including audio and easy-read versions for those with additional needs. Additionally, a dedicated and unbiased telephone information line must be available for those who are not digitally literate or unable to access online resources, ensuring that older individuals and those without internet access can receive up-to-date information and ask questions directly. Given the significant demands on clinicians - especially during a pandemic - this helpline, or a specialised counterpart, should also be available to healthcare professionals, providing them with immediate access to the latest guidance on identifying and treating potential vaccine injuries.
29. Third, the timely disclosure of safety updates must be made mandatory. The "Easter Delay" in disclosing AstraZeneca-related risks demonstrated the dangers of prioritising centralised messaging over transparency. This must never happen again. Public health authorities must be legally required to release vaccine safety updates immediately once

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<sup>7</sup> Professor Stephen Evans, [7/109/17-19].

<sup>8</sup> Ruth O'Rafferty, [2/138/22-24].

risks are identified - regardless of timing, political considerations, or public perception concerns. If it is assessed that more time is needed to prepare an announcement, the administering of the vaccine should be paused until full disclosure is made. Public health communication must always prioritise transparency over centralisation of messaging.

30. Finally, risk information must be directly paired with reporting mechanisms in the event that a person is injured. Simply telling people that vaccines are "safe and effective" is insufficient. A better system acknowledges risks, presents them clearly - such as by quantitatively stating that a specific adverse event occurs in 1 in every 1,000 people - and provides a straightforward pathway for those affected to seek support. The WHO COVAX No-Fault Compensation Scheme provides a compelling example of how vaccine safety information can be framed in a way that reduces hesitancy while maintaining transparency. Taken from their website, it states:

*"As with any medical product, in very rare cases, someone who has received a COVID-19 vaccine may suffer a serious adverse reaction related to the vaccine or its administration. In such cases, these persons should receive compensation in recognition of the impact on their lives. COVAX No-Fault Compensation Program for Advance Market Commitment (AMC) Eligible Economies (the "Program") recognises that individuals who get vaccinated, put themselves at a very small risk of injury following vaccination, for the wider benefit of the community, and acknowledges that in the very rare cases where a vaccine causes permanent impairment or death, affected individuals deserve compensation. It acts as a kind of social contract."*<sup>9</sup>

31. The COVAX approach demonstrates that trust in vaccines is strengthened - not undermined - when the public is given full and open access to both benefit and risk information, alongside clear pathways for recourse. The scheme explicitly states that in rare cases where someone suffers a serious adverse reaction following vaccination, they should receive compensation in recognition of the impact on their lives. This is the missing link in the current UK system.
32. A public health system that acknowledges risk is an important part of the safety net for those affected is one that people will continue to rely on in future health crises.

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<sup>9</sup> World Health Organization, *COVAX No-Fault Compensation Program: Explained*, 2022; Available at: <https://www.who.int/initiatives/act-accelerator/covax/no-fault-compensation/covax-no-fault-compensation-program-explained>.

## **SECTION 2: THE YELLOW CARD SYSTEM**

33. The evidence presented to this Inquiry has exposed a fundamental weakness in the vaccine safety reporting system. A robust and effective reporting mechanism is essential, as rare, delayed, and severe adverse reactions may not be fully detected through clinical trials alone - and may only become evident once a vaccine is in widespread use. The Yellow Card Scheme should have played a crucial role in monitoring safety, yet the evidence makes it clear that awareness of the system was alarmingly low across all sections of society.
34. Charlet Crichton reinforced the lack of awareness of the Yellow Card Scheme in her evidence, stating that only around 10% of people in her group knew about and reported to it.<sup>10</sup> Quite remarkably, Sajid Javid, the Health Secretary at the time, stated in evidence that he himself was unaware of the Yellow Card Scheme while in office.<sup>11</sup> Given his role in overseeing vaccine policy and public health messaging, this raises serious questions about how well the system was communicated at the highest levels, but all levels of society too. Dr Salman Waqar on behalf of FEMHO further noted that even within the healthcare workforce, the Yellow Card Scheme was *"perhaps not particularly well understood"*.<sup>12</sup> If those responsible for patient care were not properly informed, public awareness would inevitably have been even lower.
35. The consequences of this lack of awareness are significant. A reporting system that is unknown or poorly understood cannot function as an effective safety net. If too few people report adverse effects, emerging safety signals may go undetected, delaying the ability to investigate and respond appropriately. A system that depends on public engagement cannot afford to be invisible.
36. However, the problem was not just a lack of awareness. Even if the Yellow Card Scheme had functioned exactly as designed, it was never built to handle the demands of a pandemic. As Dr Gillian Richardson stated in evidence, *"It's a scheme that works in peacetime. I think in a crisis, we needed a more enhanced active surveillance."*<sup>13</sup> She explained that, while the MHRA may have been receiving reports, the fundamental issue was that many members of the public were unaware of the scheme, and even junior doctors - who are introduced to it during training - may not have been experienced in its use.

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<sup>10</sup> Charlet Crichton, [6/158/1-2].

<sup>11</sup> Rt Hon Sir Sajid Javid, [8/64/18-19].

<sup>12</sup> Dr Salman Waqar, [3/9/6-7].

<sup>13</sup> Dr Gillian Richardson, [10/102/7-9].



37. This is a critical point. The Yellow Card Scheme, in its current form, was designed for a stable environment, where safety signals emerge gradually over time. In a public health crisis, when vaccines are deployed at unprecedented speed and scale, a passive reporting system is inadequate.
38. To prevent the same failures from recurring, reform is required. The following recommendations outline the practical steps needed to ensure that vaccine safety reporting is fit for purpose - not just in routine circumstances, but in future pandemics when public trust and rapid response are paramount.

## **SECTION 2: REPORTING REFORM RECOMMENDATIONS**

39. We invite the Chair to make two key recommendations that will significantly improve vaccine injury reporting.
40. Firstly, vaccine safety monitoring and reporting must be strengthened. The MHRA and public health agencies should implement a “high suspicion index” (to quote from Professor Evans’ report<sup>14</sup>) approach during the rollout of novel vaccines, ensuring that all suspected vaccine injuries are recorded in medical notes, even where causation is uncertain. A professional recognition scheme, such as that awarded by the MHRA in 2015 to Dr (now Professor) David Hunt for his work on drug safety,<sup>15</sup> should be established to encourage healthcare workers to report vaccine-related adverse events. Vaccine safety monitoring should also be embedded into the professional development of all healthcare workers and those involved in vaccine administration, and those that are called upon to vaccinate as volunteers in mass vaccination schemes.
41. There should also be consideration of financially incentivising Yellow Card reporting by clinicians. Sir Munir Pirmohammed referenced an Irish study where incentivising reporting led to an increase in reporting while maintaining data quality.<sup>16</sup>
42. Secondly, the Yellow Card Scheme must be reformed to improve accuracy and accessibility. The system should record and automatically integrate demographic data, including ethnicity, gender, and socioeconomic background, to ensure safety signals are properly monitored across all communities. Additionally, Yellow Card reports should be

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<sup>14</sup> Professor Stephen Evans, *Expert Report for the UK Covid-19 Inquiry, Module 4 — Vaccines and Therapeutics. Hurdles and Nets: Authorising and Monitoring Vaccines*, 2024, [INQ000474707], p.63, para.6.33.

<sup>15</sup>The University of Edinburgh, *Dr David Hunt awarded drug safety prize by the MHRA*, 2016. Available at: <https://institute-genetics-cancer.ed.ac.uk/news-and-events/news-2015/david-hunt-awarded-drug-safety-prize-by-the-mhra>

<sup>16</sup> *Sir Munir Pirmohammed*, [11/141/8-12].

automatically triggered whenever a suspected vaccine-related adverse event is recorded in a patient's medical notes, minimising underreporting. Reporting must also be linked to follow-up medical care where there is an indication from a patient or clinician that this would be helpful or is required; ensuring that those who submit a report receive structured, ongoing medical support and assessment. A tear-off slip system at the point of vaccination - linking each dose to a unique barcode - could further strengthen safety monitoring. This would allow those experiencing adverse reactions to instantly connect their report to key details such as the vaccinator, vaccination centre, batch number, and administration method, helping to identify any emerging patterns, safety concerns, or issues with specific vaccination sites.

### **SECTION 3: TREATMENT AND CARE PATHWAYS**

43. The failure to recognise and support those suffering from vaccine-related injuries has been a stark omission in the evidence heard by this Inquiry. Of the 34 non-core participants who have given evidence, only two have addressed the issue of treatment and care for the vaccine-injured and bereaved - reflecting a broader failure to acknowledge and respond to their needs.

44. Professor Evans was one of the few to recognise this reality, stating:

*"As a community, we have to acknowledge that [vaccine injury] does happen in extremely rare cases, and that such people need to be looked after properly, and their relatives and those who are bereaved need proper treatment."*<sup>17</sup>

45. Yet this recognition must extend beyond those whose injuries have been formally confirmed.

46. Dr. Gillian Richardson made a compelling argument that vaccine injuries should be treated similarly to Highly Contagious Infectious Diseases (HCID). Under the HCID model, patients are automatically referred to specialist centres, ensuring access to expert care while also enabling clinicians to study emerging conditions. She highlighted a crucial point: in an HCID outbreak, the first 100 cases are studied closely to inform medical responses [10/102/7-10/103/20]. In stark contrast, the experiences of the vaccine injured and bereaved were largely met with dismissal, denial, and discrimination. Rather than learning from these cases, the system ignored them - leaving individuals

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<sup>17</sup> Professor Stephen Evans, [7/110/7-11].

without treatment and doctors without the knowledge needed to manage similar cases in the future.

47. This continued lack of specialist provision harms both patients and the wider medical community. Without dedicated treatment centres, clinicians cannot develop the expertise needed to diagnose, manage, and study vaccine-related injuries effectively.
48. If people are to be encouraged to report vaccine injuries, they must feel that there is a benefit in doing so. Without access to treatment or follow-up, many will not engage with reporting systems - undermining the accuracy of safety data. If people believe they would receive care and recognition, they would be far more likely to come forward - leading to stronger safety monitoring and better patient outcomes.

### **SECTION 3 - CARE AND TREATMENT RECOMMENDATIONS**

49. We make three recommendations. Firstly, specialist treatment centres for vaccine-related injuries must be established to ensure that those affected receive appropriate care. These centres should be staffed by clinicians with expertise in diagnosing and managing adverse effects using a holistic and trauma informed approach. The centres should follow the HCID model, allowing early cases to be properly studied and informing best treatment practices. Pharmaceutical companies should be asked to provide funding for these centres.
50. Secondly, an automatic referral pathway must be introduced for individuals experiencing suspected vaccine-related adverse effects. Rather than being left to navigate an unclear and fragmented system, those affected should be referred for specialist assessment, ensuring they receive timely and appropriate care.
51. While physical care is vital, the emotional impact of losing a loved one, witnessing their suffering, or experiencing life-altering trauma can be just as profound. Offering tailored trauma counselling, including specific support for those with PTSD, is essential to help individuals process their experiences and rebuild their lives.

### **SECTION 4: COMPENSATION SCHEMES AND THE VDPS**

52. The evidence before the Inquiry makes one thing abundantly clear: the Vaccine Damage Payment Scheme (VDPS) is not fit for purpose. Those who suffered vaccine-related injuries, or lost loved ones as a result, have been left to navigate a system that is unfair, inaccessible, and wholly inadequate in recognising their suffering or providing meaningful support.

53. The burden placed on claimants is unreasonably high. As Charlet Crichton described, seriously ill or grieving individuals are expected to complete complex forms at a time when they are least able to do so:

*"It's very traumatic for someone when they're very ill, after they've done something that they were told to do, or they've lost a loved one, to fill out the form... I was still very, very poorly in bed, and I literally put three sentences, thinking my medical records would be enough."*<sup>18</sup>

54. Expecting individuals who followed public health guidance to then fight for recognition and compensation, often while physically or financially incapacitated, is indefensible. The system does not reflect the reality of the people it affects, nor does it operate with the urgency required.

55. Beyond these barriers, the level of compensation is entirely inadequate. As Kate Scott highlighted, £120,000 bears no relation to the long-term financial impact of a vaccine injury:

*"If you did something that the state told you was safe and effective and that wasn't the case, there should be fair and adequate compensation... Jamie will never work again, so that's £120,000 - [but] the national average salary of £30,000 is gone very, very quickly in a very expensive world"*<sup>19</sup>

56. Even at the Ministerial level, the need for reform has been recognised:

*"I certainly think there was a case for us to look again at both eligibility criteria but also perhaps to look at the quantum of money that would be made available through this mechanism"*<sup>20</sup>

57. A system designed to provide redress must reflect actual need of the applicants. The rigid 60% disablement threshold arbitrarily excludes individuals whose lives have been permanently altered simply because they do not meet an artificial percentage of disablement. As Dr Gillian Richardson highlighted:

*"Any scheme that looks at compensation needs to be a sliding scale and not a threshold. If somebody is in a coma for six months, then recovers and has 49%*

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<sup>18</sup> Charlet Crichton, [6/160/20 - 6/161/3].

<sup>19</sup> Kate Scott, [2/158/18-25].

<sup>20</sup> Lord Alok Sharma, [4/31/25 - 4/32/3].

*disability, there is no compensation for the time they were unable to work, support their family, or be involved in their loved ones' lives”*<sup>21</sup>

58. It is deeply unjust that an individual acknowledged to have suffered vaccine-related disablement can be left with no financial support because their condition is assessed at 45% rather than 60%. As Sarah Moore highlighted, this is not a technical flaw - it is a failure of basic fairness:

*“These people have no other way to access redress apart from litigation, but litigation is not an option open to them... For some, there is no option to litigate at all”*<sup>22</sup>

59. The barriers to legal recourse only compound the injustice. A system intended to provide a safety net must not leave those affected in financial hardship, fighting for recognition, or without a viable route to redress.

#### **SECTION 4- COMPENSATION SCHEME AND VDPS RECOMMENDATIONS**

60. The evidence before the Inquiry is overwhelming: the VDPS is outdated, unfit for purpose, and in urgent need of overhaul. The scale of the failure demands decisive action, and there is clear precedent for this Inquiry to act swiftly. As demonstrated in the Infected Blood Inquiry, when systemic failures are identified, the Chair has the power - and we say the responsibility - to recommend urgent interim measures to provide immediate relief while broader reforms are developed.

61. The Infected Blood Inquiry interim report, issued on 29 July 2022, set a clear standard for decisive action. It opened with the following statement:

*“This interim report concerns a single issue. It is whether I should recommend that, as soon as practicable, interim payment should be made and, if so, the scope of those interim payments.”*<sup>23</sup>

62. The report ultimately recommended that interim payments of no less than £100,000 be made, demonstrating that when a scheme is unfit for purpose, immediate financial relief can and should be provided. This was in line with evidence from Sir Robert Francis KC,

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<sup>21</sup> Dr Gillian Richardson, [10/100/23 – 10/101/7].

<sup>22</sup> Sarah Moore, [11/6/2-5].

<sup>23</sup> Sir Brian Langstaff, Infected Blood Inquiry, *First Interim Report*, 2022, p.1, para 1. Available at: <https://www.infectedbloodinquiry.org.uk/reports/first-interim-report>

given to the Inquiry earlier that same month, in which he advocated for this relief. The same approach must be taken here.

63. We urge the Inquiry to issue an interim report recommending immediate financial relief as part of a bespoke compensation scheme while work begins on developing a modernised compensation scheme that reflects the true impact of vaccine injury. The following interim measures must be implemented without delay:

- i. VDPS payments that have already been made must be adjusted to reflect inflation. The current award, set in 2007, has remained unchanged despite the significant rise in the cost of living. There should be an immediate ‘top-up’ payment.”
- ii. Individuals who already have a confirmed diagnosis of vaccine injury or bereavement from their GP / a clinician or Coroner should receive an immediate payment, recognising the inadequacy of the amounts they have received to date. These interim steps will provide urgent relief to those in need while a full-scale reform of the VDPS is undertaken.

#### **CONSULTATION IN RELATION TO THE VDPS**

64. The VDPS requires urgent and comprehensive reform to ensure it meets the needs of those affected by vaccine injury. As a baseline, the Chair should recommend:

- i. The removal of the arbitrary 60% disablement threshold, replacing it with a more flexible and fair assessment that considers both physical and mental injuries, whether permanent or temporary.
- ii. A commitment to meaningful financial support for those unable to work due to vaccine injury, ensuring that they and their loved ones are not left in financial hardship. A substantial increase in the compensation awarded, aligning it with the sums that could reasonably be expected in litigation, given the significant legal barriers many claimants face in pursuing court proceedings.

65. Beyond these core changes, the finer details of reform must be shaped through urgent and transparent consultation with those who are most affected. The Government must engage directly with the vaccine injured and bereaved, ensuring that those most affected have a meaningful role in designing the reformed scheme, rather than having changes imposed upon them.

66. The Inquiry already has expert written evidence from Duncan Fairgrieve KC.<sup>24</sup> <sup>25</sup>Academic experts such as Sonia Macleod and Fanni Gyurko of Oxford University, Emmanuelle Lemaire of Essex University, and Richard Goldberg of Durham University are already conducting significant work in this area. We urge the Inquiry to closely consider Sonia Macleod and Fanni Gyurko's *Covid-19 Vaccine No-Fault Compensation Schemes Project*. There should also be an evaluation of international compensation models, to establish a fair and evidence-based framework. These experts could form part of an expert panel, along with Sarah Moore and members of our three Core Participant groups to co-design a set of principles to underpin a compensation framework.
67. The operation of the scheme must be trauma-informed, treating individuals with dignity, fairness, and empathy, rather than subjecting them to a complex and bureaucratic process that exacerbates their hardship. The system must be accessible, independent, and designed to provide real support - not further barriers. Clear timeframes must be established to prevent individuals from waiting years for a response, and the application process must be made user-friendly, removing unnecessary obstacles that deter rightful claims.
68. Finally, the reformed scheme must account for the impact of compensation on other benefits and entitlements, ensuring that financial support is meaningful and not diminished by reductions elsewhere.

## **SECTION 5: CENSORSHIP**

69. The way the Inquiry frames its findings - particularly its language - will be crucial in addressing stigma and ensuring those affected by vaccine injury do not continue to be dismissed. Language shapes public perception, and even subtle choices can contribute to censorship and the silencing of certain experiences. Censorship does not need to be overt or intentional to have a real impact; it can emerge through how information is framed, the terminology used, and the level of legitimacy granted to different perspectives.
70. Representatives of the Covid Vaccine Adverse Reaction and Bereaved raised concerns with the Inquiry about the language used in questioning, particularly the distinction between VITT (Vaccine-Induced Immune Thrombotic Thrombocytopenia) and TTS

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<sup>24</sup> Duncan Fairgrieve, Jean-Sebastien Borghetti et. al, *Comparing No-Fault Compensation Systems for Vaccine Injury*, Tulane J. of Int'l & Comp. Law Vol.31, 2023, [INQ000414146].

<sup>25</sup> Witness Statement of Professor Duncan Fairgrieve, 2024, [INQ000474539].

(Thrombosis with Thrombocytopenia Syndrome). VITT is a recognised, vaccine-induced condition. It is distinct from TTS which can occur for reasons unrelated to vaccination. Unlike TTS, VITT has been confirmed to be caused by certain vaccines, most notably AstraZeneca's COVID-19 vaccine. It is characterised by severe blood clotting and low platelet counts and has been formally recognised by leading health authorities, including the MHRA<sup>26</sup> and WHO<sup>27</sup>. Page viii of WHO's '*Guidance for clinical case management of thrombosis with thrombocytopenia syndrome (TTS) following vaccination to prevent coronavirus disease (COVID-19)*' explicitly states:

*"The term vaccine-induced immune thrombotic thrombocytopenia (VITT) has been incorporated into the World Health Organization (WHO) classification of TTS. The term VITT should be used when platelet activating anti-PF4 antibodies have been detected, with a platelet function assay or enzyme-linked immunosorbent assay (ELISA), and no alternative diagnosis exists."*

71. This distinction is important because those diagnosed with VITT were not affected by a naturally occurring medical event which occurs in the background population - they suffered a recognised adverse reaction to vaccination. We urge the Inquiry to use the proper clinical language of VITT when referencing vaccine induced thrombosis in its report.
72. Another example of where language can be exclusionary rather than inclusive is the ESM Module 4 Report's wording, which referred to *"those who believe they were injured"* rather than *"those who have experienced vaccine injury"*<sup>28</sup> This language further heightened the concerns and the trauma of the vaccine injured and bereaved, making them feel disbelieved and de-legitimised.
73. Beyond the issue of language, the evidence presented to the Inquiry made clear that government sources often failed to provide individuals with the information they needed. Professor Heidi Larson highlighted this directly:

*"Sometimes there was just an issue that they weren't getting the information they were looking for through a government source, because official information was pushing out what the government and public health felt was important for people"*

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<sup>26</sup> Witness Statement of Dame June Munro Raine CBE, 2024, [IN0000474337], p.137, para. 476.

<sup>27</sup> World Health Organization, Guidance for clinical case management of thrombosis with thrombocytopenia syndrome (TTS) following vaccination to prevent coronavirus disease (COVID-19), 2023, p. 8, para 1-3; Available at: <https://www.who.int/publications/i/item/9789240061989>

<sup>28</sup> UK Covid-19 Inquiry, *Every Story Matters record for Vaccines and Therapeutics*, 2024, [INQ000474465], p.3, para 9.



*to know, but didn't necessarily answer the questions that people had, and therefore, they would turn to alternative sources."*<sup>29</sup>

74. The failure to meaningfully engage with the public on the issue of vaccine injury during the pandemic left an information vacuum. People searching for answers had no choice but to speak for themselves and seek answers for themselves, as their concerns and experiences were absent from official sources and weren't acknowledged by public health officials. As a result, many of the vaccine injured and bereaved were unfairly labelled as spreading misinformation simply for sharing their experiences.

75. The consequences of this censorship extended beyond public discourse and directly impacted medical treatment. Ruth O'Rafferty, from SVIG, described how many individuals seeking medical help for suspected vaccine injuries were met with disbelief from doctors:

*"What we experience when we go into medical appointments [is that] medical professionals, who have not seen evidence of vaccine injury in social media or the mainstream media, actually meet us with quite a lot of disbelief."*<sup>30</sup>

76. This had two serious consequences. First, it reinforced the idea that vaccine injuries were either non-existent or too rare to matter, leaving patients struggling to access care. Second, even when doctors privately believed an injury was vaccine-related, they often avoided recording it. A survey by SVIG found that 46% of respondents were told by a doctor their condition was likely vaccine-related, yet it was not recorded in their medical notes.

*"There's an element of fear there that if you speak out against the vaccines, you're going against societal or cultural expectations that the vaccines are wonderful."*<sup>31</sup>

77. This suggests that there was a culture of fear among healthcare professionals, which discouraged them from formally documenting vaccine injuries. Beyond individual cases, this will also have suppressed vital safety data, delaying recognition of potential safety signals. The issue of censorship is therefore not just about fairness or decency for the vaccine injured - it is about public health itself. If concerns are ignored, dismissed, or labelled as misinformation prematurely, then early warning signs of genuine safety issues risk being missed.

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<sup>29</sup> Professor Heidi Larson, [3/156/2-8].

<sup>30</sup> Ruth O'Rafferty, [2/129/20-24].

<sup>31</sup> Ruth O'Rafferty, [2/130/4-7].

78. As Dr Waqar from FEMHO highlighted, the approach to misinformation during the pandemic was far too blunt an instrument. Much of what was labelled as misinformation was not wholly false but contained kernels of truth. The real challenge, he explained, was disentangling truth from misinformation - something that required proper engagement rather than outright dismissal.

*"Much of the misinformation had in it the kernels of truth, and how do you disentangle the truth from the misinformation is what became a real challenge for us."*<sup>32</sup>

79. The Inquiry heard further evidence supporting this from Susannah Storey from the DCMS, who acknowledged that public health authorities may not have had time to verify reports of vaccine injuries being discussed on social media, meaning individuals could have been speaking about real issues before official sources had caught up.

*"It may well be that public health authorities hadn't had time to verify what was being said"*<sup>33</sup>

80. If official sources had not yet caught up with discussions on social media, then treating those discussions as misinformation may have actively delayed the recognition of genuine safety signals. Suppressing discussions too early risked erasing real concerns from public discourse before they had even been properly examined.
81. Ensuring that concerns are heard and investigated is not about undermining confidence in vaccines - it is about ensuring that safety signals can be detected as early as possible. If public health messaging continues to dismiss or ignore concerns instead of engaging with them, then trust will erode, and future vaccine programmes will suffer. The cost of misplaced censorship is not just the stigmatisation of the vaccine injured - it is the potential failure to spot real risks in time.

## **SECTION 5: RECOMMENDATIONS**

82. We make two recommendations.
- i. Clarify the use of 'misinformation' and 'disinformation' in public discourse around vaccines, vaccine risk and vaccine injury - The Chair should recommend that government agencies, politicians, and social media companies adopt a more precise framework for classifying information in these

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<sup>32</sup> Dr Salman Waqar, [3/12/12-15].

<sup>33</sup> Susannah Storey, [6/143/24 - 6/143/1].

contexts. Instead of prematurely labelling discussions as 'misinformation'. Terms such as 'not yet verified' should be used where appropriate, ensuring that legitimate discussions are not unduly suppressed. The terms 'misinformation' and 'disinformation' should be reserved for cases where there is demonstrable falsehood or intent to deceive.

- ii. Protect and support healthcare professionals in recording vaccine-related injuries - The government should introduce guidance and protections for doctors, nurses, and other healthcare professionals, ensuring that they feel able to accurately record. Where necessary, anonymised reporting should be an option to encourage transparency. Additionally, training should be provided to ensure that medical professionals understand their role in vaccine safety monitoring and are encouraged to document potential adverse effects.

## **CONCLUSION**

83. The evidence before this Inquiry has laid bare a stark and undeniable truth: the UK's pandemic response failed those who suffered vaccine injury and bereavement. While billions were allocated to protect pharmaceutical companies from financial risk, no equivalent safety net was put in place for the very people who followed public health guidance and suffered as a consequence. This is not just an oversight - it is a national failing that demands urgent redress.
84. Public health cannot function without trust. That trust is not built through messaging control or silence; it is built on transparency, accountability, and the guarantee that when harm occurs, those affected will be treated with dignity, fairness, and real support. Instead, the vaccine-injured and bereaved were sadly dismissed and ignored by the very institutions that encouraged them to step forward in the first place and judged by the society that they were trying to protect.
85. We are told we are now in 'peacetime'. If there was a war, it was a war against the Covid-19 virus and vaccines were heralded as the world's most effective weapons against that virus that were deployed in that conflict. Scientists and public health officials have repeatedly acknowledged in evidence that no vaccine (and, in fact, no medicine) is without risk, and that for these novel vaccines there were likely to be adverse effects that were not identified by clinical trials but that would likely occur when the vaccines were rolled out to millions of people. Despite this, no one within government or public health planned for how to treat any casualties of that war. Each of us who received these novel vaccines was a soldier in that war. The key difference is that if soldiers die or are injured

in active service, their loss and their contribution to the struggle is acknowledged, their service is recognised in the context of the furtherance of the national interest. There is wide recognition that the loss of every life is a tragedy.

86. A mass vaccination programme is a social contract - one in which individuals accept a small but real risk for the greater good of society. But a contract is only meaningful if both sides uphold their obligations. The state encouraged vaccination as a duty to protect others, yet when harm occurred, it failed to meet its own duty to those affected.
87. Our recommendations are not radical. They are the bare minimum required to ensure that no one in a future pandemic is left to fight for recognition, compassion, care, or financial support. The issues exposed in this Inquiry must not be buried in reports or diluted by bureaucracy. They must be met with decisive action.
88. We now call on the Chair to issue an interim report with urgent recommendations on compensation and VDPS reform - ensuring that financial relief is provided immediately while a proper, modernised compensation scheme is built. We call for the fundamental restructuring of vaccine safety monitoring, so that the voices of those injured are not ignored until it is too late. And we call for an end to the culture of silence that has left people suffering in the shadows, fighting to be heard.
89. For the first time, parliamentarians are listening to the vaccine injured, and there is a genuine recognition of the urgent need for reform. The Chair's recommendations will be pivotal in driving that change forward. Any delay risks stalling momentum in Parliament, postponing the action that is needed now.

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**14<sup>th</sup> February 2025**