IN THE UK COVID 19 INQUIRY

BEFORE BARONESS HEATHER HALLETT

SUBMISSIONS FOR THE SECOND MODULE 4 PRELIMINARY HEARING
22nd MAY 2024
ON BEHALF OF
VACCINE INJURED AND BEREAVED UK (VIBUK)
UK CV FAMILY AND THE SCOTTISH VACCINE INJURY GROUP.

A. INTRODUCTION

1. The Scottish Vaccine Injury Group, the UK CV Family and the Vaccine Injured and Bereaved (VIBUK) are each recognised as Core Participants by the Chair in Module 4 of her Inquiry. They wish to be referred to collectively as the "UK Covid Vaccine Adverse Reaction and Bereaved Groups." In designating them as a Core Participant, the Chair recognised that these three groups are well placed to assist the Inquiry to achieve its aims by representing the collective interests of a broad spectrum of those who have been bereaved or adversely affected following a Covid-19 vaccination.

2. **The UK CV 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. They are 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. 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.

B. DELAY TO SUBSTANTIVE HEARINGS

5. Those we represent are deeply frustrated by the delay of the substantive oral evidence hearings. The vaccine injured and bereaved have already waited for years for their voices to be heard and their experiences to be acknowledged. The delay in the Inquiry hearings further compounds their experiences of neglect, isolation, and discrimination. The delay impacts the UK Covid Vaccine Adverse Reaction and Bereaved Groups in several ways.

6. First, there is a tangible impact of the delay on the ability of some of the vaccine injured being able to engage effectively with the Inquiry.

7. One of the Scottish Vaccine Injury Group members has genuine concerns that due to his advanced age and physical condition he may not survive until then. Others face serious deterioration in their health because they have degenerative diseases or cancer. And some have conditions they desperately need treatment for that they cannot access currently on the NHS and these conditions will only become more serious making their participation more difficult. Other members who would have loved to travel to London to offer support have said that cold weather has such a negative impact on their health and breathing that travelling is now out of the question. This delay has only served to further exacerbate feelings of marginalisation and caused considerable stress to a group who already face mental health challenges for many reasons.

8. By January 2025, some members will have been injured or bereaved for 4 years without their experiences having been heard. Many members want to be present for the module or at least outside the building. The movement of the module from Summer 2024 to January 2025 will make this impossible for many of our members who are suffering with life changing injuries that are further impacted by the time of year.

9. Second, there will be a consequential delay in obtaining the truth about the UK's Covid-19 vaccine programme and the drafting of the Chair's report, which we anticipate will now not be available before late 2025 at the earliest.

10. Third, delay in the substantive hearings and the establishment of a clear factual narrative around the Covid-19 vaccines creates a larger lacuna in the public understanding within which further serious mistrust of government and healthcare institutions will inevitably grow. Covid-19 vaccines are still

being deployed (albeit to a reduced number of groups) and therefore it remains imperative to address any issues now, to avoid any further unnecessary injury.

11. Another concern is that without intervention, medical hesitancy among the vaccine injured communities will increase. Lack of recognition of vaccine injury amongst medical personnel and lack of awareness of conditions like mast cell activation syndrome or postural orthostatic tachycardia syndrome leave vaccine injured continually sent home from medical appointments or emergency appointments without any diagnosis, most commonly with the impression they are viewed as hypochondriacs. Indeed, mast cell activation syndrome is not even diagnosed or treated in most NHS establishments. This generates hesitancy to seek medical attention, potentially leading to the risk of other serious health developments being undiagnosed. The groups had hoped that the Inquiry could highlight these shortfalls in UK healthcare and therefore changes would be made. This hope has now been deferred by yet another substantial amount of time.

12. The delay in the Inquiry recording a clear factual narrative also undermines its ability to make meaningful recommendations for change. We have impressed upon the Chair the sheer number of people within the UK likely to have been injured by the Covid - 19 vaccines. As of the 10th May 2024, we understand the Yellow Card system in the UK has received reports of 2,688 fatalities related to Covid-19 Vaccines and 486,250 individual reports. 362,336 of these were reported as serious.[1] We have also highlighted the lack of recognition, treatment and care they experience. It is hoped that many lessons can be learned from the experiences of our groups which require urgent implementation, not only for the benefit of those who have already suffered vaccine injury but also in order to inform adequate planning and preparedness for future health crises and ongoing vaccination programmes.

13. The Covid Vaccine Adverse Reaction and Bereaved Groups have urged the Chair to make critical recommendations in key areas that significantly impact their lives. These include the need for medical, financial, emotional and cultural support. A pressing example is the need for the reform of the Vaccine Damage Payment Scheme.

14. We have already raised with the Chair the fact that the VDPS is not fit for purpose because of the systemic inadequacies and inefficiencies which characterise the existing system namely the time it takes to assess and award claims, the limited eligibility criteria for causation and the all-or-nothing, 60% disablement threshold, the limited 'award'/payment of £120,000 and the need for a clear care pathway under the NHS for the vaccine injured. There is also no emotional support or signposting

[1] https://yellowcard.mhra.gov.uk/idaps which lists the Interactive Drug Analysis Profile (IDAP) for each of the Covid 19 Vaccines, from which we have calculated a total number of reports.

within the VDPS. Rejections from the VDPS are without appeal and have left many feeling desperate. The UK CV Family knows of a father who took his own life after being rejected by the scheme.

15. The Chair is now not going to hear evidence on this and other matters until 2025 and is unlikely to make her report / recommendations until the end of 2025 at the latest. Without reform, thousands of people are being left without recourse to proper compensation or financial support and exposed to ongoing disbelief, a continued lack of medical and emotional support for their injuries and online abuse.

16. The financial situation for vaccine injuries is already challenging. The groups hoped that recommendations from the Inquiry would lead to wider recognition, diagnosis and treatment and that group members could eventually return to work. Currently a majority are unable to work and their financial situation continues to deteriorate and their immediate family are responsible for supporting and caring for them full time. There are members of the groups who have had to sell their homes to survive. Others are relying on the support of charities and food banks.

17. Another urgent matter the groups hoped the Inquiry would address, that also indirectly impacts on finances, is the culture that exists amongst medical professionals who are reluctant to discuss vaccine adverse reactions. This presents an obstacle to applying to the Vaccine Damage Payment Scheme, adding even more to the stress and hopelessness of an already vulnerable group. The groups had hoped that open discussion in the Inquiry could help to alleviate this situation.

18. There is also the serious consequence that the delay in the Inquiry will mean that many of those we represent will be well beyond the 3 year limitation period for legal recourse when they learn of key evidence that could inform their claims.

19. Therefore, as the Chair receives and considers evidence, we urge the Chair to consider making interim recommendations, particularly focused on the provision of medical, emotional and financial support for the vaccine injured and bereaved.

C. SCOPE

Vaccine Safety

20. Those we represent are deeply concerned, upset and disappointed by the suggested narrowing of the scope of Module 4, and in particular the restriction of the exploration of vaccine safety. In the provisional scope (as of June 2023), the Inquiry stated that it would examine, "*The development,*

procurement, manufacture and approval of vaccines during the pandemic, including the effectiveness of UK-wide decision-making, in particular, the role of the UK Vaccine Taskforce."

21. It is important to note at the outset that the public[2] have repeatedly called for a "Single Issue" Inquiry regarding the safety of the Covid- 19 vaccines. The Government has, to date, refused to establish such an Inquiry, citing the fact that this Chair's Inquiry would examine the Covid-19 pandemic. We understand the CTI position to now be that there will not be an examination of vaccine safety within this Inquiry. The Scottish Covid Inquiry has already ruled out looking at vaccine safety. The effect of this preliminary decision by this Inquiry would leave those we represent with no independent fact finding Inquiry into vaccine safety. Those we represent feel that this step further ostracises them and a proper examination of the very real issues that they face. This is not acceptable and we submit must be reconsidered.

22. At the First Preliminary Hearing for Module 4 on the 13th September 2023, Counsel to the Inquiry Mr. Wald KC said that "*it is appropriate that a significant part of Module 4's work will also involve examining issues relating to vaccine safety, including the steps taken by safety regulators prior to authorising the Covid-19 vaccine and the systems in place to monitor any side effects post authorisation.*"[3] (Emphasis added)

23. Mr. Wald also stated that, "*the submissions on behalf of Covid Vaccine Adverse Reaction and Bereaved highlight the importance of the safety approval process for the Covid-19 vaccines and ask whether any steps might have been overlooked due to the urgent need to roll out a vaccine. The Inquiry team agrees that this too is an important topic and we will be exploring whether the appropriate balance was struck between speed and safety in that process*."[4]

24. In the CTI note dated 2nd May 2024, the position that vaccine safety is a matter of real importance to the Inquiry now appears to have shifted. It states that the focus of Module 4 will be the "*systems, processes and outcomes relating to the development, procurement, manufacture, approval and eligibility for and access to therapeutics during the Covid -19 pandemic and how they can be improved.*"[5] Our first submission is that any focus on "outcomes" must acknowledge and record the facts that for many people, those "outcomes" were injury or bereavement from the vaccine.

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[2] 107,124 people signed a petition calling for a Public Inquiry into vaccine safety.https://petition.parliament.uk/petitions/602171
[3] Transcript Preliminary Hearing 23rd September 2023 - Page 12 Line 24 to Page 13 Line 4
[4] Transcript Preliminary Hearing 23rd September 2023 - Page 21 Lines 1 to 9
[5] At Paragraph 12 of the CTI Note - 2nd May 2024

25. At paragraphs 14 -15 of the CTI note, we interpret the Inquiry's position to be that it will only examine the regulatory regime for the vaccine, as opposed to any of the underlying scientific analysis that was presented to the regulators. In our submission, this is a marked shift from the position in June and September 2023, in which regulation was "included" but not the sole focus of the Inquiry's examination. The Inquiry states that it will examine the nature and efficacy of the regulatory regime for the approval of vaccines, but we raise the question, how can the Inquiry assess regulation without understanding and scrutinising the underlying data?

26. The CTI has sought to "clarify" the scope following "*queries concerning the scope of Module 4*" made by some material providers.[6] The nature and content of these queries have not been disclosed or discussed with all CP's prior to the CTI note of the 2nd May. Those we represent are therefore concerned that the Inquiry's consideration of scope has been influenced by submissions made by a selective number of CPs/ Material providers within the context of the disclosure process.

27. The Inquiry now states that it will "*address the safety-related debate over vaccines"*[7] but will not reach a concluded view on the safety of specific vaccines or attempt to quantify the precise risk of vaccination. This is not a "debate" for those we represent. The vaccine was not safe for them and has caused physical injury and/or bereavement.

28. In our submission, the role of the Inquiry is not to "*address the safety debate*", it is to find facts and record an accurate narrative of vaccine safety. The Inquiry states it is concerned with specific vaccine related issues such as misinformation and disinformation. However, if the Inquiry does not record an accurate public narrative of vaccine safety, then a vacuum remains with a lot of probing, unsettling and unanswered questions, within which further misinformation and disinformation can be spread.

29. The Inquiry also purports to want to understand vaccine hesitancy and how to improve vaccine confidence. However, without an accurate narrative of vaccine safety, the Inquiry will not be able to understand what the factors impacting on confidence might have been in the past, which are highly likely to include concerns around safety. In our submission, any analysis of vaccine confidence is fundamentally flawed without understanding the true impact and risk of the vaccine and what was known about that risk at the time of the roll out, as well as how that risk was perceived.

30. The Covid Vaccine Adverse Reaction and Bereaved Groups are concerned that throughout the pandemic there was a persistent narrative that the vaccines were safe and that the benefits outweighed

[6] At Paragraph 8 of the CTI Note - 2nd May 2024
[7] At Paragraph 15 of the CTI Note - 2nd May 2024

the risks. In our submission, the Inquiry should examine what is meant by a vaccine having a "favourable safety profile", and how these safety profiles are assessed (e.g. what criteria were used).

31. The Government acknowledged this in April and May 2021, when age parameters were introduced advising that under particular age groups should not receive the AstraZeneca vaccine. The language of risks and benefits was often repeated throughout the pandemic, but this was never fully explained to the public in a way that was not biased towards getting vaccinated and away from an awareness of risk profiles.

32. In particular, the Covid Vaccine Adverse Reaction and Bereaved Groups are concerned that the risks that were known were not communicated to vaccine recipients in such a way that can be said to be consistent with informed consent. For example, some members of the Scottish groups recall only being provided with the safety card that accompanied their vaccine after their vaccine had been administered. In addition, trial data was not presented by the Government / NHS in a way that was accessible or easy to understand by members of the public. We ask the Inquiry to explore whether trial data can be explained more simply to the public in easy-to-understand terms.

33. This lack of transparency around the risks of the vaccines not only had a devastating impact on the health of those we represent but undoubtedly influenced vaccine hesitancy. If the public are to maintain their confidence in future Government vaccination programmes this information must be better communicated and full warnings must be given dispassionately and objectively.

34. The Inquiry may well be intending to rely solely on their instructed experts to "address the safety debate". However, our clients have no confidence that anyone providing evidence to this Inquiry is currently considering the whole picture of vaccine safety, which must include the evidence the groups provide of their own injuries and their experiences of not being believed. It is widely known that adverse reactions are vastly under-reported and the vaccine injury and bereaved groups are concerned that 'expert' witnesses may not take this into consideration.

Vaccines as a Condition of Deployment, Employment and Enrollment

35. Those we represent are grateful to the Chair for ruling that the issue of VCOD is something that Module 4 is required to explore.

36. Many group members for whom work was a reason to get vaccinated were employed in the care sector, and specifically in healthcare including the NHS. Some worked in schools or other public institutions. Others who were made aware that their job would be at risk worked in the private sector.

All sectors — public and private — appear to have maintained a policy where protecting the residents, patients, customers, or clients was to be of the utmost priority, and expected employees to put the health of others before their own, despite any personal considerations and possible negative consequences.

37. Methods used by the Government, the NHS, and private companies to ensure that all employees were vaccinated had the desired effect for some people who responded to the campaigns by getting vaccinated (however reluctantly), but at what cost to the individual, to the employer's work environment, and to society as whole? And in what way have employers accepted any responsibility for the subsequent ill-health suffered by their vaccine-injured staff? For example, a first responder paramedic in Scotland was subjected to emails being circulated to name and shame those who hadn't received their vaccines. This front-line crucial NHS worker subsequently took her vaccine and as a result was no longer fit for work and has lost her job.

38. Many of the groups aforementioned, particularly those in precarious employment situations, belong to ethnic minority communities, raising significant concerns about both indirect and structural discrimination. It is crucial for the Inquiry to explore how VCOD, and its causal impacts, affected individuals' decisions, potentially causing them to prioritise external pressures over their own health needs. Our clients' experiences strongly resonate with observations made by FEMHO in paragraph 25 of their written submissions for the Module 4 preliminary hearing dated 13 September 2023. Specifically, that individuals felt compelled to be vaccinated solely out of fear of negative repercussion if they failed to do so.

39. When individuals are placed under undue influence to consent to vaccination against their better judgement, it overlooks the possibility that the vaccine's safety outcomes may have been influenced by individuals feeling compelled to prioritise external pressures over their understanding of their own bodies and how the vaccine may affect them. This situation could have potentially led to adverse health effects that could have been avoided.

40. It will also be important for the Inquiry to examine the degree to which the Scottish, Welsh, Northern Irish and Westminster Governments differed in their position and messaging to their populations around whether vaccines were mandatory. This examination must also scrutinise any difference between Government public messaging and what was conveyed to health or social care workers. For example, even though the Scottish Government claimed vaccine mandates were not in place, this was not the message conveyed to all health or social care workers.

41. Within our groups, there are numerous doctors within the NHS who had concerns about the vaccine but were instructed to keep these concerns from the public, including their patients. This form of censorship, which we term "cultural censorship," is deeply troubling. It has forced injured doctors to hide their injuries, even now. These doctors, who were often responsible for administering the vaccine to others, faced immense pressure to receive it themselves. Despite their enhanced understanding of their own bodies and the potential impact of the vaccine, they very often felt compelled to prioritise external pressures. This situation may have led to adverse health effects that could have been avoided.

42. The groups that we represent also harbour deep concerns regarding policies that effectively mandated vaccinations in care homes. These worries are especially pronounced when considering that certain residents, such as those with dementia, will have lacked the capacity to make informed decisions. We respectfully urge the Inquiry to explore this issue, acknowledging the potential ethical implications and the imperative of safeguarding the rights of vulnerable individuals. Similarly, our clients express profound concern surrounding the Government's vaccination program for children and young people, questioning the ability children will have had to provide genuinely informed consent.

Vaccine Confidence

43. We note that the Inquiry will look more generally at the steps taken to address vaccine hesitancy. In our submission, this investigation must look at the issue from the starting point that individuals must provide “informed consent” to any medical treatment that they receive.

44. Covid Vaccine Adverse Reaction and Bereaved Groups have made the Inquiry aware of the fact that the NHS Behavioural Change Unit published a document outlining strategies to persuade people expressing concerns to take the vaccine and we ask the Inquiry to examine carefully if these tactics undermine patient autonomy.

45. Many of the vaccine injured are unsure about the impact future vaccines might have on them. The National Infection Service at Public Health England currently suggest that individuals who experience thrombosis with thrombocytopenia following the first dose of the AstraZeneca vaccine should be properly assessed and if they are considered to have the reported condition, vaccination should be delayed until their clotting has completely stabilised and they should be considered for a second dose of an alternative Covid-19 vaccine.

Reporting of Vaccine Injury

46. The Inquiry has consistently stated that the operation of the post-approval monitoring system and how the relevant bodies identified and responded to reports of side-effects is within its scope. This in our submission must include proper scrutiny of Phase 4 trials by manufacturers, and whether their sample size and diversity was adequate to give a meaningful insight into whether recipients were experiencing adverse effects from the vaccine.

47. In our submission, the scope of the Inquiry should also include whether the health care system was adequately prepared to properly identify, report and monitor vaccine injury. Medical professionals should have been provided with information and treatment protocols about possible suspicious side effects to look out for (both recognised and currently unrecognised) before the first vaccines were administered. Medical and emergency staff should have been given directives which required them to identify any conditions which appeared following vaccination and to immediately report these for best treatment protocols and for data collection of emerging side-effects, e.g via the yellow card scheme.

48. In terms of other forms of monitoring, those we represent are clear that there has been no close monitoring of their reactions once reported and ask the Inquiry to explore how the post-marketing monitoring could be improved. In many cases across the groups, the opposite has happened. Those who have been injured by the vaccine have been repeatedly contacted and asked to attend for further vaccine doses, despite reporting their injury. This has resulted in repeated trauma and distress and further injury for many group members.

49. The bereaved that we represent also have serious concerns about how the deaths of their loved ones following vaccine injury were investigated and recorded. Hospitals, GPs and Coroners were not adequately prepared to fully investigate deaths where the bereaved raised concerns about a connection with the vaccine.

50. One of the members of the Scottish Vaccine Injury Group waited 7 months for the coroner's report to cite VITT (Vaccine Induced Thrombotic Thrombocytopenia) as the cause of her husband's death and then waited a year before an updated death certificate was issued. This delayed receiving the Vaccine Damage Payment Scheme. Suddenly losing a loved one following a 'safe and effective' vaccination is a massive trauma. Then being told that the cause of death is not related at all to the vaccine adds considerable distress. Members of our groups are still fighting for cause of death to be recognised and are unable to get closure over the loss of their loved ones.

51. In our submission, given the importance of accurate reporting of deaths caused by the vaccine by the ONS and other data and statistical bodies, the Inquiry should examine these post-death processes carefully with a review to making recommendations that will ensure a more robust and compassionate reporting system for the future.

52. We also note that there have been only 2 Prevention of Future Death Reports following deaths caused by the Covid-19 vaccination. [8] As this Chair will recognise, Coroners' Prevention of Future Death Reports are an important tool for raising concerns and prompting action by those who can make real changes to reduce the future risk of fatalities. Given this lack of proper recording and reporting by Coroners, the Inquiry has an important role to perform in reducing the risk of future deaths.

The Provision of Medical, Psychological, and Financial Support to the Vaccine Injured and Bereaved.

53. The CTI Note is entirely silent on the proposals of the UK Covid Vaccine Adverse Reaction and Bereaved Groups made at the First Preliminary Hearing that the Inquiry must consider how the vaccine injured and bereaved have been discriminated against by the lack of medical and emotional support for their injuries and trauma. We refer back to our previous written submissions for the First Preliminary Hearing at paragraph 12,[9] and our oral submissions for the same.[10]

54. In our submission, the Inquiry should investigate why the Government did not adequately plan for a clear diagnosis and care pathway to ensure people were treated quickly and that patients had a care pathway to ensure appropriate medical and emotional support was provided promptly across the country to all who needed it. Clearly, rapid diagnosis is also important for accurate vaccine safety tracking, which benefits the whole of society and not just the individual patient.

55. Anthony Shingler was a fit, healthy 57-year-old when he had his AstraZeneca vaccine on 5th March 2021. Due to vaccine injury being labelled as misinformation Anthony was turned away from his doctors twice and hospital twice. The vaccine caused GBS,[11] and he was hospitalised for 14 months.

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[8] Alexander Reid, Prevention of Future Death Report (2021) https://www.judiciary.uk/prevention-of-future-death-reports/alexander-reid-prevention-of-future-deaths-report/ and Oli Hoque (2022) https://www.judiciary.uk/wp-content/uploads/2022/10/Oli-Hoque-Prevention-of-future-deaths-report-2022-0316_Published-1.pdf

[9] https://covid19.public-inquiry.uk/wp-content/uploads/2023/09/13160934/2023-09-05-Covid-Vaccine-Adverse-Reaction-and-Bereaved-Written-Submissions-for-preliminary-hearing-M4.pdf

[10] Module 4 First Preliminary Hearing - Transcript - 13th September 2023- Page 99, Line 21 - Page 100, Line 12

[11] Guillain Barre Syndrome https://www.nhs.uk/conditions/guillain-barre-syndrome/

56. His wife experienced verbal abuse when suggesting to medical professionals she thought it was from the vaccine. Anthony said "*Our trust of having any transparency was shattered. My GP and our local MP also have failed to support myself or my family going through this horrendous time in our lives. My trust has completely gone, and no humanity whatsoever has been shown to the vaccine injured. We have been labelled "misinformation", yet I have a diagnosis, an "anti vaxxer", but how can I be when I had it. My family has suffered an enormous amount of stress on top of what happened to me and now with the disabilities I am left with. I am unable to balance or walk unaided, I have permanent damage to my hands preventing me from doing things independently. I have nerve damage in my lower legs and feet causing drop foot, so I must wear supports to lift my feet. I use a stairlift and a wheelchair/scooter to assist my mobility. My wife is now my carer which no husband wants*."

57. We draw to the Chair's attention that NICE Rapid Guidelines for Vaccine Induced Thrombosis and Thrombocytopenia (2022),[12] which included a proposal that those suffering from this type of vaccine-injury, and their carers, should be offered psychological support. The guidance stated, "*Consider referral for psychological support for people who have, or have had, VITT. Take into account that family members and carers of people with VITT may also benefit from psychological support, particularly if the person has been seriously ill, and give them information on available support services*." The UK Covid Vaccine Adverse Reaction and Bereaved Groups submit that this support should be extended to all those who are suffering from a severe vaccine adverse reaction regardless of whether it is caused by VITT or not.

58. However, we note with concern that since the First Preliminary Hearing, the NICE Rapid Guidelines for VITT have been withdrawn, without adequate explanation. Those we represent view this as a significant step backwards in the provision of adequate psychological support for the vaccine injured, and that it creates an even larger care gap for this vulnerable cohort of patients.

59. Having developed the NHS guidance on VITT, the Chair of the Expert Haematology Panel, Dr Sue Pavord of Oxford University Hospitals would be best placed to provide information regarding how well-prepared the NHS was to deal with a rare, unexpected, and life-threatening response to a Covid vaccine; and lessons that could be learned for future health crises.

60. We believe Dr Christian Buckland, Chair of the UK Council for Psychotherapy (UKCP) would be a good expert witness for the Inquiry to consider relating to the psychological impact of an adverse reaction to a Covid-19 vaccine. This psychological impact does not just affect the vaccine injured, but also their carers and their families. It also impacts on the bereaved, which also includes children.

[12] COVID-19 rapid guideline: vaccine-induced immune thrombocytopenia and thrombosis (VITT) Version 5.1 published on 06.10.2022 (Provided to the Inquiry as Appendix 4 of the UK CV Family Rule 9 Statement)

The Vaccine Damage Payment Scheme

61. In our submission the scope of the Inquiry's examination of the VDPS must include the degree to which it was given proper consideration and whether it was adequately prepared prior to the roll-out of the vaccine. The Vaccine Damage Payments Act 1977 was introduced as a "stopgap" or interim measure until an adequate compensation scheme was prepared. It has never been replaced with a permanent, adequate scheme. It has only ever been intended to provide interim relief to ease the burden for victims and families.

62. We note that at present, the Inquiry does not propose to hear any expert evidence on the Vaccine Damage Payment Scheme. VIBUK[13] proposed that the Inquiry obtain evidence from Professor Duncan Fairgrieve KC, an International Expert on comparative Vaccine Damage Payment Schemes. We are grateful that a Rule 9 Statement has been requested from Professor Fairgrieve. In our submission, he can provide insight into how the UK VDPS works, and a comparative analysis of information regarding alternative ways in which the VDPS could be structured. We ask for clarification that this is what he has been asked to comment upon in his written evidence.

63. VIBUK have given the Inquiry examples of other countries that operate functioning no-fault vaccination injury payment schemes that do not have such high or antiquated 'disablement' eligibility criteria or such low limits on the payment amount. These include New Zealand, Norway, Australia and Canada. We ask that this analysis is considered by Professor Fairgrieve in the evidence he provides to the Inquiry. VIBUK's primary focus for the last three years has been lobbying the government for the reform of the VDPS.

64. UK CV Family also propose that the Inquiry obtain evidence from Dr. Sonia Mcleod, Researcher in Civil Justice Systems at the Centre for Socio-Legal Studies, Oxford. Dr. Mcleod is leading research into "No Fault Schemes" for compensation globally.[14] UK CV family campaigning on the VDPS has included meetings with parliamentarians both individually as part of the All Party Parliamentary Group on Covid-19 Vaccine Damage. Their focus has been on increasing support and compassion within the scheme, as well as proper financial compensation.

Discrimination

[13] At Paragraph 54 of the VIBUK Statement

[14] https://www.law.ox.ac.uk/content/news/researchers-find-covid-19-vaccine-compensation-schemes-increased-during-pandemic

65. While it is welcomed that the Inquiry intends to examine structural discrimination within the context of the vaccine rollout, this narrow focus risks overlooking critical manifestations of structural discrimination that directly impacted those we represent. We are concerned that the current scope of the Inquiry will be insufficient in addressing matters surrounding structural discrimination in respect of the incidence and reporting of vaccine injury.

66. The Inquiry's stated aim to "*address the safety-related debate over vaccines"*[15] necessitates an examination of whether certain demographic groups disproportionately experienced adverse effects from vaccines. Failing to do so would imply a presumption of homogeneity across the entire population, disregarding the diverse experiences and vulnerabilities inherent in different demographic groups - an approach that does not align with the Inquiry's stated objective.

67. We submit that the Inquiry should examine whether structural discrimination as it manifests within our society, for example resulting in a large proportion of health and social care staff being from ethnic minority backgrounds, and therefore with vaccines as a condition of deployment, means that there was a disproportionately high risk of injury within these groups. To be clear, we are not suggesting that there are biological factors which increase susceptibility to vaccine injury between people from different ethnic backgrounds.

68. Moreover, a genuine concern arises regarding what those we represent perceive as a significant deficiency in the dissemination of vaccine risk information, both generally, but in particular among individuals from minoritised backgrounds, potentially attributed to structural discrimination. This structural discrimination, potentially evidenced by factors such as more limited access to healthcare resources, language barriers, and distrust in medical institutions may have hindered marginalised communities' understanding of the risks associated with vaccination.

69. It is therefore essential for the Inquiry to investigate whether these factors compelled individuals from minoritised backgrounds to consent to vaccination without fully comprehending the risks involved. Any decision in which individuals are not properly informed of the risks and benefits of medical intervention means that they cannot balance the information they receive with knowledge of their own body and autonomy. This situation could have potentially resulted in an increase in preventable adverse health effects for particular marginalised communities, including women and disabled people.

70. For example, the men and women in the groups we represent have been affected significantly in multiple ways. For example, from our client group data there appears to be a higher ratio of female to

[15] At Paragraph 15 of the CTI Note - 2nd May 2024

male injury. This brings forth the important aspect of women already being at a disadvantage regarding their healthcare for the following reasons:

a. Medical knowledge is skewed toward knowing more about men and their bodies and their diseases.
b. Gender bias affects diagnosis, treatment, and health outcomes, reducing the quality and effectiveness of healthcare.
c. Women are far more likely than men to report they feel challenged to prove the legitimacy of their symptoms and pain levels, and the gender disparity rises even more sharply when the subject is a woman of colour.

71. Those we represent also express genuine concern that vaccine injuries among individuals from minoritised backgrounds may have gone unreported due to some of the structural barriers highlighted above. This is likely to translate into an incomplete understanding of national vaccine injury incidence, any relevant data analysis by ethnicity or other protected characteristic. This undermines any proper understanding of risks for future mass vaccination programmes. Any effort to address vaccine safety remains incomplete without consideration of whether factors such as structural discrimination hindered certain groups from effectively reporting vaccine-related injuries.

D. EXPERT EVIDENCE

72. Our clients note from paragraph 53 of the CTI note that draft reports will be provided to Core Participants in Summer / Autumn 2024. We would respectfully request that all finalised reports are disclosed to Core Participants at the earliest opportunity.

73. We request that Professor Dani Prieto-Alhambra is provided with a copy of all of the Covid Vaccine Adverse Reaction and Bereaved Groups' Rule 9 statements and that he is asked to consider and address their content when finalising his draft report.

74. We would also request that our Groups' Rule 9 statements are provided to Professor Ben Kasstan-Dabush, Professor Heidi Larson, and the expert instructed to provide a report covering therapeutics for their consideration when finalising their draft reports.

Further Expert Evidence for the Inquiry's Consideration

75. In our submission, the Inquiry should obtain evidence from Professor Duncan Fairgrieve KC and Dr Sonia Mcleod on the Vaccine Damage Payment Scheme (see submissions at paragraphs 62 to 64 above).

76. We believe the Inquiry should seek to speak with Professor Paul Bennet. He has written two research papers, one of which explores the experiences of people up to 18 months after being diagnosed with vaccine induced immune thrombocytopenia and thrombosis (VITT) and a second paper that explores the experiences of family members of patients who died or survived following a diagnosis of vaccine-induced immune thrombocytopenia and thrombosis (VITT). We believe these experiences could be generalised to other conditions.

77. In our submission, the Inquiry should also obtain evidence from Dr Sue Pavord on how well-prepared the NHS was to deal with a rare, unexpected, and life-threatening response to a Covid vaccine and lessons that could be learned for future health crises (see submission at paragraph 59 above).

78. We believe the Inquiry should also obtain evidence from Dr Christian Buckland on the psychological impact of an adverse reaction to a Covid-19 vaccine (see submission at paragraph 60 above).

E. WITNESS EVIDENCE

79. Those we represent express deep concern regarding §57 of the CTI note. When interpreted literally, it appears to exclude the Inquiry hearing evidence of the lived experience of our clients, their grief, and, significantly, their valuable insights. It is firmly submitted that it is impossible to comprehend the impact of the pandemic without understanding the impact of the vaccine. Absent the insights of our clients; an accurate depiction will not be possible. It's an uncomfortable truth for many but vaccine injury and death are very sadly a part of the pandemic story.

80. For that reason, it undermines the factual reporting of that story that the Inquiry has in other Modules heard from those injured and bereaved through Covid, including those suffering from Long Covid, but is proposing not to hear from those injured by the Covid vaccine. In our submission, all of those lived experiences are vital for the Inquiry to hear evidence from and should all be part of the Inquiry's examination of the impact of the pandemic.

81. The then Prime Minister, Boris Johnson wrote a letter to a VIBUK Member on 11 August 2021, which said "*I am deeply sorry to read about Jamie's condition*[16] *and the immense consequences for you. You*

[16] Jamie Scott spent four weeks in a coma, 124 days in hospital and remains seriously disabled as a result of a Covid vaccination and the permanent brain injury it caused.

have suffered a heart-breaking and frightening change, but I would like to pay tribute to your strength in proposing changes which you think could improve the situation. You are not a statistic and must not be ignored. I am deeply touched by your story".

82. This Inquiry has a unique opportunity to ensure that the Covid Vaccine Adverse Reaction and Bereaved are not ignored. To not hear evidence from them as part of the oral evidence hearings would be to simply reduce them to an (inaccurate and under reported) statistic.

83. We can propose a list of those who are able to speak on behalf of the groups we represent, as well as their own lived experience.

84. We further respectfully bring to the attention of the Inquiry a significant oversight in the proposed list of Rule 9 recipients, specifically regarding individuals who can provide insights into the political management of online misinformation, censorship and social media policies related to the vaccine. We firmly believe that Rule 9 statements should be sought from the following individuals:

    a. Oliver Dowden, MP Digital Secretary, who engaged in communications with Matt Hancock and social media companies regarding policies and vaccine-related information online.
    b. Nadine Dorries, who succeeded Oliver Dowden MP.

85. Both individuals could offer valuable insights into the approaches taken regarding social media policies concerning adverse reactions to the vaccine. Including these individuals as Rule 9 recipients would contribute significantly to understanding the decisions and actions taken regarding misinformation and social media policies surrounding the vaccine; thus ensuring a comprehensive understanding into critical aspects of public health communication.

F. DISCLOSURE

86. To effectively prepare for Module 4 and provide valuable submissions to support the Inquiry, it is imperative that we are provided with comprehensive disclosure of all relevant materials. As at the date of these submissions, although a significant volume of materials has been disclosed, a substantial portion remains outstanding.

87. We respectfully request a clear indication of when we can expect to receive this additional disclosure. Such clarity is essential to ensure that we can adequately inform the particularly vulnerable client group we represent and afford us ample time to gather instructions and prepare accordingly.

88. Those we represent are largely very ill patients with fluctuating disability, including some with cognitive dysfunction which requires additional time to process information. They require adequate time to process information and provide instructions to us as part of the reasonable adjustments the Inquiry can make to ensure fairness to all Core Participants.

G. PARLIAMENTARY PRIVILEGE

89. The Covid Vaccine Adverse Reaction and Bereaved Groups note the CTI observations at §29-49 of their note. We agree that the issue of Parliamentary Privilege does not need to be resolved at this stage, but we reserve our position in relation to if it does in fact apply to material before this Public Inquiry until such stage as the matter requires legal submissions from Core Participants.

H. CENSORSHIP

90. Our clients have faced alarming levels of censorship. A poll of all UK CV Family members revealed that 74% had been censored when talking or posting about their adverse reaction to a Covid-19 vaccination on social media[17] and, when a family member posted an article written by the British Medical Journal on the UK CV Family facebook page which looked into data integrity issues in Pfizer's vaccine trial, that Facebook page soon had a warning placed on it by Meta claiming that UK CV Family had violated Facebook's fact checking service[18]. So concerned was the British Medical Journal about this censorship, which had also resulted in other groups receiving warnings as a result of sharing it, that the BMJ wrote an open letter to Mark Zuckerberg (CEO of Facebook) raising 'serious concerns.'[19] Even as of writing, UK CV Family's charity page on Facebook is currently "under review" and restricted from advertising, with no explanation provided by Facebook. This restriction is perplexing given that previously advertisements were reviewed, approved and accepted by Facebook without issue.

91. Unfortunately, this censorship continues into our clients' engagement with this Inquiry. YouTube removed a video featuring oral legal submissions made by Anna Morris KC on their behalf during the Module 4 preliminary hearing on September 13 2023. Despite requests for a thorough review by our clients, YouTube cited a violation of its 'medical misinformation policy' as grounds for removal.

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[17] At Paragraph 307 UK CV Family Rule 9 statement
[18] At Paragraph 318 UK CV Family Rule 9 statement
[19] Available at: https://www.bmj.com/content/375/bmj.n2635/rr-80

92. This incident of censorship is not an isolated occurrence but rather part of a broader pattern of treatment our clients have endured. Such censorship not only stifles the voices of those directly affected but also sends a chilling message to potential witnesses who may consider sharing evidence that is critical of the vaccine from their own lived experience.

93. The fear of reprisal, whether in the form of censorship, social backlash, or professional repercussions, looms large for individuals who may have valuable insights to contribute to this Inquiry. This fear may lead individuals to hesitate or withold candid evidence, undermining the Inquiry's integrity and depriving it of the diverse perspectives necessary for a comprehensive examination of the issues.

94. Addressing censorship is crucial not only to protect the rights of those affected but also to foster an environment where individuals feel safe to share their experiences openly and honestly with this Inquiry and elsewhere. It is imperative that individuals providing evidence feel confident they will not face repercussions for their testimonies.

95. To restore confidence in the Inquiry process, our clients respectfully request that the Chair publicly acknowledges instances of Inquiry originating content being unjustly removed from online platforms. Additionally, those we represent urge the Chair to establish clear protocols for reporting any instances of reprisal, even after the Inquiry concludes, which in our submission are essential to uphold the credibility of her Inquiry.

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I. SUPPORT FOR THE COVID VACCINE ADVERSE REACTION AND BEREAVED GROUPS

97. We ask the Inquiry to consider from the outset how it will hear evidence from the Covid Vaccine Adverse Reaction and Bereaved as part of the oral evidence hearings. The applicants are the only

individuals who can give first hand evidence to the Chair of their experience of the vaccine injury, their experience of reporting their injury, and their experience of the VDPS.

98. We also ask that the Inquiry be mindful that our clients are significantly health impacted and/or bereaved and will need support and appropriate accommodations from the Inquiry Legal Team to attend hearings and participate effectively. Early conversation with the ILT as to how this can be facilitated would be beneficial.

99. We ask the Inquiry to consider that the physical conditions that members of the Covid Vaccine Adverse Reaction and Bereaved Groups suffer from include pain therefore they need to move around, sound and light sensitivities so they need to wear protective glasses, mast cell activation syndrome therefore can be very (even dangerously) sensitive to chemicals and/or deodorants, air fresheners, and vapes. The water provided at the hearings will need to be filtered and good ventilation will also be required.

100. Members suffer chronic fatigue and may need to give evidence early in the day given they may not be in a fit state to do so later on. Frequent breaks will be required during the hearing. Members also suffer Postural Orthostatic Tachycardia Syndrome and they need to sit with their feet up or even lie down. Requiring them to stand may present major issues. The members who give evidence at the hearing may be in wheelchairs and additional space will be needed for them.

101. Members also suffer from brain fog, memory loss and a variety of cognitive issues and we would request that witnesses be presented with questions in advance as this would help them to prepare notes and refer to documents to support them.

J. EVERY STORY MATTERS

102. In our written submissions for the First Preliminary Hearing, we identified a number of additional KLOE'S for the Inquiry to explore that are of significant relevance to the Covid Vaccine Adverse Reaction and Bereaved. These were;

a. *Experiences of vaccine-related injury and bereavement*
b. *Whether particular underlying medical conditions made it more likely for individuals to experience vaccine injury*
c. *Whether particular factors such as age, gender, race, ethnicity made it more likely for individuals to experience vaccine injury*
d. *The experience of the vaccine injured in reporting their injury*

e. *The mental health impact on those experiencing vaccine injury*

f. The experience of any discrimination of stigma on the basis of their vaccine injury or bereavement (this can include from health care providers, employers, the media or members of the public)

g. The experience of the vaccine injured and bereaved in applying for/obtaining funds from the VDPS scheme.

103. Given that we now understand that the Module 4 ESM report is due to be provided to the Inquiry in late Summer 2024, we would be grateful for confirmation from the Inquiry that these KLOE's were included in the ESM process.

K. TIME ESTIMATE

104. In addition to the concerns set out above regarding delay and narrowing of scope, the Covid Vaccine Adverse Reaction and Bereaved are further alarmed by the Inquiry's reduction in the duration of the oral hearings. Even on the scope proposed in the most recent CTI note, we submit that a thorough and adequate investigation can not be achieved within 3 weeks. The Chair has currently requested statements from 120 witnesses, we ask how is it possible to hear the significant evidence that those witnesses provide in this condensed time scale? In our submission, the Chair should reconsider the timetable and allow proper time for oral evidence to be heard from witnesses within the original time estimate.

Anna Morris KC
Mark Bradley
Christian Weaver

Terry Wilcox
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15th May 2024