Witness Name: Charlet Crichton
Statement No.:1
Dated: 17 October 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF UKCV FAMILY

I, Charlet Chrichton, will say as follows: -

BACKGROUND

1. I am the founder of UKCVFamily, which I set up in November 2021. I was already an admin on an international group of vaccine-injured whom I had found after suffering an adverse reaction to the AstraZeneca vaccine myself. It was clear that support and information relevant to adverse reactions to the Covid-19 vaccine were severely lacking for those who were specifically dealing with the British healthcare system.

2. I experienced adverse reactions to two doses of the AstraZeneca vaccine in early 2021. These reactions were initially acute and are now chronic health conditions. During the pandemic, I volunteered in my local vaccination centre, which is why I was offered the vaccine earlier than others in my age group. Prior

to that, I ran my own sports therapy business in Kent, which I established in 2009. I have a Level 5 Diploma in Sport and Remedial Therapy and a Level 3 Diploma in Sports Therapy and Gym Instructing. I have been unable to return to my business since vaccination, and I now manage UKCVFamily, whilst dealing with my own ill-health, full-time and on a volunteer basis.

3. My role within the group includes managing the online support group, being our media representative, overseeing fundraising, holding discussions with scientists and doctors, organising talks to the group, coordinating the admin team, coordinating volunteers, sign-posting for mental health support, organising events, and keeping up to date with medical developments. Much of my work involves researching adverse reactions to vaccines and the issues our members face.

4. I work very closely with Caroline Pover, an award-winning writer, entrepreneur, speaker, and philanthropist, who was diagnosed with an adverse reaction to her first and only dose of the AstraZeneca vaccine early 2021. She was an admin on an international group before it was shut down by Facebook, is a Founding Member of UKCVFamily, and author of the *Covid Vaccine Adverse Reaction Survival Guide* (Chelsea Green Publishing, 2023). Ms Pover runs UKCVFamily alongside me, and is able to answer questions from the Inquiry, should I be unwell enough to do so myself. It should be noted that Ms Pover has specific knowledge about UKCVFamily's

interactions with MPs and the media, and produces most of our published material.

5. Ms Pover and I represent UKCVFamily on the React19 International Coalition [CC/01-INQ000377482], a group of 42 individuals running support groups for the vaccine-injured throughout the world. Countries represented include Australia, Argentina, Canada, Israel, Netherlands, New Zealand, Spain, Switzerland, Belgium, Denmark, Ireland, Italy, Germany, France,and the United States. Scottish VIG (also Core Participants in Module 4 of the Inquiry) are also members of the React19 International Coalition. The coalition monitors, discusses, and shares the latest scientific research, government policy-making, media coverage, and possible treatment pathways from around the world. The coalition also works with scientific academics to further encourage more research into vaccine injury. UKCVFamily's presence within the coalition means that we are sometimes more aware of the latest international medical progress regarding vaccine-injury than most doctors, scientists, and researchers within the UK.

PRODUCTION OF THIS WITNESS STATEMENT

6. This Witness Statement has been produced by Ms Pover and myself along with the support of a number of our admin team. We rely on the advice of Terry Wilcox of Hudgell Solicitors and the rest of the legal team that represent UKCVFamily in the Inquiry. This Statement is based primarily on the

UKCVFamily Information Pack — a 22-page document initially created for MPs. It is also based on information and input we have gathered directly from our members, sometimes by surveying membership about specific issues. Where surveys are cited, at least one hundred members responded.

7. Dr Harriet Caroll (PhD), Mr Brian Howard, Ms Alexandra Kelly and Mrsm Claire Parham, members of UKCVFamily, have also made substantial contributions to this witness statement.

8. None of the members of UKCVFamily, including myself and Caroline Pover, have received any financial support or been paid in any way, in the production of this witness statement. We have all attempted to create this witness statement while managing our ongoing health challenges as a result of experiencing an adverse reaction to a Covid-19 vaccine. We appreciate the flexibility that the Chair has provided regarding deadlines.

9. We include a number of case studies, which we gathered directly from our members, some of which were given in-person to a number of MPs at a private event in Westminster on 11th July 2023. These case studies are limited to 500 words for the Inquiry's convenience, and further details of individual cases are available should the Inquiry request them.

10. This Witness Statement covers UKCVFamily's concerns relating to the following

topics requested by the Inquiry: vaccine development, vaccine safety issues, public messaging, rollout implementation, vaccination as a condition of deployment, other new/existing therapeutics and/or medications, and the Vaccine Damage Payment Scheme, with a focus on the lessons learned and preparation for future health crises. We have also included other topics that are of concern to the vaccine-injured and -bereaved, with a specific focus on the NHS preparedness for managing adverse reactions.

11. As a rule, UKCVFamily never comment on the safety nor the efficacy of the Covid-19 vaccines. We have learnt that this is highly distracting to our members' needs and that members have differing opinions on this subject. In order to be able to represent and support *all* of our members, we remain neutral in our opinion on the wider issues. However, the Inquiry has specifically asked UKCVFamily to provide evidence regarding safety concerns within this document, thus on this occasion we have made an exception.

12. This Witness Statement is backed up by material published by the NHS, the MHRA, NICE guidelines, peer-reviewed scientific papers, government websites, the Covid-19 vaccine manufacturers, and mainstream media.

INTRODUCTION TO UKCVFAMILY

13. The Covid-19 vaccine-injured and bereaved throughout the world have found each other online, and established country-specific and international groups

through which members share practical information and emotional support. Facing social stigma for talking about their symptoms, for some members these groups are the only places where they feel safe enough to speak freely. And for the majority, these groups are the only places where the vaccine-injured are receiving any kind of health and emotional guidance.

14. UKCVFamily is the largest online support group for the Covid-19 vaccine-injured and bereaved in the UK. We are run entirely by volunteers, all of whom are vaccine-injured, caring for those that are vaccine-injured, or -bereaved themselves. Formed in November 2021, we specifically focus on the needs of UK-based patients, providing help and advocacy; and actively raising awareness amongst the British healthcare system, media, and government. We mostly provide support through our very active Facebook community. We also host online social events, in-person outreach events, provide MP and GP letter-writing support, and organise presentations from healthcare practitioners. Our very existence shows that the UK was not prepared to meet the needs of those adversely impacted by the Covid-19 vaccine rollout.

15. Our funding is generated by donations from the public, and by admins paying for items out of their own pocket. Our running costs include hosting our website; the printing of public information leaflets, our Information Packs, Medical Trauma cards (for those of our members now suffering from PTSD in healthcare environments due to the gaslighting they have experienced); and postage of

aforementioned material. We receive no funding from the vaccine manufacturers, the government, the NHS, or any other public bodies.

16. UKCVFamily is currently in the process of applying for charity status and have engaged Third Sector Experts LTD. a company registered in England and Wales, company number: 1286085, to complete our application. Our application includes me as Executive Director and a Trustee, Ms Pover as the Chair of Trustees, and three other Trustees, all of whom are also vaccine-injured.

17. As of October 2024, UKCVFamily has more than 2,000 members in its vaccine-injured group, and about 15 new people join every week. Members are 75% female and 25% male, and ages range from 14 through to 76 years. The most prevalent age range is 45–54 years. 19% of our members work in the healthcare sector, or have worked in the healthcare sector in the past, and are well-placed to offer useful information not only to fellow members, but also to the Inquiry.

18. Membership is limited to people who have had adverse reactions to a Covid-19 vaccine, unless the patient is a child, in which case their parent may join on their behalf. We have strict criteria for joining — those curious about vaccines or seeking information to use for their own agenda are not permitted to join.

19. We also have a support group called UKCVFamily Extended with approximately 320 family members, carers, and friends who are supporting someone with a

vaccine injury. As UKCVFamily is limited to the injured — or carers of those who are unable to engage themselves, eg. children — the Extended group was set up as a place for those supporting them to connect and share.

20. We also have a third group called UKCVFamily Bereaved with approximately 163 members who have lost a loved one post Covid-19 vaccination. Our UKCVFamily Bereaved group is made up of a mixture of those who have causation of death cited as one of the Covid-19 vaccines — and those that are still fighting for investigation of their loved ones death. Our bereaved group members believe the timings of some of the deaths are extremely questionable. Dealing with coroners and pathologists is an extremely difficult task when grieving. Our aim in the UKCVFamily bereaved group is to give support to all, regardless of what stage they are at in their quest for justice and answers. The group share updates on political and medical issues, on the Vaccine Damage Payment Scheme and actions they can take. Most importantly the bereaved share experiences, which can be of some comfort, in such a unique and difficult situation.This mutual sharing often brings advice and support from other members. This is an invaluable support group, as no one knows better than our members, how hard and lonely this can be. Whilst the world is congratulating itself on the Covid-19 Vaccine rollout, the Covid vaccine bereaved are left to navigate a system that is neither compassionate nor understanding of their situation.

21. The three UKCVFamily groups comprise approximately 2,500 people who have been severely impacted by health problems or a death following a Covid-19 vaccination. Some have adverse reactions or death confirmed by a medical professional as being due to a Covid-19 vaccine; some are still seeking acknowledgement. This lack of recognition is a complex area resulting in multiple problems, which I have explained in more detail in several places in this document.

22. Our members as individuals may have differing opinions regarding the Covid-19 vaccine or vaccination in general, and those opinions may understandably have changed (or be in the process of changing) since experiencing an adverse reaction, seeing their loved one deal with an adverse reaction, or losing a loved one. UKCVFamily as a group steers clear from any public commentary regarding vaccination and actively avoids the topic within group discussions. We consider conversations around the topic to be highly distracting to what are now extremely urgent health needs of our members.

23. UKCVFamily exists because people have been left alone to deal with a highly complicated and taboo subject, which this country has had the opportunity to tackle on multiple occasions in the past, prior to Covid. For example, TIME FOR ACTION is a UK campaign group formed in 2009 by parents whose daughters experienced serious health problems after HPV vaccination. Also, the UK Association of HPV Vaccine Injured Daughters was formed in 2015. Throughout

the late nineties, Olivia Price MBE, successfully campaigned to improve the Vaccine Damage Payment Scheme, but there were no improvements made in the provision of non-financial forms of support. There have been opportunities in the past to learn from the experiences of other vaccine-injured, and those opportunities have been ignored. Olivia Price MBE, Jackie Fletcher, Steve Hinks from other vaccine injury support groups as well as Helen Drake and Caron Ryalls from Time for Action would be best placed to offer the Inquiry insights as to how the vaccine-injured have been treated in a historical context.

24. UKCVFamily has played a vital role in the Covid-19 vaccination rollout, whereby individuals who are themselves struggling have filled the gap that existed in the UK by governments historically ignoring the needs of those affected by vaccine adverse reactions.

ADVERSE REACTION SYMPTOMS

25. Members' symptoms are complex, and we have multiple symptoms at a time — very few of our members are dealing with just a couple of symptoms. 52% of members we surveyed have dealt or are dealing with between ten and twenty-five symptoms — affecting not only specific organs but also affecting entire systems. We frequently find that when one symptom becomes manageable, another symptom becomes unmanageable and a relapsing-remitting phenotype is common. For many of our members, these symptoms have now morphed into

chronic symptoms lasting for well over two years. Previously healthy and active people now find that life has become a constant management of symptoms, which indicate widespread damage.

26. Neurological symptoms include stroke, transient ischemic attack, cognitive difficulties, vertigo/severe dizziness, severe headaches, speech problems, seizures, catatonic states, fainting, memory loss, paraesthesia and nerve pain. Cardiovascular symptoms include abnormal heart rates (low and high) and rhythms, aortic aneurysm (bulge in main vessel from the heart), chest pain/pressure, and heart failure. Dermatological issues include hair loss, face drooping, burning, rashes, psoriasis, eczema, and face pain. Eye problems include severe pain, vision disturbances, blindness, drooping eyelids, and blocked eye glands. Ear, nose, and throat symptoms include tinnitus, hearing loss, ear/jaw pain, difficulty swallowing, burning mouth, throat swelling, chemical sensitivity, and cracked teeth. Gastrointestinal symptoms include loss of bowel control, stomach lining inflammation, food intolerances/allergies, gut bacteria overgrowth, and vomiting. Sensory symptoms include numbness, burning, tingling, crawling sensation under skin, extreme pain, electric shock sensations, temporary paralysis, and stabbing chest pain. Musculoskeletal symptoms include paralysis, difficulties moving, twitching, spasms, and sudden onset arthritis. Hormonal and gynaecological symptoms include menstrual changes, persistent genital arousal, genital swelling and pain, hot flushes, sudden onset perimenopause, vaginal dryness, and pelvic pain. Genito-urinary symptoms

include urinating blood, erectile dysfunction, and incontinence. Immunological symptoms include swollen lymph nodes, shingles, inability to regulate temperature, anaphylaxis, mast cell issues, light/noise sensitivity, and blackouts.

27. Haematological and circulatory symptoms include blood clots, sticky blood, reduced blood flow, high/low blood pressure, very low and high white blood cells, vasculitis, anaemia, bulging veins, blocked blood vessels, and inexplicable bruising. Respiratory symptoms include breathing difficulties, throat clamping, tight chest, and low oxygen saturation. Sleep symptoms include insomnia, nightmares, and sleep apnoea. Energy level symptoms include fatigue, exercise intolerance, exercise-induced anaphylaxis, and post-exertional malaise. Psychological symptoms include suicidal thoughts, severe anxiety, depression, low mood, involuntary crying, PTSD, and hallucinations. This is not an exhaustive list. [CC/02 - INQ000377514].

28. I will discuss the difficulties many vaccine-injured experience in having symptoms recognised, investigated, and diagnosed later in my Statement. Those of us who have managed to get our symptoms recognised, been provided with appropriate testing, and had referrals accepted, have been diagnosed with the following conditions: Acute Disseminated Encephalomyelitis (ADEM), Acute kidney Injury, Acute onset Reactive Arthritis, Acute onset Autoimmune Hepatitis, Acute Necrotising Pancreatitis, Alopecia, Atrial

fibrillation, Autoimmunity, Autonomic Nervous System Dysfunction, Bell's Palsy, Brain haemorrhage, Bullous Pemphigoid, Cerebral Venous Sinus Thrombosis, Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP), Chronic Mononeuritis Multiplex, Chronic Myo/Pericarditis, Chronic Pain Syndrome, Deep Vein Thrombosis, Dorsal Root Ganglionopathy, Dysautonomia, Dystonia, Erythromelalgia, Exacerbation of Hemicrania Continua, Essential tremor, Fibromyalgia, Functional Neurological Disorder, Gastroparesis, Giant Cell Arteritis, Graves Disease, Guillain-Barré Syndrome, Heart Failure, Hemiplegic Migraine, Hyperacusis, Hypothyroidism Myxoedema, Hyper immune response to Covid 19 vaccination, Hypoaldosteronism, Hyperprolactinaemia, Idiopathic thrombocytopenic purpura, Immune Thrombocytopenia Purpura, Inappropriate Sinus Tachycardia, Intercranial Hypertension, Mast Cell Activation Syndrome (MCAS), ME/CFS, Medical Post Traumatic Stress Disorder, Mastocytosis, Motor Neurone Disease, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Myocardial Ischemia, Myocarditis (chronic and acute), Neurogenic Bladder, Nodular Panniculitis, Nystagmus, Optic Neuritis, Pericarditis, Pericardial Effusion, Peripheral Neuropathy, Pernicious Anaemia, Polymyositis, Postural Orthostatic Tachycardia Syndrome (POTS), Post Traumatic Stress, Post-Vaccination Syndrome, Pneumonitis, Pulmonary Emboli, Progressive Bulbar Palsy, Psychosis, Pulmonary Sarcoidosis, Pudendal Neuralgia, Rapid Onset Glioblastoma, Reactivated Epstein Barr Virus, Reactivated Lyme Disease, Reactivated Shingles, Secondary Hypogonadism, Scleroderma, Seizures, Sjogren's Syndrome, Shoulder Injury Related to Vaccine

Administration (SIRVA), Small Fibre Neuropathy, Stevens-Johnson Syndrome, Stroke, T-Cell Lymphoma, Thyrotoxicosis, Tinnitus, Transverse Myelitis, Trigeminal Neuralgia, Uveitis, Vaccine-induced Raynaud's Syndrome, Ventricular Tachycardia, Vasculitis, Vaccine-induced Immune Thrombocytopenia and Thrombosis (VITT), Vestibulopathy.

29. Some of the above conditions are life-threatening if left untreated. All of these conditions are life-altering. Some of our members have multiple diagnoses. Some of us have spent thousands of pounds on testing — both in the UK and overseas — that has resulted in these diagnoses.

30. A poll of our members confirmed that 60% of those surveyed had no prior health conditions prior to having a Covid-19 vaccine. Of those who have had a previous underlying condition, 9% did not have any symptoms of the condition prior to the vaccine, 28% had an ongoing condition that was being managed well and just 3% had a prior condition that they were still struggling with at the time of having their vaccine.

THE PSYCHOLOGICAL IMPACT OF AN ADVERSE REACTION

31. A survey we conducted indicated that 76% of our members had considered suicide since experiencing their adverse reaction. The psychological impact of an adverse reaction to the Covid vaccine can be devastating not just because of the debilitating, life-changing symptoms, but also because of the controversial

nature of the illness and the unkind social climate around vaccine injuries. Medical related psychological trauma, if not treated early can result in medical PTSD which can put patients at risk of suicide and suicidal thoughts. Sadly, in 2022, UKCVFamily lost their first member to suicide. UKCVFamily members have experienced most of what follows. [CC/03 - INQ000377640].

32. Shock, denial, disbelief: It can be devastating to realise that your life has been changed out of all recognition by a major loss of health, and people usually struggle to accept that, trying to carry on as before as best they can, often making it worse. Our members grieve deeply for the lives they had before.

33. Change of identity: In order to accept their new circumstances, an injured person needs to change how they see themselves. This change of identity can impact us personally and professionally. We will never feel the same confidence in our health and bodies, and our lives can feel torn apart.

34. Fear: Great fear accompanies a sudden loss of health; many of us are frightened for our lives, especially as medical support is often rare where vaccine injuries are concerned. Symptoms can be frightening. Doctors, not knowing what to do and having few guidelines, often resort to palming off the vaccine-injured patient or passing them along to another consultant. We then feel gaslit and abandoned, our futures can feel terrifying.

35. Anger: There is a strong sense of betrayal felt by many, not just because we took the vaccine in good faith, but because we believed that were something to go wrong, help would be available. The vaccine-injured and bereaved can feel angry with healthcare providers, the government, and the media.

36. Hopeless, desperation, despair: Chronic illness often leads to chronic mismanagement and medical invalidation by the medical profession, which struggles to help with complex symptoms without a supportive system allowing for a diagnosis of vaccine injury. The injured can then fall into hopelessness and desperation, as we search for a helpful treatment. Hope is raised and crushed time and time again. Rejection of the Vaccine Damage Payment Scheme can have a detrimental effect. The lack of publicity of this marginalised group has also added to our despair. Shame and loneliness are very common; whilst Long Covid clinics exist, there are no clinics for the vaccine-injured.

37. Trauma: Losing your health and being plunged into a world of disability, where you are often dismissed by the medical profession, has been traumatic for most if not all in our group. The cumulative effect of numerous negative medical encounters has led to associated trauma symptoms, in turn making visits to hospital too difficult to bear. Medical PTSD is common to the extent where UKCVFamily provides “Medical Trauma” cards for our members to hand to any healthcare professionals during appointments.

38. Loss of Trust: When you do what your trusted institutions tell you to do and disaster follows, there is a large loss of trust — in the healthcare system, the government, and the media. It can lead to a loss of trust in other people in general, and more unsettlingly, a loss of trust in one's own instincts.

39. Courage: Although something has happened to us that we would never have chosen, none of us want to feel or to be seen as a victim. It takes huge courage to face each day, to adapt to different circumstances, to maintain our sense of who we are, and to maintain some degree of hope or faith in the future. For many of us, it takes huge courage not to give up.

40. Social exclusion/loneliness: Any chronic illness can lead to social exclusion. The vaccine-injured find the same, due to long periods of inability to leave the home and adjustments to how and when we can socialise due to symptom management and medications. However, the Covid-19 vaccine-injured and bereaved have faced several issues alongside this in the form of (i) the restrictions posed due to the pandemic — many members had an adverse reaction to their first Covid-19 vaccine in early '21 and weren't well enough to "come out" of lockdown, and (ii) the suppression of the immune system — sometimes due to the adverse reaction itself — and the worry of contracting illness on top of their adverse reaction symptoms. Many of our members can't or won't have another Covid vaccine due to their adverse reaction and are concerned about contracting Covid-19. These circumstances have led to a

feeling of loneliness and isolation in the Covid-19 vaccine-injured and bereaved.

41. In the since withdrawn NICE Rapid Guidelines for Vaccine Induced Thrombosis and Thrombocytopenia [CC/04 - INQ000315791], it was included that those suffering from this type of vaccine-injury, and their carers, should be offered psychological support. The guidance states "*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."* We would like this support to be extended to *all* those who are suffering from a severe vaccine adverse reaction regardless of whether it is caused by VITT or not.

42. A qualitative study of survivors of VITT '*Living with vaccine-induced immune thrombocytopenia and thrombosis: a qualitative study'* [CC/05 - INQ000377885], noted the same issues that UKCVFamily members suffer, regardless of whether diagnosis was of VITT, or not. The study concludes "*In addition, future mass vaccination programmes need to consider not just the benefits of any programme, but how to respond directly and immediately to individuals directly damaged by it, in a way that ameliorates rather than adds to their problems. Such responses should include meaningful and rapid financial reparation and the provision of relevant support services, both physical and psychological*."

43. The NHS Every Mind Matters campaign [CC/06 - INQ000377923), states that "*a long-term physical illness or a life-long or chronic condition, like diabetes, is more likely to lead to: stress, worry or anxiety, especially over appointments or test results; low self-esteem, or feelings around discrimination or stigmatism; social isolation or loneliness, possibly due to long stays in hospital or having to stay home more; anger, frustration, or grief, especially if being ill stops us from socialising or doing things we enjoy; sleep problems, which might be caused by pain, sickness, or from the side effects of some medicines; some less common mental illnesses, such as eating disorders, or psychosis.*" We see evidence of all of these amongst our community, yet when we surveyed our members, 57% of them said that NHS staff had mostly treated them as if they had a mental health illness, rather than considered any mental health issues suffered as being caused by the impact of dealing with chronic physical health issues. Only 18% of our members said that NHS staff had treated them according to the NHS Every Mind Matters statement — as if the chronic illness had challenged their mental health.

44. UKCVFamily 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.

THE FINANCIAL IMPACT OF ADVERSE REACTIONS

45. The financial implications for the vaccine-injured are huge. We conducted a survey amongst our members and found that 90% of those responding had paid privately for testing or treatment, and in doing so had depleted their life's savings, gone into debt, or had crowdfunders where members of the public could support them. UKCVFamily bereaved members have, in some cases, lost the main wage earner of the family and in many cases, have pursued costly legal advice and aid.

46. One of the UKCVFamily bereaved members, Alexandra Kelly, has found it necessary to set up a crowdfunder to help members seek legal counsel, and in doing so, allows members to access vaccine-injury specialist lawyer, Peter Todd. Peter Todd would be best placed to provide more information regarding the legal implications of dealing with pharmaceutical harm, and has specific experience of dealing with vaccine injury. His professional background is included in the appendices [CC/07 - INQ000377936].

47. As of July 2023, UKCVFamily members had each spent an average of just over £6,000 in their attempts to deal with their adverse reaction to a Covid vaccine, with two members both spending around £50,000.

48. A poll of our members showed that 17% surveyed had a loss of income of over £60,000 as of September 2023 directly as a result of their adverse reaction. The average loss of income from those surveyed was £23,500.

49. The vaccine-injured and/or their carers often need to claim benefits for loss of income or disability, the process of which can take well over a year and be extremely challenging in itself.

THE WIDER IMPACT OF ADVERSE REACTIONS

50. Vaccine injuries place significant pressure on family members. For some of us, our family members (including children) have become our carers, we can no longer participate in normal family life, and we are no longer able to fulfil our practical obligations to our family. For many of us, our household finances have been affected by a possible decrease in income or increase in healthcare-related expenses (see above) which can add to pressure within the home [CC/08 - INQ000377950].

51. The taboo nature of vaccine-related illness may mean that our families are alienated from our social support network and gradually withdraw from society. Some of our members feel abandoned by lifelong friends who are uncomfortable with being close to someone who has been vaccine-injured.

52. In some cases, the lack of recognition of vaccine injuries from the media and medical professionals have caused friction within families and friendships themselves — if it isn't mentioned in the mainstream media, or if a doctor diagnoses someone with a mental health problem, then some family members and friends simply do not believe what their vaccine-injured loved one is saying.

53. Vaccine-injury also has a wider impact on society. The vaccine-injured often take extended periods of time off work sick, or give up employment altogether, creating problems for employers. Some vaccine-injured and/or their carers are no longer able to participate in the workforce at all. We are also aware of the development of hostile work environments toward employees whose sickness is due to adverse reactions to vaccination. And the lack of diagnosis can lead to the vaccine-injured being unable to claim or prove they have a condition which would entitle them to benefits or help at work.

54. As there are no clear clinical pathways for the vaccine-injured, we place an enormous amount of burden on our local healthcare services. We have multiple doctors appointments, referrals to specialist consultants for each body system affected and unfortunately, in a lot of cases, multiple trips to A and E and extensive hospital stays. Many of our members have had multiple and repeat scans and tests. With an already struggling NHS, the lack of a clear medical pathway for the vaccine-injured means that we are using services that aren't prepared to deal with our condition and are ill informed about vaccine adverse reactions.

UKCVFAMILY CONCERNS: VACCINE DEVELOPMENT

55. There are two elements of the Covid vaccine development that were significantly different from the development of other vaccines, and that need to be kept in

mind: firstly the speed of the development, and secondly how differently the Covid vaccines work when compared to how other vaccines work.

56. The speed of this vaccine development compared to how vaccines are usually developed, was covered by a BBC article [CC/09 - INQ000377967] *Coronavirus: How soon can we expect a working vaccine?* (9th November 2020) stating that "*A process that usually takes five to 10 years, from research to delivery, is being pared down to months.*" accompanied by a graphic indicating the differences as follows:

a. pre-clinical (non-human) analysis took around six weeks whereas ordinarily it would take six months;

b. Phase 1 testing took around three months whereas ordinarily it would take 18 months (Phase 1 testing involves "small numbers" of people); Phase 2 testing took around six months whereas ordinarily it would take one year (Phase 2 testing involves "hundreds" of people);

c. Phase 2 testing took place concurrently with Phases 1 and 3 whereas ordinarily it would take place chronologically;

d. Phase 3 testing took around six months whereas ordinarily it would take two years (Phase 3 testing involves "thousands" of people);

e. Regulatory review, approval, and distribution took around six months whereas ordinarily review, approval, and manufacture would take about five years; and

f. Manufacture of the Covid vaccines began during Phases 1–3 of the trial.

57. According to the aforementioned BBC article, the Covid vaccines were made available within a two-year development process, when vaccine development usually takes ten years. We understand that funding is often a deciding factor in the time for normal vaccine development, and that significant funding, participant availability, manufacturing, and approval (ethical and regulatory), were made available to accelerate the development of the Covid vaccines. The British Society of Immunology explained the process in its article [CC/010 - INQ000377483], *How have COVID-19 vaccines been developed so fast?*; however, we question whether the acceleration may have meant that adverse reactions were not investigated (see below).

58. We are extremely concerned about how adverse reactions during vaccine development were handled. The *International Journal of Risk & Safety in Medicine* 34 on 4th May 2023 [CC/011 - INQ000377494] published a paper "*The coverage of medical injuries in company trial informed consent forms*," which included case studies from the Phase 3 trials for both Pfizer BioNTech and the AstraZeneca Covid vaccines.

a. The trial participants were "blind" (unaware whether they received a vaccine or a placebo) and the case studies in the aforementioned paper — having become unwell after vaccination — requested to be unblinded. This necessitated them to withdraw from the trials. Both case studies were then recorded as having withdrawn for personal reasons, rather than for having an adverse reaction. Their data did not form part of the clinical trial results. We are concerned about how the total number of trial participants who were recorded as withdrawing, may in fact have been withdrawing because of ill-health possibly due to the vaccine.

59. As with all trial participants, the sponsors (Pfizer and AstraZeneca) agreed to provide immediate medical attention (and associated finances) should the individuals suffer any ill-health as a consequence of their participation in the trials. Yet neither of the case studies received medical or financial support, and it wouldn't be unreasonable to assume that the challenge of dealing with the lack of support from the sponsors would have exacerbated any emotional distress caused. We are concerned at how those who suffer adverse reactions are treated during clinical trials in general, and have specifically been treated during the Covid vaccine clinical trials. The vaccine manufacturers would be best placed to provide more information regarding how they supported those who suffered ill-health during the trials. Also, Brianne Dressen, who participated in the AstraZeneca trials, and Maddie de Garay who participated in the Pfizer trials,

would be able to provide information on how they were recorded and treated after suffering from adverse reactions during the trials.

60. The same paper also states, "*A submission by Pfizer to the European Medicines Agency review of significant adverse events from this trial includes 7 deaths of which 4 were linked to myocarditis. In these cases, Pfizer note the investigator did not link the myocarditis to the vaccine, although a link between myocarditis and these vaccines is now widely accepted*." We are concerned about how many other adverse reactions that occurred during the trials were not fully investigated and have since come to light as being related to the vaccine. For example, since myocarditis is now recognised as a side effect of COVID-19 vaccination, the causal assessment of AEs in trials looks to be inadequate.

61. The vaccine manufacturers may be able to provide further information regarding how myocarditis was managed during the trials.

62. It is reasonable to assume that most UK residents are aware that the Covid vaccines were developed quicker than usual, but we are concerned that not only the general public — but also healthcare workers including vaccinators and GPs — are not aware of the different mechanisms. A survey amongst our members indicated that, prior to vaccination, 77% were not aware that the Covid vaccines worked differently to other vaccines. Some of our members, almost three years since the rollout began, are still not aware. It may be useful to request evidence

of how NHS staff were educated about the Covid vaccine mechanisms, when compared to their education about other vaccines.

63. With regard to how differently the Covid vaccines work when compared to how other vaccines work, traditional vaccines contain a microbe (dead or alive) that provokes an immune response. The Covid vaccines contain genetic material that instructs the body to make spike protein (a part of the Covid virus) and the presence of this spike protein provokes an immune response.

64. In 2020, researchers discussed the need to understand biodistribution of the vaccine (e.g. CC/012 - INQ000377505, CC/013 - INQ000377506 Florindo *et al.*, 2020; Wang *et al.*, 2020). The Brighton Collaboration (which the UK Green Book and WHO base some of their vaccine safety information off) published a template for risk assessment of RNA- and DNA-based vaccines, which included biodistribution [CC/014 - INQ000377507, Kim *et al.*, 2020).

65. The *European Medicines Agency (EMA)* in 2021 reported biodistribution data from Moderna [CC/015 - INQ000377508] based on the same lipid nanoparticle (LNP) as the final product, but with a different mRNA (mRNA-1647) in rats, and for Pfizer, a LNP with a surrogate luciferase RNA in mice and rats [CC/016 - INQ000274041). Both showed biodistribution beyond the injection site, but at low levels which were deemed non-concerning. In other words, neither Moderna nor Pfizer were required to submit data on the biodistribution of the final product,

nor were they required to investigate the biodistribution of spike protein or its degradation.

66. The *EMA* (2021) reported [CC/017a - INQ000377510 and CC/017b - INQ000485963] biodistribution data for AstraZeneca based on a different (albeit similar) viral vector (ChAd63), as well as the viral vector used in the final vaccine (ChAdOx1) but with a hepatitis virus insert. A study using the final product was underway. In other words, neither AstraZeneca, Moderna, nor Pfizer were required to submit data on the biodistribution of the final product, nor were they required to investigate the biodistribution of spike protein or its degradation. To our knowledge, these data were used for MHRA approval within the UK (see assessment and authorisation documents for AstraZeneca and Pfizer, CC/018 - INQ000377512).

67. There was an assumption that mRNA was rapidly broken down (within days) with no or limited biodistribution, but more recent research has challenged this assumption, both in terms of biodistribution, and mRNA remaining detectable for possibly up to 60 days (Castruita *et al.*, 2023; Fertig *et al.*, 2022; Hanna *et al.*, 2023; Krauson *et al.*, 2023; Röltgen *et al.*, 2022 Exhibits CC/019 - INQ000377513, CC/020 - INQ000377515, CC/021 - INQ000377526, CC/022 - INQ000377537, and CC/023 - INQ000377548).

68. In December 2021, government guidance stated "*It is unknown whether the*

COVID-19 mRNA Vaccine BNT162b2 is excreted in human milk."; recent research has demonstrated this may be occurring [CC/026 - INQ000377526, Hanna *et al.*, 2023]. The implications of this are still unclear, and we urge further research to understand this.

69. In addition, growing evidence is suggesting spike protein (or its fragments) produced from vaccination may not degrade within days as initially assumed and instead may remain detectable for 5 days or as long as ~6 months [Bansal *et al.*, 2021; Brogna *et al.*, 2023; Cognetti & Miller, 2021; Ogata *et al.*, 2022; Röltgen *et al.*, 2022, Exhibits CC/023 - INQ000377548, CC/025 - INQ000377559, CC/025 - INQ000377570, CC/026 - INQ000377581, and CC/027 - INQ000377592].

70. The implications of persistent mRNA and/or spike protein (fragments) is unclear. UKCVFamily ask the Inquiry to explore why biodistribution and pharmacokinetics were not explored in such detail until after the rollout, whether this should be a requirement in the future, and urge researchers to understand the implications for this long-term in healthy people, as well as whether it is contributing to illness in those suffering adverse events.

71. In addition, thrombocytopenia as a result of viral vectors has been known about since at least 2007 [Stone *et al.*, 2007, CC/028 - INQ000377603]. We ask the Inquiry to investigate why this risk was not fully explored *a priori.*

72. The AstraZeneca trial had many anomalies, including changing registered study plans throughout the trial period, which it appears regulators may not have fully probed. For example, some participants (UK sites) received a meningococcal vaccine in the placebo arm. This potentially reduces the chances of detecting adverse events if both vaccines given cause similar problems. Furthermore, participants in other sites (e.g. Brazil) were given a saline placebo. These cohorts had different and unstandardised dosing regimes, as well as different placebos, and not all the data from the Brazilian cohort were reported. There was also a dosing error in some participants, giving half a dose as the first shot, and the trials contained relatively few participants aged > 55 years. Considering such large differences between trial sites, it is unclear how this passed as a single Phase 3 trial. Indeed, trial concerns were taken on board by the *Food and Drug Administration* in the US, resulting in no emergency use authorisation.

73. In addition, several serious adverse events occurred in the AstraZeneca trials, some of which caused the trial to be paused. Potential adverse reactions included transverse myelitis and multiple sclerosis [CC/029 - INQ000377629 and CC/030 - INQ000377641, Bastian, 2020; Phillips et al., 2020). AstraZeneca also included paracetamol to reduce its high rates of adverse events, with some improvement in acute side effects [CC/031 - INQ000377665 Ooi *et al.*, 2022]. However, the rollout did not advise the public to take paracetamol as part of taking the vaccine.

74. There was concern regarding the lack of transparency regarding adverse events occurring during the AstraZeneca trial [CC/032 - INQ000377678 Mallapaty & Ledford, 2020]. We believe future trials should offer full transparency, including the reaction, the investigations being undertaken, and how a causal link to the vaccine has been ruled *out* (rather than ruled in).

75. Considering the above, we ask the Inquiry to investigate the regulatory approval and level of scrutiny the AstraZeneca trial received through the approvals process.

76. In addition, it is noted that in the Pfizer Phase 3 trial published in the *New England Journal of Medicine*, it is stated "*Few participants in either group had severe adverse events, serious adverse events, or adverse events leading to withdrawal from the trial*" [CC/033 - INQ000377682 Polack et al., 2020]. UKCVFamily ask what level of scrutiny this statement came under, at what level of detail they were reported to the MHRA, and how non-causality to the vaccine was determined.

77. Furthermore, UKCVFamily suggest that the Covid-19 Vaccine Benefit/Risk Expert Working Group and the Covid-19 Vaccine Safety Surveillance Expert Working Group would be in an excellent position to answer some of the above questions. Both Expert Working Group's were established in May 2020 by the

Commission on Human Medicines and have been referred to several times in parliament and in government publications [CC/034 - INQ000377689] as being an advisory group to the MHRA. Minutes of the Expert Working Group's meetings haven't been publicly published and UKCVFamily feel that these minutes should be scrutinised by the Inquiry in order to gain a fully informed picture of the processes and decisions made by the MHRA during and before the roll out of the Covid-19 vaccines.

78. UKCVFamily are concerned that the specific safety recommendations in [CC/035 - INQ000377700] *Nature*'s article, *mRNA vaccines — a new era in vaccinology*, published 12th January 2018, were not considered during the development of the Covid vaccine. We draw specific attention to this paragraph: "*... recent human trials have demonstrated moderate and in rare cases severe injection site or systemic reactions for different mRNA platforms. Potential safety concerns that are likely to be evaluated in future preclinical and clinical studies include local and systemic inflammation, the biodistribution and persistence of expressed immunogen, stimulation of auto-reactive antibodies and potential toxic effects of any non-native nucleotides and delivery system components. A possible concern could be that some mRNA-based vaccine platforms induce potent type I interferon responses, which have been associated not only with inflammation but also potentially with autoimmunity. Thus, identification of individuals at an increased risk of autoimmune reactions before mRNA vaccination may allow reasonable precautions to be taken. Another potential*

safety issue could derive from the presence of extracellular RNA during mRNA vaccination. Extracellular naked RNA has been shown to increase the permeability of tightly packed endothelial cells and may thus contribute to oedema. Another study showed that extracellular RNA promoted blood coagulation and pathological thrombus formation. Safety will therefore need continued evaluation as different mRNA modalities and delivery systems are utilized for the first time in humans and are tested in larger patient populations." We are not aware of any information indicating that the vaccine development process included testing and monitoring in high-risk individuals such as those mentioned above.

79. UKCVFamily are concerned that these trials were not conducted on an appropriate representation of the UK population, and therefore the likelihood of adverse reactions was not accurate for a product that was to be rolled out to the general population. Nor were the possible comorbidities associated with adverse reactions able to be examined. For example, Phase 3 of the AstraZeneca trial included those who were at "*increased risk of SARS-CoV-2 infection; medically stable*," and excluded those with "*confirmed or suspected immunosuppressive or immunodeficient state; significant disease, disorder, or finding; prior or concomitant vaccine therapy for COVID-19.*"

80. On their own website, AstraZeneca states, "*Immunocompromised individuals represent approximately 2% of the overall population*" [CC/036 - INQ000377710]

which equates to 1,340,000 people in the UK (population around 67 million). 53 million people took the first vaccine, so the Covid vaccine was possibly taken by over a million immunocompromised in the general population without them being informed that there was no data available showing that it was safe for them to do so. UKCVFamily would like the Inquiry to investigate whether any specific safety monitoring of this patient group has been undertaken considering the above information.

81. Alongside those with comorbidities, the Covid-19 vaccines were not tested on those who were pregnant yet the government stated in their 2021 guidance [CC/037 - INQ000377733) "*Administration of the COVID-19 mRNA Vaccine BNT162b2 in pregnancy should only be considered when the potential benefits outweigh any potential risks for the mother and foetus*" without any indication or knowledge of what risks and benefits could be.

82. The government and Royal College material encouraged vaccination in pregnant people based on the fact that others had been vaccinated with no (known) problems. This recommendation by the JCVI was extremely early as you can see from Exhibits [CC/038 - INQ000377744 and CC/039 INQ000377755] though risks and monitoring are mentioned the vaccines hadn't been tested on pregnant women in the clinical trials.

83. The Medicines and Healthcare Regulatory Authority state in the updated 'Information for Healthcare Professionals on COVID-19 Vaccine Pfizer/BioNTech (Regulation 174) Updated 5 September 2023' [CC/018 - INQ000377512] that *'There is limited experience with use of the COVID-19 mRNA Vaccine BNT162b2in pregnant women'*, and again in the Governments' 'Summary of Product Characteristics for Vaxzevria [CC/041 - INQ000377778) - Last updated June 2023', in section 4.6 it states *'There is a limited experience with the use of Vaxzevria in pregnant women'* UKCVFamily would like the Inquiry to investigate whether any specific safety monitoring of pregnant and breastfeeding women has been undertaken, when this monitoring started in the timeline of the rollout, and the scope of that monitoring bearing in mind the above information. UKCVFamily would also like the inquiry to investigate the MHRA's quantitative benefit/risk assessment in relation to the licensing of the Covid-19 vaccination of pregnant women in light of this information.

84. Trial participants were accepted if they were "medically stable," legally defined as "in good physical health, with no acute or chronic health problems for which medical treatment beyond routine medical care is required or anticipated." By contrast, "medically unstable" is defined as "a state of worsening or fluctuating clinical symptoms, signs and lab examination data, and important vital signs like blood pressure, breath, pulse, temperature and pain are abnormal." The vaccine development process did not include any medically unstable individuals whereas the mass rollout did not include methods by which to determine whether an

individual was medically stable or not.

85. The trials did not include long covid patients, and this group appears to suffer worsening symptomology, post vaccination~18 % of the time [Strain *et al.*, 2021 CC/042 - INQ000238591]. This study was a patient led study, and we ask why such integral research was left to patients to conduct after the rollout.

86. Within the UKCVFamily, women seem more commonly affected. Considering known differences between male and female immune responses (including being well documented for pre-Covid-19 vaccines) which predisposes to sex differences in immune-mediated diseases, we ask why this was not taken into account during vaccine development, for example, by giving women a lower dose as have previously been suggested [Klein & Flanagan, 2016, CC/043 - INQ000377800)

87. Oxford University's Oxford Vaccine Group describes Phase 4 testing: "*Even after licensing, vaccines continue to be monitored. The manufacturer of the vaccine may continue to test for safety, effectiveness, and other potential uses of the vaccine. This is sometimes called a phase 4 study, or post-license monitoring.*". To our knowledge, only one Phase 4 study has been published in the UK, with n = 756 participants [Lazarus *et al.*, 2021, CC/044 - INQ000377811]. Its focus is on the safety of simultaneous administration of a COVID-19 and influenza vaccine. Since the original vaccine trials had > 10,000

participants and failed to detect a safety signal with regards to the adverse reactions our members have had, including the now well-recognised VITT and myocarditis, it is unclear how such a small sample is adequately capturing safety beyond extremely common events. The study was conducted between April and June 2021. According to Ralise *et al.* [CC45 - INQ000377823] (2023), another 14 (non-UK) Phase 4 trials have been published in total; sample sizes range from ~150 to ~3,400, some including participants with particular conditions (e.g. autoimmunity). The *BMJ* have previously published concerns with regards to small sample sizes in Phase 4 trials, and the problems this has with regard to detecting adverse events [Zhang *et al.*, 2016, CC/046 - INQ000377834]. We therefore urge the Inquiry to request evidence of thorough Phase 4 testing.

88. We also ask whether future trials should take and store pre- and (longitudinal) post-vaccine serum samples. This might help understand whether adverse reactions in trials are causally related to vaccine (e.g. evidence of a cytokine storm) and allows tracking of physiological changes over time. If adverse events do then become apparent during the post-marketing phase, there will be a stock of samples to investigate using tests that researchers may not have previously thought about (e.g. fibrinoid micro clots).

89. UKCVFamily ask whether the MHRA and JCVI properly scrutinised data, particularly with regards to those who did not complete the trial.

90. UKCVFamily ask whether the methods used to determine an adverse reaction as having a causal relationship to vaccine during vaccine development could be improved, particularly when there is inadequate data to demonstrate a clear higher proportion of adverse reactions in the non-placebo trial arm.

91. In addition to Phase 4 testing, many of our members interpret the word "monitoring" to mean that our reactions would be closely monitored and investigated, which has not been the case (as evidenced elsewhere in our submission). Doctors are not obligated to write up our cases in the medical literature which would help inform post-marketing surveillance and the design (e.g. target sample) of Phase 4 trials. According to the *National Academy of Medicine*, case studies with proper exploration of pathophysiology provide equally strong evidence as population signals from epidemiological research regarding causal links of adverse reactions to vaccines [Stratton *et al.*, 2011, CC/047 - INQ000377845]. We ask the Inquiry to explore how Phase 4 trials and post-marketing surveillance could be improved, particularly with regard to investigating currently unrecognised adverse reactions (including those without population signals).

92. We note that some members of the public have now had > 5 doses of a COVID vaccine, including different dosing schedules, brands, medical histories, and history of (potentially multiple) infections. To our knowledge, the recommendation for this many vaccines under such diverse circumstances is

not based on large scale human trials investigating safety, but predominantly based on *in vitro* antibody neutralisation studies or small human trials investigating immune responses to vaccination. We ask whether this is standard in other medical interventions, and if not, whether this is an appropriate and informed approach to vaccination scheduling.

93. We note that the Government has published the number needed to be vaccinated (NNV) in 2022 and 2023 [CC/048 - INQ000377856], with regard to boosters. We ask whether this calculation was done prior to the rollout, and what NNV was determined to provide acceptable protection, outweighing any risks. UKCVFamily members have often found that "underlying conditions" have been suggested as the reason for their ill-health, almost in a way that suggests that it is the patient at fault, rather than with a desire for further exploration as to why possible underlying conditions may not be compatible with the Covid-19 vaccines. It stands to reason that if certain underlying conditions may make some individuals more prone to ill-health after vaccination, then research needs to be conducted into what exactly those underlying conditions are, for the purpose of protecting others who may have that same underlying condition. But that research is not happening, UKCVFamily ask the Inquiry to question why.

94. Although limited, some preliminary data from Denmark suggest that certain batches of vaccines were associated with a higher rate of adverse reactions [Schmeling *et al.*, 2023, CC/049 - INQ000377870]. In addition, data from

Germany suggested possible impurities in AstraZeneca lots, which appeared to contain impurities in excess of *EMA* specifications [Krutzke *et al.*, 2022, CC/050 - INQ000377886].

95. The WHO (2023) state [CC/051a - INQ000377892] "*As with any vaccine, it is essential to closely monitor the safety and effectiveness of COVID-19 vaccines. If a serious health problem is reported following vaccination, a thorough investigation should take place by the relevant health authorities in the country. [...] Sometimes they [serious adverse reactions] are related to how the vaccine has been stored, transported, or administered*". To our knowledge, none of the members in our support group have been investigated in this way. As such, we urge the Inquiry to support full investigation for all our members.

96. In the UK, the government (2020) [CC/051b - INQ000377891] and *National Institute for Biological Standards and Control* [Rose *et al.*, 2021, CC/052 - INQ000377893] assured us that independent quality control testing occurred for each batch. In light of the preliminary Danish data, we would like reassurances that such testing occurred for every batch administered in the UK, and that no batches were of inferior quality. We also ask whether the UK should run a batch analysis to determine whether certain batches were associated with higher rates of adverse events, and (if applicable) explore any vaccine production, procurement, transport, or other issues that may be responsible for this.

97. Even in 2021, it was recognised that Novavax appeared to carry lower risk of side effects with equivalent efficacy [Tinari & Riva, 2021, CC/053 - INQ000377894]. We ask the Inquiry to explore why there was such a delay in approval for Novavax, and why the availability and ability to choose vaccine type has been so limited.

98. Do we know if there is any validity to the Pfizer switch, which if so, rolled out a vaccine that hadn't been tested.

99. In 2021, Kate Bingham, part of the UK's Vaccine Taskforce stated "*However, we do not know that we will ever have a vaccine at all. It is important to guard against complacency and over-optimism. The first generation of vaccines is likely to be imperfect, and we should be prepared that they might not prevent infection but rather reduce symptoms, and, even then, might not work for everyone or for long*". Bingham, K. (2021) [CC/054 - INQ000377895]. The UK Government's Vaccine Taskforce: strategy for protecting the UK and the world. It seems clear therefore the UK Government were aware of the likely limited ability of vaccines to control the pandemic. We ask what the role of the Vaccine Taskforce was if the Government were not obligated to heed their warnings, resulting in a "vax and relax" pandemic strategy. Kate Bingham may be able to provide further information [CC/055a - INQ000377896, CC/055b - INQ000508051, CC/055c - INQ000377898, CC/055d - INQ000377899, CC/055e - INQ000377900, CC/055f - INQ000377897, CC/055g - INQ000377902, CC/055h - INQ000377915,

CC/055i - INQ000377904, CC055j - INQ000508052, CC/055k, INQ000377906, CC/055l - INQ000377907, CC/55m - INQ000377908, CC/055n - INQ000377909, CC/055o - INQ000377910, CC/055p - INQ000377911, CC/055q - INQ000377913, CC/055r - INQ000377912, CC/055s - INQ000273405, CC/055t - INQ000508053, CC/055u - INQ000377916, and CC/055V - INQ000377917].

UKCVFAMILY CONCERNS: VACCINE SAFETY

100. The Oxford English Dictionary definition of "safety" reads as follows: "*The state of being protected from or guarded against hurt or injury; freedom from danger*" (noun) and "*To protect against failure, hazard, or damage*" (verb). In simple terms, the general public would consider something defined as "safe" would not cause any harm. In this section we will address firstly whether the Covid vaccine was produced and administered in a way that ensured it did not create any hurt, injury, damage, or danger to the recipients; and secondly whether steps were put in place to ensure that the Covid vaccine was not a failure.

101. The BBC published an article on 9 December 2020 [CC/056a - INQ000377918], "*What you need to know about vaccine safety*," and first and foremost explained the relevance of balancing the risk of harm from Covid with the risk of harm from vaccines, stating that "*One in 1,000 of the entire UK population has already died after being infected with coronavirus during the pandemic*." Public Health

England COVID-19 Epidemiology Cell published the "*COVID-19 confirmed deaths in England (to 31 December 2020): report*" [updated 28 April 2023, CC/056b - INQ000377919] confirming these statistics.

102. The Public Health England report defined deaths as:

a. *a death in a person with a laboratory-confirmed positive COVID-19 test and either died within 60 days of the first specimen date, or*

b. *died more than 60 days after the first specimen date, only if COVID-19 is mentioned on the death certificate*

And goes on to state "*This data does not report cause of death, and as such represents deaths in people with COVID-19 and not necessarily caused by COVID-19.*"

103. The "*One in 1,000*" quoted in the BBC article to reassure the public about the importance of balancing the risk of harm from vaccines with the risk of dying from Covid, is actually referring to people who died within 60 days of a positive Covid test, regardless of whether Covid caused the death or not.

104. he BBC article then goes on to say "*There are some drugs that have truly brutal consequences on the body, but are still approved because they are considered*

worth the risk." and gives chemotherapy drugs and ibuprofen as examples. However, the author failed to clarify that chemotherapy drugs have been used on humans since 1942, have been studied extensively, were originally derived from chemical weapons used during World War I, and were banned in 1925. Ibuprofen was discovered in 1961, and another BBC article interviewing the pharmacist behind it states, "*Now 92, Dr Adams remembers the years of research, the endless testing of compounds and the many disappointments before he and his research team pinpointed ibuprofen as a drug with potential …*" *The hangover that led to the discovery of ibuprofen*, BBC 15 November 2015. It is inappropriate and misleading to compare the Covid vaccines to other pharmaceutical products that have at least sixty years of development and administering to the public, especially in the context of safety.

105. In addition, the comparison to treatments that heal pathology may be inappropriate. Treatments for (e.g.) cancer (chemotherapy) or pain (ibuprofen) are designed to help patients gain something from an already diseased state (e.g. extended life span for chemotherapy; less pain in the case of ibuprofen). In such situations, the tolerance for risk is shifted, i.e. it is acceptable to feel awful for a few days after chemotherapy because that typically means many extra months of life. In the case of Covid-19 vaccines, administration is to those currently unaffected by the disease in question, with the aim to reduce harm upon exposure. When vaccine injuries occur, quality of life has been removed with little discernible gain. It is therefore misleading to compare preventative

measures to treatment measures.

106. The 9 December 2020 BBC article mentioned above, on vaccine safety, then goes on to reassure the public that the Medicines and Healthcare products Regulatory Agency (MHRA) will determine whether a product is safe or not: "*Regulators make the assessment based on far more data than has been made publicly available ... There will be nowhere to hide — if there are safety concerns then the regulators will see them.*"

107. Recent WhatsApp messages by Matt Hancock MP [CC/057 - INQ000377920] infer that he thought there were issues with the current pharmacovigilance system saying that he was worried that 'details will be shonky' in relation to post vaccine adverse reactions. We would like the Inquiry to investigate these conversations further

108. I have contacted Dame June Raine, the Chief Executive of the MHRA, several times and requested a meeting with her to discuss the concerns of UKCVFamily members, to make her aware of the adverse reactions that our community has experienced [CC/058 - INQ000377921]. I have not received one reply from Dame Raine herself but several from the MHRA's customer service team, addressing none of our concerns nor taking up UKCVFamilies offer of a meeting to discuss our concerns [CC/059 - INQ000377922, CC/060a INQ000377925, CC/060b - INQ000377924 and CC/060c - INQ000377926]. Dame June Raine would be

excellently placed as an expert witness so that the Inquiry can learn more about:

a. Any possible safety issues that may have been declared during the approval process but were ultimately determined to be outweighed by the benefits of the vaccine, and
b. The approval process of a novel pharmaceutical product that has had its development accelerated during a health crisis.
c. Why the MHRA was slower than other national regulators to react to problems with the AstraZeneca vaccine such as VITT and why the MHRA subsequently gave the AstraZeneca vaccine renewed conditional marketing approval in June '22 despite it no longer being in use in the UK.
d. How the MHRA define (at the point of licensing) an absolute tolerable rate of fatal/serious adverse events and/or tolerable benefit/risk ratio?
e. Why patient led advocacy groups, such as UKCVFamily, are not responded to nor acknowledged by Dame June Raine herself when such groups are expressing genuine concern for patient safety. UKCVFamily did not feel the correspondence they sent was considered nor responded to appropriately.

109. One of our members, Covid-19 scientist, Dr Harriet Carroll, contacted Public Health Scotland on behalf of the vaccine-injured. Public Health Scotland replied with generic information regarding vaccine safety. A request to speak to Dr Claire Cameron (who helped lead the vaccination campaign in Scotland). An FOI request [FOI2022-001429, CC/061 - INQ000377927] revealed that Dr

Cameron did not engage with the request to discuss, but instead suggested a generic reply about the MHRA and the Yellow Card scheme. Dr Cameron may be a good witness to understand the decision-making powers (or lack of) that public health bodies have. If they do lack decision-making powers, it raises questions the Inquiry may want to investigate regarding the purpose of public health bodies.

110. In addition, Dr Carroll was working in the NHS on the UKHSA SIREN (SARS-CoV-2 Immunity and Reinfection Evaluation) Study [CC/062 - INQ000377928) and asked the study to include vaccine adverse reactions in their sub-study about Long Covid. They said it wasn't in their remit. She asked if she could take her own stored samples from participating in SIREN (the samples were going to get thrown away) so she could independently arrange for analysis. She did not receive a response. Key researchers from UKHSA involved in the SIREN study are Professor Susan Hopkins, Dr Victoria Hall who may be good witnesses to help understand why such a landmark study failed to investigate vaccine safety, or understand the injuries of those participating.

111. During her time working in the NHS, Dr Carroll was asked to speak at a NHS Scotland conference about Long Covid research. She discussed her own case as an example of how to find and treat pathology to show how the current research can be applied within NHS guidelines. Dr Carroll mentioned that her case was a case of vaccine-induced Long Covid but the pathology was largely

the same. The hospital emailed her saying this did not "toe the party line", resulting in the hospital withdrawing themselves from the conference. This meant vital information about both long COVID and long COVID-like vaccine injuries was withheld from healthcare workers due to an unwritten "party line". The case is currently being investigated by the Independent National Whistleblowing Officer (INWO) due to an unsatisfactory whistleblowing investigation. INWO asked Dr Carroll in the initial meeting why she did not raise vaccine concerns via the "appropriate means". It is unclear what these appropriate means are, if attempts to speak to Public Health Scotland, get inclusion in one of the largest UK tracking studies, and present at a NHS Scotland conference are all blocked. Beyond publishing papers, and discussing these reactions with the (WHO-affiliated) Global Vaccine Data Network, what are the appropriate means? We ask the Inquiry whether some "proper means" for legitimate scientists involved in the topic should be introduced, and Dr Carroll would be happy to work with the MHRA or similar to help initiate these.

112. It is noted that the hospital in question has confirmed that they will accept vaccine-induced long COVID patients into their long COVID services; they clearly acknowledge the problem but do not want to say publicly.

113. The 9 December 2020 BBC article on vaccine safety [CC/056a - INQ000377918], then goes on to discuss "*rarer problems*" stating that the Covid vaccine trials have been enough "*... to detect common problems. But they may*

not pick up something that affects one-in-50,000 people who are immunised." with Dr Penny Ward, from King's College London and the Faculty of Pharmaceutical Medicine confirming, "*You can't always spot them before you license without a trial of millions of people if the side-effect is vanishingly rare.*" With a UK population of around 67 million, a "*one-in-50,000*" rare problem could have impacted up to 1,340 people after the first dose alone.

114. The article later quotes Dr Ward again, who says, "Not many of us think twice about driving somewhere, but the risk of a car accident is a lot higher than serious effects of a vaccine." Comparing an adverse reaction to a vaccine to a car accident is not appropriate for many reasons:

a. The UK emergency services know what to do in the case of a car accident — there are protocols in place whereas there are no protocols in place for identifying and dealing with an adverse reaction to a vaccine, other than initial anaphylaxis;
b. The NHS has detailed symptoms and advice regarding possible outcomes of a car accident, eg. articles on their website such as "*After an incident*," "*Head injury and concussion*," and "*Whiplash*." The only information offered relating to adverse reactions to Covid vaccines is "*rest and simple treatments*" in the case of myocarditis (heart inflammation).
c. The government website has detailed guidance on what to do if you're in a car accident, whereas it doesn't appear to have guidance on what to do

if you have an adverse reaction to a Covid vaccine.

d. Vehicle insurance is mandatory in the UK, so in the event of an accident there is financial support available, whereas vaccine insurance doesn't exist.

e. If a car accident is due to faulty manufacturing, then the car manufacturer is liable for any injury caused, whereas a vaccine manufacturer is indemnified against any injuries experienced.

f. Cars are designed with safety in mind, and have been regulated to avoid common injuries (e.g. the inclusion of seat belts, tyre tread requirements, and structural/material improvements based on crash testing). Many injuries our group have suffered were discussed for previous (non-COVID vaccines) in the academic literature and dismissed by regulators (e.g. CC/063 - INQ000377929, Brinth, 2015, Responsum to Assessment Report on HPV-vaccines released by EMA November 26th 2015.), offering little incentive to research vaccine-induced pathophysiology and improve vaccine safety. Even as injuries have become better recognised (e.g. myocarditis), there has been no attempt to modify the vaccines to mitigate risk.

115. The BBC article then goes on to say, "*The danger is people falsely assume health problems that happen by coincidence are caused by the vaccine*" which contributes to a culture whereby even those dealing with adverse reactions that have been medically diagnosed as vaccine-related are dismissed by the general

public and in some cases their own family and friends.

116. The media's response to illnesses related to COVID-19 and those associated with the vaccines displayed marked differences. During the early stages of the pandemic, media coverage was saturated with alarming statistics, harrowing stories of COVID patients, and the race for a vaccine. Fear and uncertainty dominated headlines, with an emphasis on the global crisis and its devastating impact. However, as vaccines became available, media coverage shifted towards hope and the promise of a way out of the pandemic. Reports on vaccine development, efficacy, and distribution were accompanied by positive narratives of healthcare heroes and success stories. For those harmed by the vaccine this creates an environment in which speaking about your adverse reaction is incredibly difficult across the board from social media communications, speaking to medical professionals and even family and friends.

117. The BBC article concludes by reassuring the public that " … *safety is monitored long after a vaccine is approved to see if there are any unknown health problems. The MHRA has a Yellow Card scheme for reporting concerns and monitors anonymised data from GP surgeries for any warning signs.*"

118. 91% of our members surveyed have their adverse reactions recorded on the Yellow Card System. Of these filed reports, 6% were filed by a medical practitioner, and 94% reported it themselves (or a family member or friend

reported it). We have a number of serious concerns regarding the Yellow Card System, which we detail below.

119. 41% of our members surveyed have written confirmation from a medical professional that their health problems are certainly or likely related to the Covid vaccine, whereas only 6% of our members' Yellow Card System reports were made by a healthcare practitioner. We would like to know what might be preventing healthcare practitioners from reporting suspected adverse reactions. Were they reminded of the Yellow Card System as part of the rollout?

120. We are concerned that public awareness of the Yellow Card campaign was limited at the time of the rollout. A letter dated 9 August 2021 [CC/064 - INQ000377930) from Nadhim Zahawi MP — at the time Minister for COVID Vaccine Deployment — to one of our members' MPs, stated that "*We are running a targeted social media campaign in the coming weeks, and would encourage anyone who has not already done so to report suspected side-effects through the Coronavirus Yellow Card reporting site.*" At that time the rollout had been ongoing for eight months, and 53 million people had received at least one vaccine. A "targeted social media campaign" informing the general public to report any potential side effects should have been a key part of the rollout in the first place.

121. On 20 September 2021, one of our members conducted a survey on their social

media page to find out whether their UK-based friends knew what the Yellow Card System was, where they had heard about it, and whether they had seen it advertised through any social media campaign. 47% of those who responded were aware of the Yellow Card System, with 11% having heard about it from a vaccine-injured person, 10% having learned about it through independent research during or before 2021, and 8% being aware because they worked in the healthcare industry. Only 2% were told about it by their doctor. 53% were unaware of the Yellow Card System as of September 2021 (nine months after rollout). Not one person had seen any advertising on their social media feed, or any kind of social media campaign for the Yellow Card Scheme since 9th August 2021. We would like to know more about what exactly happened with the "targeted social media campaign" that Nadhim Zahawi, MP planned. We would also like to know exactly who the campaign was targeting and why a more generalised campaign wasn't organised, given that the rollout was targeted at the entire UK population.

122. We are concerned about the Yellow Card System being relied upon for safety surveillance, not only because of the lack of awareness of its existence but also because of the unreliability of the actual numbers using it as a reporting system. Professor Carl Heneghan, Professor of Evidence based medicine at the University of Oxford also shared this concern at the Pandemic Response and Recovery All Party Parliamentary Group on 17 July 2023 [CC/065 - INQ000377931), saying, "*In theory, the Medicines and Healthcare products*

Regulatory Agency (MHRA) relies on the early warning system provided by Yellow Card reports of suspected adverse drug reactions (ADRs) to signal possible harms from pharmaceuticals. In practice the system is woefully inadequate, much too complicated and is failing. If you consider that ADRs are a major cause of hospital admissions, 6.5%, then Yellow Card reports represent a valuable source of information not only to protect public health but reduce the cost to the health system, which can only be a good thing. But the ability to detect signals and assign causation are hindered by substantial problems, not least under-reporting".

123. UKCVFamily would like the Inquiry to investigate why it wasn't considered that it should be mandatory for medical practitioners to report any suspected adverse reactions to the Covid-19 vaccine that their patients suffered, particularly when the product that caused the adverse reaction is novel. Professor Carl Heneghan may be a useful expert witness to the Inquiry.

124. According to the MHRA, as of 28 June 2023, there are reports of 481,239 people with potential adverse reactions to the Covid vaccines (177,056 for Pfizer/BioNTech monovalent, 4,881 for Pfizer/ BioNTech bivalent, 248,292 for AstraZeneca, 42,970 for Moderna monovalent, 5,412 for Moderna bivalent, 2,550 brand unspecified or not in routine use in the UK, and 78 Novavax). These reports are made by medical professionals as well as individuals themselves. The MHRA website specifies that this data should be considered in the context

of the reactions being suspected only and not necessarily confirmed, however, according to gov.uk, "*It is estimated that only 10% of serious reactions and between 2 and 4% of non-serious reactions are reported.*" [CC/066 - INQ000377932).

125. The MHRA employed targeted active monitoring on some people getting vaccinated in 2021: "*The objective of this is not necessarily to detect very rare risks, as the intention is to recruit the same numbers that are generally included in a clinical trial (i.e. several thousand), but to compare the frequency and severity of side effects to groups that were included in trials to allow further characterisation of the safety profile.*"[CC/067 - INQ000377933]. This included a subgroup of pregnant vaccinees. However, information about this initiative is unclear and we are unable to find outputs related to adverse events in this cohort. UKCVFamily request the Inquiry to investigate:

a. Whether these data have been collected

b. Where the data and related analyses can be found

c. Lessons learnt regarding open data (e.g. immediate publication of data on an open repository, pre-planned analyses published, and a clear and easy to find report

126. One study of pregnancy using other methods outlined by the MHRA (cited in previous point), was published in 2023, with the following conclusion: "*Obstetric outcome data will be obtained by December 2021. However, women should not delay vaccination whilst awaiting further safety data to emerge.*" (Richardson *et al.*, 2023, CC/068 - INQ000377934)

127. UKCVFamily therefore ask where the 2021 data are, and why it has still not been published?

128. UKCVFamily also query the recommendation to vaccinate without being fully informed regarding risks. Such a recommendation in a scientific publication seems to breach medical ethics.

129. There is legitimate debate regarding the veracity of Yellow Card reports, and identifying which symptoms were more likely to be causally related to the vaccine *versus* which are coincidental. To our knowledge, the primary method of causal inference that is used is based on population signals; in other words, are events happening more likely after vaccination than would be expected.

130. However, population signals are only one form of causal inference. The National Academy of Medicine (formerly the Institute of Medicine) in the US acknowledges the limitations of population signals and highlights that case studies with biological plausibility offer equal weighting in causality assessments

(Stratton *et al.*, 2011, CC/069 - INQ000377701).

131. The key difference between the two methods of causal inference is that population signals tell us whether an event is more likely to occur after vaccination across a population, whereas case studies tell us that an event *can* occur due to vaccination, even in a minority of people. It is this latter category that many of our members find ourselves in. This impacts not only our Vaccine Damage Payment Scheme claims, but also precludes informed consent for people getting vaccinated without the full scope of side effects, and limits the likelihood that clinicians know what to look for in post-vaccine syndrome patients. We highlighted this nuance in a letter to the Editor of the *BMJ* (Deans *et al.*, 2022, CC/070 - INQ000377937), after an article by the *BMJ* claimed there was little risk in terms of neurological side effects based only on population data.

132. To give an example, myocarditis can be caused by bacterial, fungal, and viral infections, certain drugs, certain autoimmune diseases, and vaccination. Based on population signals alone, if the background rate of myocarditis is 75 people per 100,000, and 100/100,000 people get myocarditis after vaccination, we do not know which of those 100 cases was caused by vaccination; indeed the rise could be coincidental. By understanding pathophysiology, we can now more confidently claim the causal relation between vaccination and myocarditis (e.g. from studies showing spike protein in cardiac tissue from case studies/small studies; Baumeier *et al.*, 2022, CC71 - INQ000377938).

133. This level of biological understanding helps explain how many of our members have ended up with problems like mast cell activation syndrome, postural orthostatic tachycardia syndrome, blood clots, Guillain Barre syndrome, autoimmunity, myalgic encephalomyelitis, connective tissue disorder worsening, etc, even if these conditions do not always show up with population-based assessments (i.e. they do not increase risk at a population level, but do pose a risk to some individuals).

134. In addition, prior probability is seemingly not taken into account when assessing causality. For example, some people may indeed have a stroke with no obvious cause, but we understand that an immune reaction can cause clotting (i.e. immunothrombosis). Therefore, if they had an immune stimulus, such as a vaccine, prior to the event, it increases the odds that the vaccine is causally related to the event. UKCVFamily would like clarification on whether (and what) priors are taken into account when assessing vaccine risks.

135. We therefore propose that vaccine safety monitoring could be improved by having specialist post-vaccine clinics which aim to understand pathophysiology underpinning patients presenting with currently unrecognised side effects. Once pathophysiology is identified, researchers would be well-prepared to work towards understanding whether a vaccine can cause such pathology. UKCVFamily would ask the Inquiry to investigate why post vaccine research

clinics weren't proposed in the planning of the Covid-19 vaccine roll out and why none have been set up since. The JCVI or the Covid 19 vaccine expert working groups may be best placed to answer this question.

136. We propose that this method has significant benefits. Since the majority of people in the UK have been vaccinated, and have had COVID-19 (which can cause similar sequelae to those suffering vaccine reactions, with a higher incidence rate), identifying accurate population signals might become more difficult. Identifying pathophysiology also allows vaccine manufacturers to work on improving vaccine safety, as well as identify higher risk patients. In addition, as extensively discussed in this document, many of our members struggle to get even basic tests, let alone accurate diagnoses. This means population signals are highly inaccurate and significantly lag behind reality (e.g. if it take 5 years to get small fibre neuropathy diagnosed, it is too late to inform people getting vaccinated now that this is a risk).

137. Such an approach would tamper down discussions regarding whether Yellow Card reports are a true reflection of injuries as monitoring would include a full range of methods for causal assessment.

138. In order for this to be effective, those with post-vaccination sequelae would need immediate medical attention, including tests and accurate biomedical diagnoses. Currently many UKCVFamily members did not receive timely tests

or still have not had accurate diagnoses (discussed further elsewhere in this document). It becomes harder to be confident of a causal link the longer the time between vaccination and evidence of pathology is found. The fluctuant nature of many of our conditions also means disease progression may occur with the passage of time which needs to be understood. This time course is also missed when rapid thorough testing is not conducted. In other words, delays in accurate diagnostics precludes accurate adverse event warnings on vaccine inserts.

139. UKCVFamily would ask the Inquiry to investigate whether MHRA are doing any kind of clustering of symptoms/reports to identify trends. Some of our members have syndromic illness, very much akin to Long Covid. Long Covid includes over 200 symptoms, and a variety of pathologies. Similarly, so do Postural Orthostatic Tachycardia Syndrome and Mast Cell Activation Syndrome, which many of our members have been diagnosed with post adverse reaction. If our members are experiencing something similar, then population signals will unlikely be found if MHRA is looking *only* at individual symptoms. However, if they clustered symptoms according to Long Covid or Postural Orthostatic Tachycardia Syndrome definitions, a signal might show, which could be explored.

140. Within clustering, we aso urge the Inquiry to examine whether MHRA should also have asked for test results from those with chronic and/or severe adverse reactions. If not then we suggest from a learning perspective that this might offer clues into underlying pathophysiology, whilst encouraging clinicians to

investigate vaccine injuries more thoroughly in the future.

141. In addition, as we have mentioned elsewhere in this document, it may be useful to ask patients who attend a medical appointment with a new ailment whether they have recently been vaccinated, similar to how smoking, medication use, and drug use is often asked about.

142. A more proactive monitoring system would benefit the UK by offering some of the most comprehensive safety monitoring, putting us as leaders in terms of patient safety. This would likely improve public trust in healthcare and government bodies.

143. UKCVFamily ask whether rates of acceptable adverse events should be defined *a priori*. Currently it seems that we find a risk, quantify it, then continue telling the public the vaccines are safe. It would be useful instead to have definitions of what constitutes a severe or moderate adverse reaction, ensure any data collected accurately captures the true severity (e.g. we have cases of myocarditis which have led to patients losing their job, despite the narrative that vaccine-induced myocarditis is "mild"), and predefine at what incidence rate per million doses requires a vaccine campaign to be halted. AstraZeneca vaccines were somewhat swiftly halted for due to VITT, but life-ruining conditions such as myalgic encephalomyelitis (which have a worse quality of life than even cancer or lung diseases; Hvidber *et al.*, 2015, [CC/072 - INQ000377939] are not even

recognised as adverse events. We ask the Inquiry to investigate how much harm the Government defines as justifiable, particularly when there are other ways to mitigate COVID-19 risks (discussed elsewhere in this document)?

144. UKCVFamily believe that if the above does not fit within MHRA's remit, we ask whether a new pharmacovigilance body/similar should be set up to thoroughly investigate potential pharmaceutical/vaccine harms?

145. Another concern is how difficult the Yellow Card System is for people to use, especially for those who are dealing with cognitive difficulties. This may deter patients from reporting adverse reactions they have experienced as the process itself may have a further negative impact on patient health. Around half of our members surveyed stated that they found it difficult completing the Yellow Card Report with 24% being unable to complete it. Some reasons for this difficulty include being too physically unwell, not being able to find a symptom they were looking for, having no understanding of complex medical terms listed and where their symptoms fit, feeling that the system was unintuitive and difficult to navigate and having no option to label severity of the symptoms.

146. UKCVFamily would like the inquiry to investigate if reasonable adjustments were considered ie disability, illness and cognitive difficulties, within the practical context of the yellow card reporting system when planning for the pandemic and during the roll out of the Covid-19 vaccines.

147. 'As of 20 October 2021, for the Pfizer/BioNTech, COVID-19 Vaccine AstraZeneca and COVID-19 Vaccine Moderna, the overall reporting rate of suspected adverse reactions is around 3 to 6 Yellow Cards per 1,000 doses administered. This was per the MHRA board meeting of 16 November 2021. 'There has been a significant increase in Yellow Card reporting since December 2020 which saw the authorisation for use of COVID-19 vaccines. Numbers of reports have started to fall but are still significantly higher than numbers received before the pandemic and roll out of the COVID-19 vaccines, where around 3,000 to 4000 reports were received per month.'

148. Many members were initially diagnosed with "adverse reaction to a Covid-19 vaccine" then later went on to be diagnosed more specifically. When making a first report for example, undiagnosed myocarditis may be reported as chest pain, palpitations and dizziness but not until later as 'Myocarditis'. Similarly, dizziness, palpitations and tremor may then go on to be diagnosed at a later date as Postural Orthostatic Tachycardia Syndrome. Yellow Card reporters should be contacted regularly after the first report to update diagnoses and to ascertain if the reporter is still unwell or recovered.

149. 90% of our members have not received any follow up, other than an acknowledgement of their submission or to email updates, to their Yellow Card

System reports. One of our members who did get a follow up response was asked if they could access our members medical records but when asked about the data protection of this never received a reply from the MHRA. Another was sent a copy of information held annotated by Astrazeneca which the MHRA later admitted was not meant to be sent to our member. UKCVFamily are concerned that, in light of their members' experiences outlined above, the Yellow Card System should be investigated with regards to how well it has operated, and interacted with those, reporting serious adverse events during the roll out of the Covid-19 vaccines.

150. The MHRA board meeting agenda of 16th May 2023 [CC/073 - INQ000377940], references a quote from a BBC article by the MHRA stating that the fact that more people were reporting to the scheme was expected, "given the scale of the Covid-19 vaccination programme, and publicity in the context of the pandemic," rather than indicating a real rise in side effects. Given that so few of our members have received any follow up or requests for further details from their Yellow Card reports we are concerned as to the MHRA's ability to verify this statement.

151. The acknowledgment emails received by our members to the filing of their Yellow Card System report stated that *'a team of safety experts which includes doctors, pharmacists and scientists will continually evaluate reports and consider other information, such as medical literature and data from international medicines regulators to help ensure that the benefits of the vaccine continue to*

outweigh any risks.' No patient involvement is included in this process and patients are not provided with any further information as to who has access to this data and how it is being used to inform the general public, medical professionals and vaccine recipients with regards to safety surveillance. The failure in communication post filing of a Yellow Card System report does little for public trust in the safety monitoring process. By the time many of our community had been injured by their Covid vaccine many thousands of reports had already been lodged with the Yellow Card Scheme. None of this information was provided to prospective recipients of the vaccine; indeed, many of our reactions are still not recognised.

152. We also note that many UKCVFamily members have found that their Yellow Card Reports have been deleted and they have had to get these reinstated by emailing or have even had to resubmit a new Yellow Card report. In an email to one of our members, an unnamed person from the Yellow Card team replied by saying "*I can confirm that the Yellow Card account associated with the email address [redacted]has now been reactivated. Yellow Card accounts were previously automatically deactivated if the account has been inactive for 6 months. However, this requirement has now been removed for Yellow Card accounts so this will not occur again."* (CC/074 - INQ000377941) UKCVFamily would like the Inquiry to investigate why Yellow Card accounts were deactivated after six months when the patient reporting had not recovered nor had a follow up email from them.

153. In addition, UKCVFamily members have had to email the Yellow Card to follow up reports themselves. Most of our members have suffered an acute phase of illness followed by chronic illness and/or worsening of symptoms periodically. Without our members emailing Yellow Card every six months, would these patients be presumed to be recovered and well? It may be useful to the Inquiry to ask the MHRA why longer term, chronic adverse reactions aren't followed up and why it is left to the patient to do so.

154. To our knowledge only two members of UKCVFamily have been written up as a case study in the scientific literature, and for one of those patients, they wrote the case up themselves. In a survey of about 100 members in our support group, 94 % stated they would be keen for their case to be written up. We therefore question the thoroughness of the Yellow Card system/MHRA/JCVI in relying on published literature as a key source of information. To improve the methods, Yellow Card could ask vaccinees if they are happy for Yellow Card to access their medical record at the time of the report. Interviewing clinicians may also be helpful, but as evidenced in this document, many clinicians dismiss the idea of vaccine injury; however, a more active and engaged Yellow Card/similar system might proffer an environment conducive to being open about such injuries. Following this, Yellow Card can examine the clinical presentations and (if they have been done) test results themselves, and potentially make more informed decisions about the type of reactions that may occur post-vaccine.

155. In addition, we believe Yellow Card should directly engage with scientists who are involved in understanding the pathophysiology of vaccine reactions. The inclusion of patient partners/support groups within the Yellow Card system would help to identify the most appropriate experts. We can take lessons from Germany who have actively engaged with clinicians who set up a post-vaccine syndrome clinic to help drive a research agenda (e.g. CC/075 - INQ000377942, Pieper, 2023, Post-vac syndrome — the forgotten COVID victims).

156. The report of the Independent Medicines and Medical Devices Safety Review (IMMDs) chaired by Baroness Cumberledge in 2020, 'First Do No Harm' [CC/076 - INQ000361115] revealed many of the same issues that the Covid vaccine-injured face. *"The review found that the healthcare system, which in this definition means the NHS, private providers, the regulators and professional bodies, pharmaceutical and device manufacturers and policymakers, 'is disjointed, siloed, unresponsive and defensive. It does not recognise that patients are its raison d'etre'* and that *'the system is not good enough at spotting trends in practice and outcomes that give rise to safety concerns".*

157. The report goes on to speak of the safety monitoring concerns that were discovered *"For both medicines and medical devices there is a need for more robust publicly accessible post-marketing surveillance. This should include mandatory requirements on healthcare organisations to report adverse events*

within a designated time period". Concerns were found with the Yellow Card reporting system which echo UKCVFamily members experiences, "*The spontaneous reporting platform for medicines and devices, the Yellow Card system, needs reform. It needs to provide a user-friendly, accessible, transparent repository of adverse event reports".* UKCVFamily feel that the inquiry would benefit from hearing from the lead researcher involved with the 'First Do No Harm' report, namely Dr Sonia McCleod who can elaborate on recommendations made in that report and how they may apply to the Covid-19 vaccine-injured and bereaved.

158. One of the recommendations that was actioned following the 'First Do No Harm' report was the post of a Patient Safety Commissioner, currently Dr Henrietta Hughes [CC/077 - INQ000377944]. The role was defined as *"The appointment of a Patient Safety Commissioner who would be an independent public leader with a statutory responsibility. The Commissioner would champion the value of listening to patients and promoting users' perspectives in seeking improvements to patient safety around the use of medicines and medical devices".* UKCVFamily have contacted the Patient Safety Commissioner several times [CC/078a - INQ000377945, CC/079a - INQ000377948, CC/081a - INQ000508109, CC/081a - INQ000508110, CC/082a - INQ000508111 and CC/053a - INQ000508112) and unfortunately, we were told that due to lack of resources (staffed by a small team of 4) efforts are being concentrated on those damaged by Sodium Valporate and Mesh at this time. Dr Hughes did however

meet with Sir Christopher Chope MP, to discuss the Vaccine Damage Payment Scheme, but has not yet spoken directly with UKCVFamily members regarding their adverse reactions and the issues they face. UKCVFamily are concerned that the newly appointed Commissioner doesn't have the resources to address the issues that the Covid vaccine injured and bereaved face specifically. However, we do feel that Dr Henrietta Hughes would be in a good position to inform the Inquiry of the difficulties patients in general face when suffering from a medical trauma, and the issue of wider culture change needed across the healthcare system for the future.

a. The NHS have stopped the use of their internal reporting system [CC/084a - INQ000377961) which integrated point of care application to NHS digital using MESH digital messaging hub for adverse reactions to Covid Vaccines within a vaccination centre/hospital/GP. This has now been retired and the system is entirely reliant on the Yellow Card Scheme. UKCVFamily would like the Inquiry to investigate why, when the Covid vaccines are still relatively new and still under temporary authorisation, this internal reporting system has been retired.

159. In the UKHSA guidance manual 'Training recommendations for Covid-19 vaccinators' [CC/085 - INQ000377962] it states that *'The number of vaccinators required has exceeded the number of trained and experienced vaccinators who were giving vaccines prior to the pandemic'* and that *'It has therefore been necessary to rapidly train healthcare workers who have not vaccinated for some*

time or who have not previously given a vaccine in order to maximise vaccine uptake in a short time period'. This raises concerns regarding the timing to train those administering the vaccines and whether enough information was provided in terms of ongoing adverse reaction warnings. The document does state that in terms of training *'Updating should be seen as a continuous process rather than purely as an annual one-off requirement. However, it is recommended that vaccinators do take the opportunity, annually, to review what training updates are required (including statutory and mandatory training).'* We have concerns given the speed at which adverse reactions were becoming apparent whether an annual review would be sufficient for vaccinators to be aware of the ongoing adverse reaction risks.

160. The MHRA guidance on reporting adverse reactions by medical professionals 'The Yellow Card scheme: guidance for healthcare professionals, patients and the public [CC/086 - INQ000377963] states that 'For established medicines and vaccines you should report all serious suspected ADRs, even if the effect is well recognised'. Just 6% of our members had their Yellow Card Scheme reports filed by their medical professionals. This will include cases where our members have had their adverse reactions confirmed by medical professionals. We would ask why so many doctors and consultants are not filing Yellow Card Reports in line with this guidance?

161. Patient Information Leaflets for Covid vaccines have dramatically changed in the

UK since the rollout began. For example, according to Regulation 174 Information for UK recipients package leaflet: Information for the recipient, published on www.gov.uk, the number of words as of 3rd March 2021 listed on the AstraZeneca leaflet and related to possible side effects was 231. Exactly one year later, on 3rd March 2022, the same leaflet contained 1408 words relating to possible side effects. For example Guillain-Barré syndrome (temporary loss of feeling and movement) is now recognised as an adverse reaction and one which several in our group have experienced and yet this was not included in the original 2021 Patient Information Leaflet. Anyone who has been experiencing any of the symptoms listed in the updated leaflets should at least have vaccination considered as a possible cause, should have thorough testing for the conditions that have now come to light as being related to vaccination, should have immediate treatment for their symptoms, and should have assistance from a medical professional in filing a Yellow Card report. The new information reflected in the updated leaflets needs to be used to support the treatment of those that are still suffering from vaccines administered before the leaflets were updated. UKCVFamily would like the Inquiry to establish why this hasn't been addressed.

162. Guillain-Barré syndrome mentioned above is one of many neurological disorders that have subsequently been identified as adverse reactions to Covid-19 vaccines. A review of neurological side effects of COVID-19 vaccination [CC/064 - INQ000377964] in the European Journal of Medical Research describes some

of the conditions suffered as follows: 'Neurological effects of the COVID-19 vaccine include weakness, numbness, headache, dizziness, imbalance, fatigue, muscle spasms, joint pain, and restless leg syndrome are more common, while tremors, tinnitus, and herpes zoster are less common. On the other hand, severe neurological complications included Bell's palsy, Guillain–Barre syndrome (GBS), stroke, seizures, anaphylaxis, and demyelinating syndromes such as transverse myelitis and acute encephalomyelitis'. All of the above are commonly found symptoms suffered by our members. Reports of neurological side effects were spotted in the trials [CC/088 - INQ000377965] for AstraZeneca to the extent that the trials were put on pause due to reports of severe neurological symptoms. *'A spokesman for the pharmaceutical giant said the woman, who had received a dose of the experimental vaccination, reported symptoms consistent with transverse myelitis'. 'the drug-maker said its "standard review process triggered a pause to vaccination to allow review of safety data.'* It is evident that many of the neurological symptoms that our members are suffering with were known before the rollout to the general public.

163. Recently, a link between statin use and myasthenia gravis has been revealed [CC/089 - INQ000377966]. This was based on just 10 cases over 18 years of monitoring, out of 9.5 million statin-using patients. Many injuries seen in UKCVFamily members far exceed these numbers, yet no safety signals have been raised. The advice given by the Government states "Advise patients taking statins to be alert to new symptoms for myasthenia gravis", yet as new side

effects of COVID-19 vaccinations have become apparent (some of which have a gradual or delayed onset), patients were not alerted. UKCVFamily feels that the Inquiry should investigate why the public have not been alerted to the possibility of more gradual, delayed onset adverse reactions.

164. Many of our members have developed conditions that were not disclosed as being possible side effects on the original Patient Information Leaflet. This has led to a lack of recognition and swift treatment of their conditions. Some of these conditions are life-threatening if left untreated and some of us have been left untreated for over two years. All of these conditions are life-altering. Some of our members have multiple diagnoses. Some of us have spent thousands of pounds on testing — both in the UK and overseas — that has resulted in these diagnoses. Had our symptoms been taken seriously from the beginning, these diagnoses would have been obtained via the NHS, in some cases via those referrals that were rejected. While most of these diagnoses have no cure, there are multiple treatments available through the NHS that can at least alleviate symptoms and improve quality of life for patients. Considering the safety profile of some of those treatments — such as antihistamines, mast cell stabilisers, ivabradine, and HBOT — and the length of time our community has now been suffering, we need to urgently start at least trying some treatments, even if we do not have the test results to warrant them.

165. The United Kingdom has no reliable data upon which to base its understanding of just how many of its citizens have been affected by serious adverse reactions to the Covid vaccine. This leads to speculation on both sides of the vaccine debate, and irresponsible neglect of the vaccine-injured. The speculation urgently needs to be stopped so that attention can be directed to the appropriate care needed by those who have been affected. According to the UK government website updated on 6th April 2023, 53,813,491 people in the UK had had the first dose, and 50,762,968 had had the second. Those numbers were reported up to 11th September 2022. That leaves 3,050,523 (6%) who stopped after the first. Over three million people in the UK didn't come forward for the second part of what was clearly marketed as a two-part vaccine course. We don't know why anyone would refuse the second dose, but it wouldn't be an unreasonable assumption that a significant number of those may have done so because of how unwell the first dose left them. Accurate numbers must be found — a simple way to determine the number of vaccine-injured in the UK would be to immediately survey the three million who did not return for a second vaccine. The persistent emails, letters, and phone calls sent by the NHS, urging that three million to book a second vaccine, show that this country clearly has the technology to do this kind of survey. UKCVFamily would like the Inquiry to investigate why surveys like the aforementioned have not been undertaken, given that it would provide excellent follow up post-vaccination data.

166. Adverse reactions to a Covid-19 vaccine are usually presented as a small

percentage, however with more than [CC/090 - INQ000377968] 13 billion doses administered worldwide, a small percentage is not represented by a small number of people. There is confusion between the percentage of people affected and absolute numbers of people affected, which seems to be manipulated or not quantified to suit political or medical agendas.

167. According to the Jenner Institute "The (Oxford) University sought assurances that the chosen partner would manufacture vaccine in large volumes 'at risk' [CC/091 - INQ000377969] (before it was clear whether the vaccine would work), including in LMICs, and preferably in partnership with Serum Institute of India (which had been working since mid-March to prepare for manufacturing and had uniquely large capacity). AstraZeneca provided these assurances and undertook to supply the vaccine not-for-profit globally".

168. Members of UKCVFamily were given Covid-19 vaccines manufactured in different countries, including three specific batches from India [CC/092 - INQ000377970]. In July 2021, there were reports that people travelling from the UK to EU countries (where proving Covid-19 vaccination status is needed to enter), were being refused entry because of the type of vaccine they'd had. We would like evidence on how the safety of these vaccines were monitored and what quality control procedures would have been in place in these centres outside of the UK.

169. The JCVI recommended that anyone under the age of 30 be offered an alternative to the AstraZeneca vaccine on 7th April 2021 [CC/093 - INQ000377971] This was extended to all those under 40 on 7th May 2021 as a result of the MHRA receiving 242 reports of blood clotting cases in people who also had low levels of platelets in the UK, following the use of Oxford/AstraZeneca vaccine. Denmark and Norway temporarily suspended the use of the AstraZeneca vaccine much earlier, on 11th March 2021 [CC/094 - INQ000377972] According to the BBC article 'AstraZeneca vaccine: Denmark stops rollout completely the vaccine was completely withdrawn on the 14th April 2021 [CC/095 - INQ000377973]. This raises concerns as to why there was simply a recommendation to provide an alternative and why there was a delay in the UK by the MHRA to recognise Vaccine Induced Thrombosis and Thrombocytopenia. Many of our younger members would have been given the Astrazeneca vaccine in the period before the JCVI made the above recommendations. Unfortunately we have UKCVFamily members who lost a loved one due to blood clots caused by Astrazeneca vaccination in this time period. Why weren't members of the public given earlier notification of warning signs and symptoms to look for after the Astrazeneca vaccination? UKCVFamily would like the inquiry to seek an explanation for why the MHRA and the government were still not connecting the Astrazeneca vaccine to the blood clotting events until weeks after other countries in Europe.

170. An article in the Financial Times said "*Because the MHRA is generally held in*

very high regard in UK medical circles — and praised for its speed in reviewing new Covid-19 therapies and vaccines for clinical trials and emergency use in the pandemic — experts have been unwilling publicly to criticise its response to AstraZeneca side-effects. But several scientists have told the FT that the regulator was too slow both to pick up on the reports of the adverse reaction and communicate its findings to the medical profession, the public and the media. Prof Stephan Lewandowsky, a psychologist at the University of Bristol studying the rollout of Covid-19 vaccines, said other European countries had taken a far more cautious attitude to immunisation than the UK throughout the pandemic. This had led to greater vigilance in the search for side-effects and faster communication of risks to the public. "The MHRA was slow in responding to the emergence of a specific constellation of symptoms associated with the AstraZeneca vaccine and slow to communicate what they were finding — and I am not the only one who thinks so," he said." [CC/096 - INQ000377974]. It may be helpful if the Inquiry spoke to Prof Stephan Lewandowsky.

171. Minutes from the JCVI meeting held on the 16th March 2021 [CC/097 - INQ000354491] reveal that members had raised questions already regarding blood clotting adverse events, *"In anticipation of the next JCVI meeting, the Chair asked the MHRA if there were any urgent safety updates about the recently reported thrombotic events following vaccination. MHRA noted that there would be a CHM expert working group meeting later in the day. MHRA was continuing to work with European and international colleagues and to share*

any data. In the UK there had only been a very small number of reports of potential thrombotic events." and "*Members highlighted the importance of being informed of any potential safety signals and would value receiving updates on data from other countries as well".*

172. Haematologists in the UK were already aware of the emerging adverse reaction now known as VITT and had circulated a letter [CC/098 - INQ000377976] on the 22nd March 2021 to all hospitals alerting them of the pathophysiology, testing and warning signs, yet the MHRA continued to downplay the link between the blood clotting disorder and the AstraZeneca vaccine to the public, stating on the 18th March "*A causal relationship with the vaccine has not yet been established*," June Raine, chief executive of the MHRA [CC/099 - INQ000377977].

173. Phil Bryan, head of the UK medicines regulatory agency MHRA, said on 11th March that [CC/100 - INQ000377484] "reports of blood clots so far didn't exceed what would have occurred naturally in the vaccinated population. "Available evidence does not confirm that the vaccine is the cause."

174. A letter dated 1st April 2021 [CC/101 - INQ000377485] sent to all staff involved in the Covid-19 vaccination process, from the NHS, still advised clinicians that the blood clotting reactions had not been found to be causally linked to Covid-19 vaccination. It wasn't until May 2021, that the AstraZeneca vaccine was *advised* to not be used in under '40s.

175. Given that the MHRA were slower than other European regulators to accept a causal link between blood clotting and the AstraZeneca vaccine, we ask the Inquiry to investigate why this was. What processes in the safety regulatory body failed in order for this to happen and why were the British public not informed earlier of the risks, signs and symptoms to be aware of post AstraZeneca vaccination with regard to blood clotting? Learning how and why this happened is critical for future emergencies. Members of UKCVFamily lost loved ones due to VITT in this time period, they have said that had they of known what symptoms to be aware of they would've sought medical attention earlier for their loved ones.

176. Astrazeneca vaccine use was then reduced further and is now barely used as part of the UK rollout, however in June '22 the MHRA renewed the AstraZeneca vaccine temporary authorisation for use in the UK [CC/102 - INQ000377486]. UKCVFamily are concerned that the MHRAs processes for safety monitoring may not be as effective or as proactive as other European regulatory bodies and ask the Inquiry to investigate why the AstraZeneca vaccine has continued to be authorised in the UK.

177. Blood clotting adverse events [CC/103 - INQ000377487] have also been reported after the Moderna, Pfizer and Johnson & Johnson vaccine, though the latter is not in use in the UK. However, a study by the BMJ [CC/104 - INQ000377488] in 2021 observed a 30% increased risk of thrombocytopenia

following first dose ChAdOx1-S compared with first dose BNT162b2.

178. The NHS website defines Phase IV testing of trials stating that 'the safety, side effects and effectiveness of the medicine continue to be studied while it's being used in practice.' [CC/106 - INQ000377489] UKCVFamily would like the Inquiry to investigate what additional studies are being conducted to monitor the long-term effects and safety of the Covid-19 vaccines and what information is being provided to the public. We would like to see engagement with UKCVFamily as part of this process.

179. The UKHSA guidance regarding storage of Covid-19 vaccines [CC106 - INQ000377490] states that it is recommended that vaccines are stored between +2°C and +8°C from production right up until they are given to the patient. Vaccines that have been recommended for use after falling outside this approved temperature range are called 'off-label' vaccines. We have no data as to how many recipients were given 'off-label vaccines. The guidance states that 'small temporary changes are not likely to affect the safety of the vaccine'. What further studies and monitoring have been conducted in relation to those who have been given these 'off-label vaccines'? How is the possibility of human error in this process monitored? Dame Jennifer Harries, Chief Executive of the UKHSA may be able to assist the Inquiry.

180. No provision for weight, gender or any personal factors are considered when

administering the Covid-19 Vaccines. A person who is 50kg may well respond differently to a person who is 100kg. There is no evidence of personal circumstances being taken into account in the monitoring of safety signals. Some of our members have pre existing conditions and were advised by the NHS to take the vaccine despite there not being any studies on how those with particular conditions may respond. Many of those with pre-existing conditions have found these to have exacerbated post vaccine.

181. For example, some UKCVFamily members had pre-existing Myalgic Encephalomyelitis which was managed and stable yet after Covid-19 vaccination has become 'significant and prolonged (now over a year) relapse of ME' The M.E association also recognises this has happened with some of its members "*We have heard from a number of people with ME/CFS who have reported a prolonged and sometimes serious reaction to one of the Covid-19 vaccines. We also know that a wide range of vaccines can occasionally trigger the onset of ME/CFS and, more commonly, can cause a relapse or exacerbation of ME/CFS symptoms."* [CC/107 - INQ000377491] Indeed, some members of UKCVFamily have been diagnosed with an adverse reaction to a Covid-19 vaccine *causing* ME/CFS.

182. In 2011, Steve Hinks, Vice Chair of the Association of UK Vaccine Injured Daughters, reported that his daughter Lucy suffered a severe adverse reaction to HPV vaccination which resulted in severe Myalgic Encephalomyelitis

(CC/108). ME has been known to develop after other types of vaccine yet is denied by the Vaccine Damage Payment Scheme as causally linked. Why is the MHRA not finding these safety signals yet patient groups are?

183. UKCVFamily members who had reactions to childhood/other vaccines in the past, were given no additional advice or precautions recommended by the administrator of the vaccine when this was raised with them.

184. Many of our members had a two dose schedule of one manufacturer's Covid-19 vaccine and were then given an alternative for their booster vaccine.

185. A freedom of information request response dated 22nd September 2021 [CC/109 - INQ000377493] from the MHRA stated that *'vaccines cannot be mixed between the first and second doses because there is not enough data available on the administration of different vaccines for the first and second doses.*' The Joint Committee on Vaccination and Immunisation (JCVI) also recommended in FOI/202100230743 [CC/110 - INQ000377495], that '*you should receive the same vaccine type for both the first and second doses. This is because data has shown an increased chance of side effects occurring if a different vaccine brand is used for the second dose than a person has received for the first'*.

186. A BBC article ''Mix and match' UK Covid vaccine trial expanded' [CC/111 - NQ000377496] stated that 'Health experts generally agree that the mixing and

matching of the vaccines should be safe'. UKCVFamily are concerned that follow up safety studies to investigate the long term safety of mixing vaccines have not been published or conducted and would like the Inquiry to investigate these concerns.

187. Spike protein from the mRNA vaccine is different to that of the spike protein from the Covid virus. Research labs have been able to identify the difference in post mortems, Per the MHRA guidance 'Myocarditis and pericarditis after COVID-19 vaccination: clinical management guidance for healthcare professionals' 'as of 23 November 2022, there have been 851 reports of myocarditis and 579 reports of pericarditis following the use of the Pfizer/BioNTech vaccine. There have been 251 reports of myocarditis and 149 reports of pericarditis following the use of the Moderna vaccine' [CC/112 - INQ000377497]. As a result of the delays in recognising the correlation between Covid-19 vaccines and cardiovascular health problems, many of our members were left without a diagnosis of post-vaccine myocarditis and pericarditis for up to 2 years. The Office of National Statistics report 'Risk of death following COVID-19 vaccination or positive SARS-CoV-2 test in young people, England: 8 December 2020 to 25 May 2022' [CC/113 - INQ000377498] also confirmed that there was evidence of an increase in cardiac death in young women after a first dose of non-mRNA vaccines, with the risk being 3.5 times higher in the 12 weeks following vaccination, compared with the longer-term risk. The risk of myocarditis was known historically to be associated with the small pox vaccine (132.1

cases/million doses) [CC/114 - INQ000377499].

188. A Pfizer press release from October 2023 [CC115 - INQ000377500] confirmed the risk of Myocarditis and Pericarditis. *'Authorised or approved mRNA COVID-19 vaccines show increased risks of myocarditis (inflammation of the heart muscle) and pericarditis (inflammation of the lining outside the heart), particularly within the first week following vaccination.*' Many in our vaccine injured community have been suffering with symptoms of post-vaccine myocarditis and pericarditis for over 2 years now.

189. Several studies have now provided strong evidence between COVID-19 vaccination and myocarditis and pericarditis, for example:

a. Alami *et al.* (2023) [CC/116 - INQ000377501] : Systematic review and meta-analysis comparing vaccinated *versus* unvaccinated patients, demonstrating double the risk of myo/pericarditis with vaccination

b. Gao *et al.* (2023) [CC/117 - INQ000377502] Systematic review and meta-analysis of myo/pericarditis risk, including with different vaccine doses, finding double the risk of myo/pericarditis with vaccination, which doubled again with a second vaccine.

c. Yasuhara *et al.* (2022) [CC/118 - INQ000377503] Systematic review and meta-analysis of myo/pericarditis after mRNA vaccination in adolescents

and young adults. Study found the second dose was more commonly associated with myo/pericarditis The study states that most cases were "mild" with "only" 1.3 % of cases being severe. Despite this claim, the authors also find that 92.6 % of cases required hospitalisation, with 23.2 % requiring ICU admission, the use of inotropes (which help the heart contract) was "only" 1.3 %. No patients died or required mechanical support. Average hospital stay was ~2-4 days.

d. Oster *et al.* (2022) [CC/119 - INQ000377504]: VAERS analysis of the association between mRNA vaccines and myocarditis from December 2020 to August 2021, finding average onset was ~2 days with an average age of 16-31 years, and 82 % male. After the second dose, myocarditis rates were found to be at 70.7 per million doses in aged 12-15 year males (Pfizer); 105.9 cases/million for males aged 16-17 years (Pfizer), and ~52-56 cases per million for males aged 18-24 years (Pfizer and Moderna). It is noted that neither the abstract nor discussion include information on females, potentially giving a skewed overview. In females aged 12-15, myocarditis rates were 6.4 cases per million doses (Pfizer); 11.0 cases per million for those ages 16-17 years (Pfizer); and 6.9 cases per million doses for those aged 18-24 (Moderna); and 8.2 cases/million for those aged 25-29 years (Moderna). 96 % of patients required hospitalisation, with 87 % having resolution of symptoms at discharge.

e. Patone *et al.* (2022) [CC/200 - INQ000377516]: Case series of

myocarditis in those aged ≥ 13 years, finding a 33 % increased risk after AstraZeneca, and between 52-72% increased risk (depending on dose) for Pfizer. In women, the excess risk post-vaccination (second dose mRNA) was similar to the risk with COVID-19 infection (7 *versus* 8 times the risk, respectively).

190. As stated elsewhere in this document, it is a concern that this link between myo/pericarditis is so well established, yet no efforts have been made to mitigate this risk. We would ask the Inquiry to investigate why.

191. Since the risk is shown to be higher with mRNA vaccines, the role of LNPs should have been a research priority with the aim to reduce their immunogenicity (Tsilingiris *et al.*, 2022, CC/201 - INQ000377517). Several studies have found or suggested immune dysfunction as implicated in myocarditis post-vaccination, with evidence only continuing to grow (e.g. Baumeier *et al.*, 2022, CC/202 - INQ000377518; Bozkurt *et al.*, 2021 CC/203 - INQ000377519; Cadegiani, 2022, CC/2004 - INQ000377520; Gill *et al.*, 2022, CC/205 - INQ000377521; Schwab *et al.*, 2023, CC/206 - INQ000377522; Schreckenberg *et al.*, 2023, CC/207 - INQ000377523; Yonker *et al.*, 2023, CC/208 - INQ000377524). UKCVFamily would like the Inquiry to investigate what efforts have been made to temper this?

192. We also note the relative paucity of evidence after vector vaccines (e.g. AstraZeneca), which may skew healthcare worker perceptions that myocarditis

cannot occur after these vaccines (rather than the risk is lower; as the study by Patone *et al.* [CC/200 - INQ000377516] above shows, the risk is still elevated). Indeed, UKCVFamily members, both men and women, have been affected by Myocarditis post administration of viral vector vaccines.

193. In addition, we do not know the risks of repeated vaccination. We are aware of some people who have had in excess of 5 Covid-19 vaccinations now. UKCVFamily would like the Inquiry to investigate what safety data this repeated dosing is based on. Since we are increasingly understanding the pathophysiology of myo/pericarditis post-vaccine, could smaller mechanistic studies be utilised to understand potential risks? For example, Nakahara *et al.* (2023)[CC/209 - INQ000377525] recently used ^{18}F-FDG uptake (a method used to identify myocarditis) in 700 asymptomatic vaccinated patients, finding they had signs of inflammation which unvaccinated controls did not have. The study cites research investigating other aspects of vaccination using this same method, dating back to 2021. In addition, another study utilised ECGs to identify heart rhythm abnormalities after vaccination in a young population, finding a sensitivity of 100 % and specificity of 99.1 % to identify cardiac events (e.g. myocarditis, arrhythmias) (Chiu *et al.*, 2023, CC/210 - INQ000377527). Further research like these studies should have been done rapidly to identify the effects of the vaccine on the heart.

194. Risks of vaccine-induced myo/pericarditis also need to be considered in the

context of repeat Covid-19 infections (alongside repeat vaccinations). Limited evidence suggests risk of myocarditis after Covid-19 is reduced in those vaccinated (e.g. Patone *et al.*, 2022, CC/200 - INQ000377516) but it is unclear what risk repeat vaccination and infection (i.e. exposure every few months, potentially) confers.

195. Furthermore, risks of vaccination need to be considered within the context of prior myo/pericarditis. For example, one case study showed COVID-19-induced myocarditis to recur after the first vaccination (Pasha *et al.*, 2022, CC/211 - INQ000377528).

196. We are also unaware of any campaign from public health bodies or the Government to warn people of such risks, what signs to look out for, or when it is appropriate to seek urgent medical care which we will discuss later in this document.

197. UKCVFamily ask what the Government/MHRA done to ensure myo/pericarditis risk is minimised with booster vaccines?

198. In addition, UKCVFamily ask what the Government/MHRA doing to ensure everyone who has current or prior signs of myo/pericarditis are swiftly and thoroughly investigated so safety monitoring is accurate? As stated above, some of our members took > 1 year to get a diagnosis, which is not conducive to

accurate safety monitoring. Others are likely still suffering but may have stopped seeking healthcare, or still without a diagnosis, partly due to the medical abuse and gaslighting many of us have been subject to (discussed in more detail elsewhere).

199. One systematic review and meta-analysis we are aware of compared myo/pericarditis risk between Covid-19 and non-Covid-19 vaccines (Ling *et al.*, 2022, CC/212 - INQ000377529). Previously, myo/pericarditis has been researched in the context of influenza (n = 2 studies), smallpox (n = 6 studies), and a variety of other non-COVID-19 (n = 3 studies) vaccines. Grouping all non-COVID-19 vaccines together demonstrated 56 cases per million doses of myo/pericarditis (*versus* 18 cases/million doses for all COVID-19 vaccinations across all populations; higher for mRNA vaccination, particularly in younger males with second dose). Most notably, the smallpox vaccine in particular was associated with 132 cases/million doses. The studies on the smallpox vaccine were done > 4 years prior to the COVID-19 pandemic.

200. UKCVFamily would like the Inquiry to question why the public health bodies, regulators, and pharmaceutical companies did not researching what caused this from the smallpox vaccination, and whether there was anything that could be done to reduce this risk? Equally, this is a lesson to learn going forward; we now understand vaccines can cause unexpected harm, what will be done in the future to understand these risks and design vaccines to mitigate these risks? The

implication is that many, if not all, myo/pericarditis injuries could have been avoided had these studies been taken seriously prior to the pandemic.

201. Since this (and many other risks) are not unique to Covid-19 vaccination, we urge research to understand how to make safer vaccines in general, as well as understanding mechanisms of harm that may be unique to each vaccine type.

202. In addition to this point UKCVFamily are concerned that Covid-19 and flu vaccination is now being encouraged at the same time. The Covid-19 vaccines should still technically be in Phase 4 trials, they are still only temporarily authorised and co-administration has not been widely studied.

203. Regulation 174 for Healthcare Professionals states [CC/018 - INQ000377512] "Concomitant administration of COVID-19 mRNA Vaccine BNT162b2 with other vaccines has not been studied in trials conducted by Pfizer/BioNTech (see section 5.1)." It goes on to say "Data assessed by the MHRA that support concomitant administration of COVID-19 mRNA Vaccine BNT162b2 with influenza vaccines (but at separate injection sites) are based on the ComFluCOV study [EudraCT Number: 2021-001124-18}, which investigated concomitant administration of COVID-19 mRNA Vaccine BNT162b2 with several influenza vaccines. The data show that the antibody responses are unaffected and that the reactogenicity profile is acceptable. The MHRA has needed to rely

on these data in advance of them being publicly available, including to Pfizer/BioNTech, but is satisfied as to the arrangements for its expected publication, and this section will be updated once the data are published." The study this refers to is the ComFluCOV study [CC/213 - INQ000377530] of just 679 participants.

204. UKCVFamily ask the Inquiry to investigate how the two individual vaccines can be monitored for safety in the population when they are administered together? Given the small study size of ComFluCOV is it appropriate to offer the, still temporary authorised Covid-19 vaccines, alongside the yearly flu vaccines from a safety monitoring perspective?

205. UKCVFamily have members with permanent scarring of the heart caused by post-vaccine myocarditis after delayed diagnosis and treatment. This scarring can cause arrhythmias within the heart and subsequently, reduced quality of life. Many UKCVFamily members have presented to medical practitioners with chest pain, palpitations and other myocarditis symptomatology, only for their condition to be minimised by the practitioner. Members have tried to manage these symptoms at home themselves, only to find that months later, the symptoms worsen again. For some members, it's only been through funding a private cardiology appointments and cardiac MRI that Late Gadolinium Enhancement has been discovered within the heart suggesting prior Myocarditis and subsequently cardiac ischemia or fibrosis. A longer holter monitor such as a 3

,or preferably, a 14 day one has been found to show arrhythmias caused by this scarring. UKCVFamily members have been diagnosed with the following arrhythmias; Ventricular Tachycardia, Paroxysmal Ventricular Tachycardia, Atrial fibrillation, Atrial flutter, Supraventricular Tachycardia, Bradycardia, AV Heart Block, Inappropriate Sinus Tachycardia.

206. Some UKCVFamily members have then had to undergo procedures to mitigate these arrhythmias such as cardiac ablation and cardioversion. Some members are managed with medication but unfortunately, UKCVFamily do still have members who have not received any proper investigation into their cardiac symptoms.

207. In a poll taken in December 2022, by UKCVFamily members who have had post-vaccine myo/pericarditis, 65% were female and over the age of 30, a further 13% were female and under the age of 30, and just 22% were male sufferers. The available NHS information 'Myocarditis and pericarditis after COVID-19 vaccination' [CC/214 - INQ000377531] states that '*Overall, two thirds of myocarditis cases were in men, and men were significantly younger (median age 33) compared to women*'. UKCVFamily are concerned that inequalities in healthcare for women may be a contributing factor in the delayed and misdiagnoses of women who have post-vaccine myocarditis leading to under-reporting of safety signals in this group of patients.

208. UKCVFamily members have found their myo/pericarditis returning multiple

times, making this condition more chronic and life altering than the current literature suggests. The British Heart Foundation states [CC/215 - INQ000377532] '*While reports of myocarditis following any Covid-19 vaccine are rare, cases are more common in young males aged 18-29 years following the second dose. Most people who have been affected have experienced a mild illness and recovered without medical treatment'*. On the NHS guidance 'COVID-19 vaccines side effects and safety' [CC/216 - INQ000377533], there are two sentences stating '*Most people who had this recovered following rest and simple treatments'*. This is not the experience of UKCVFamily members. Indeed in the UK Government's own guidance for 'Myocarditis and pericarditis after COVID-19 vaccination: clinical management guidance for healthcare professionals' [CC/214 - INQ000377531], two studies from the US are quoted, noting '*significant left ventricular fibrosis has been described in a high percentage of those children admitted to hospital, with a small percentage of these having non-sustained ventricular tachycardia (VT)'*. The guidance then goes on to state that '*no long-term follow-up data is available yet on hospitalised patients'* and that '*the long-term consequences of this condition secondary to vaccination are yet unknown, so any screening recommendations need to be balanced against the frequency and severity of the disease with the aim to prevent complications, in particular of myocarditis (arrhythmias, long-term myocardial damage or heart failure)'.*

209. An article in the British Medical Journal [CC/2017 - INQ000377534] states in

conclusion to a review undertaken to review reports of myocarditis and pericarditis '*There is an urgent need for further pharmacoepidemiological studies to be conducted to provide more accurate estimates of the frequency, clinical course, long-term outcome, effects of treatment and impact on quality of life, to address many of the limitations of spontaneous reporting'.* The use of the term mild to describe Myocarditis significantly undermines the actuality of the condition itself, seemingly a narrative 'trick'. Heart inflammation should never be described as mild and indeed in many of our members' cases, has caused long term illness and damage. Rest and simple treatments have not led to resolution of symptoms.

210. UKCVFamily members are concerned that they have not had long-term follow up nor investigation of cardiac symptoms relating to post-vaccination myo/pericarditis. Many are still unable to exercise or even walk far, nearly three years later due to cardiac problems. UKCVFamily would like the Inquiry to investigate why these follow up studies are not being completed.

211. The concerns around myocarditis and pericarditis were shared by the JCVI particularly with regards to giving the Covid-19 vaccine to children. Professor Adam Finn who is a member of the JCVI said [CC/218 - INQ000377535] "there is very little benefit" to vaccinating heathy 12 to 15-year-olds against Covid-19. He said the committee has been getting "*very up to date*" information from paediatric cardiologists in the US, who are managing children who have

experienced myocarditis - inflammation of the heart muscle as a side effect. He added that although there were "small numbers" of children suffering with the side effect, there are still "some early concerns" that it might be a "*problem in the longer term*". *"We really do want to take care that we avoid a scenario, a theoretical scenario, where a vaccine programme is seen to be doing more harm than good*," he said. It might be useful to the Inquiry to speak to Prof Adam Finn.

212. An article for Sky News [CC/219 - INQ000377536] stated that "The Joint Committee on Vaccination and Immunisation (JCVI) has resisted intense pressure from ministers by refusing to recommend coronavirus vaccines for 12 to 15-year-olds." 'The JCVI told the government that "the health benefits from vaccination are marginally greater than the potential known harms", but the uncertainty around risks like this mean it has not recommended expanding the vaccine programme.' It is clear that the JCVI were under pressure despite their concerns regarding the rollout to younger cohorts, UKCVFamily would like the Inquiry to examine to what extent this political pressure played a role in authorising Covid 19 vaccination for children. Members of the JCVI may be able to assist.

213. The Covid-19 vaccines were added to the school immunisation program in September 2021. We believe this may have been based on just one clinical trial in the US (CC/220 - INQ000377538) that stated *"no specific safety concerns identified that would preclude issuance of an EUA"*.

214. The World Health Organisation Covid-19 vaccine safety surveillance manual [CC/221 - INQ000377539] states that *'for COVID-19 immunisation-related AEFIs, in addition to standard information, it is important to record the brand name, the manufacturer, as well as the batch numbers'*. Many members UKCVFamily have had reactions to the same batch numbers. UKCVFamily are concerned that there may be no studies being conducted within the Yellow Card System with regards to these particular batch numbers [CC/222 - INQ000377540]. Access to this data, if any available, should be sought by the Inquiry. In Scotland no vaccine cards were issued meaning that the only way members would be aware of their batch numbers would be by accessing their medical records.

215. UKCVFamily members are also concerned about blood donation requirements and those suffering chronic Covid-19 vaccine adverse reactions. Recently it has been noted that those suffering from Long Covid are no longer able to donate blood [C223 - INQ000377541]. Dr Charles Shepherd, Honorary Medical Adviser for the M.E association says: "Until we know more about the cause and perpetuation of Long Covid, the ban on blood donations should continue – just as it should in ME/CFS and PVFS."[CC/224 - INQ000377542]. Currently, there are no restrictions on those suffering Covid-19 vaccine adverse reactions and blood donation. As these reactions are not yet fully understood, not being researched, and in some cases not recognised in medical records, we are

concerned that blood may be donated that shouldn't be or could be detrimental to the recipient.

216. The Prevention of Future Deaths (PFD) [CC/225 - INQ000377543] are written by Coroners following an inquest, if it appears there are factors which represent a continuing risk of future deaths. The PFD report is issued to people or organisations to follow up on actions to reduce that risk. These were recommended by Baroness Hallett per the Coroners Inquests into the London Bombings of 7 July 2005, per Lady Justice Heather Hallett, Assistant Deputy Coroner for Inner West London, ruling 6 May 2011, transcript p15. There were 440 PFD reports issued by coroners in 2021 [CC/226 - INQ000377544]. Upon a search of those PFD reports published there were hardly any associated with 'vaccines', 'adverse reactions', 'AstraZeneca', 'Pfizer', 'vaccine-induced', 'vaccination'. No reports were found pertaining to any UKCVFamily bereaved members. Given that knowledge of Covid-19 vaccine related deaths were present at this time, UKCVFamily are concerned that there is only one such publicly available PFD report associated with the Covid-19 vaccine. We also ask why reports weren't made for other Covid-19 vaccine related deaths. Such reports could have been crucial in highlighting adverse event signals, issues that families had when looking for answers regarding their loved ones death and problems encountered by histopathologists and Coroner's relating to these deaths, which could have mitigated any risk of future deaths and given public health bodies the knowledge of what to look out for in relation to vaccine adverse

events. UKCVFamily would urge the Inquiry to investigate why Coroner's have not filed PFD reports regarding those who have died as a consequence of an adverse reaction to a Covid-19 vaccine. Mark Lucraft QC, Chief Coroner 2016-2021 or Judge Thomas Teague, currently Chief Coroner may be able to answer these questions.

217. One PFD report that was filed [CC/227 - INQ000397148] and made public was in relation to a 26 year old man who passed away as a result of vaccine induced cerebral venous sinus thrombosis. The coroner's concerns with the MHRA were stated as follows: *'the Inquest heard evidence from a senior medical assessor from the Medicines and Healthcare Regulatory Agency (MHRA). The Inquest heard that from the 25th February 2022 the MHRA investigated the potential signal of immune thrombocytopenia. This identified three cases of cerebral venous sinus thrombosis which could possibly be associated with the AstraZeneca Covid 19 vaccine. The MHRA could not fully consider these cases as they did not receive all of the necessary clinical information. The Inquest heard that the MHRA do not have the power to compel relevant clinical information, to assist them with safety investigations. In light of the clear public interest in ensuring that the MHRA are able to carry out robust safety investigations, it is a matter of concern that the MHRA are unable to compel the timely production of relevant clinical data.*' These comments highlight the concerns with the MHRA's ability to timely respond to real time data as the rollout continued. UKCVFamily would like the Inquiry to investigate why the MHRA

couldn't respond adequately to vaccine related deaths and what can be put in place so that this isn't a barrier to critical and robust safety investigation in the future.

218. In response to reports of neurological side effects from the covid vaccine Pfizer stated that they [CC/228 - INQ000377546] 'took adverse events associated with its vaccine "very seriously", collecting information to send to regulators. It added that "hundreds of millions of people around the world have been vaccinated with our vaccine". AstraZeneca said patient safety was of the "utmost importance", and it worked with regulators to monitor safety information. Its coronavirus jab "has a similar safety profile to other vaccines and the [European Medicines Agency] and other international bodies including the WHO, have all stated the benefits of vaccination continue to outweigh any potential risks".' As previously mentioned these safety concerns were shown within the trials so the manufacturers were aware of these adverse reactions. We would ask the Inquiry to consider how underprepared the NHS were in acknowledging and responding to these events and how this affected the safety of patients suffering from an adverse reaction to a Covid-19 who sought NHS care.

UKCVFAMILY CONCERNS: PUBLIC MESSAGING

219. By "public messaging" we are specifically referring to information that was shared by the government, by individual MPs to their constituents, by

mainstream and social media, by the NHS, and by prominent public figures such as celebrities. We asked our members about their level of trust in these institutions and/or individuals before they experienced their adverse reactions, and 45% described themselves as having a "mid level" of trust, defined as trusting 3 or 4 of them; and 39% described themselves as having a "low level" of trust, defined as trusting 1 or 2 of them. 15% described themselves as having "zero trust" in any of them. It would be reasonable to consider that 85% of those who chose to get vaccinated, at the time of vaccination had some level of trust in either the government, their own MPs, mainstream media, social media, the NHS, or prominent public figures such as celebrities. The information that those six sources shared as part of public messaging around Covid vaccination may well have been relied upon by a considerable proportion of UK residents.

220. We are extremely concerned with the lack of information about adverse reactions to the Covid-19 vaccines in all public messaging — we are still concerned about this lack of information in today's public messaging. We believe it is important to examine this lack of information in the context of what was actually shared about the Covid-19 vaccines during general public messaging both before and after rollout. It is also relevant to briefly acknowledge what has been shared about adverse reactions to other vaccines in the past, in order to understand the culture that existed in the past regarding the vaccine-injured.

221. The Government employed an extensive advertising campaign to encourage

vaccination. For example, in April 2021, the Government announced that TV adverts were to begin from Monday 26th April, with campaign slogans such as "Every vaccination gives us hope." [CC/229 - INQ000377547]. Typically, advertising prescription-only medications (which vaccines are classed as; UK Government, 2013, [CC/230 - INQ000377549]) is illegal in the UK. According to the MHRA Blue Guide [CC/231 - INQ000377550], (2020), vaccines can be exempt from such regulations: "Advertisements for a licensed vaccine product that have been approved by Health Ministers as part of a Government controlled vaccination campaign are exempt from this prohibition". However, to our knowledge, certain regulations must still be adhered to, per the Human Medicines Regulations (2021)[CC232 - INQ000377551]. These include (according to the UK Government, 2023) that the advert must: comply with the particulars of the Summary of Product Characteristics ("SmPC"); not be misleading; and encourage the rational use of the product by presenting it objectively and without exaggerating its properties

222. In addition, the Blue Guide [CC/231 - INQ000377550] (Chapter 5) states: "Advertising to the general public should not suggest that one product is better than (or equivalent to) another identifiable treatment or product, or that the effects of taking it are guaranteed"

    a. "Advertisements to the public must include the name of the medicine and the common name where the product contains only one active ingredient."
    b. "There should be a clear and legible invitation to read carefully the

instructions on the leaflet contained within the package or on the label as the case may be."

c. "Advertising should not suggest that a product does not have any side-effect"

223. "The MHRA considers that it is not appropriate to refer to any medicine as "essential" in advertising. Medicines are indicated for people suffering from a specific condition rather than the general population, and they may not be suitable for everyone." We appreciate vaccines differ slightly here as they are for the general population, but the essence of this point seems pertinent, described below.

224. "Advertisements to the general public should not contain material which refers to recommendations by scientists or healthcare professionals, or which refers to recommendations by celebrities who, because of their celebrity, could encourage consumption of products." Many Covid-19 vaccine adverts included the use of celebrities as you will see evidence of further in this document.

225. We draw the Inquiry's attention to two adverts from the UK Government and NHS. The first is from 15 December 2021 from Chris Whitty. In the video [CC/233 - INQ000377552] Mr Whitty states: "*Every adult in the country needs to get a COVID-19 booster vaccine" and "boosters give you the best possible protection against the virus*". We query whether such an advert is in line with regulations.

Firstly, to our knowledge, the SmPC does not provide evidence or state that vaccination is "the best" possible protection against the virus, and such a claim ignores other methods of protection such as respirators, ventilation, and shielding. Additionally, language such as "best" infer a guaranteed (and comparative) level of protection which seems to go against the Blue Guide. Secondly, the claim that "everyone" should get a booster is not substantiated by evidence; indeed, there are valid exemptions, plus many of our members were harmed by repeat vaccination doses and therefore it is likely harmful to imply further vaccines are beneficial for the whole population; this statement seems to contravene the Blue Guide too. Thirdly, these claims surmount to potentially being an exaggeration of the properties of the vaccine. Finally, no mention of the active ingredient was given, and there was no reference to the vaccine insert (which contains information on side effects). YouTube representatives may be able to provide information as to why they chose to publish a video that seemingly went against its own regulations.

226. Another example is of a NHS-endorsed advert can be found on the Guardian News channel on 10 February 2021 [CC/234 - INQ000377553], where there is no mention of side effects, but more importantly, an inference that the vaccines are completely safe, with statements such as "I'm still standing" and "that didn't hurt". The use of celebrities may also contravene the Blue Guide, as well issues similarly described above for the Chris Whitty advert.

227. UKCVFamily therefore question the legality of the vaccination advertising campaign that took place and ask the inquiry to explore how future vaccination campaigns can be improved, both in terms of complying with the law (if it is found to have been broken) and in terms of giving the public platonic, factual, and fair information.

228. Public messaging regarding adverse reactions over recent years has been through a social media campaign known as Med Safety Week and supportive material. However, under-reporting is still a major issue. UKCVFamily members often join the group not knowing who the MHRA are or what a Yellow Card report is. We believe that for public messaging regarding adverse reactions to be effective, a much larger and more prevalent advertising campaign should be proposed with details given, before vaccination on how and when to report. We also believe that any future vaccination advertising campaigns should, by law, have to include information on how and when to report an adverse reaction and also what else you should do if you believe you are suffering from an adverse reaction.

229. In August 2009 the BBC wrote an article on the Swine Flu [CC/235 - INQ000377554] vaccine stating that *'a new vaccine for swine flu is most likely to be targeted at vulnerable groups such as young children and pregnant women. But a Radio 4 documentary has discovered that little or no data exists on the safety or effectiveness of flu vaccines on these groups*.' This is vastly different

to the constant *'safe and effective'* narrative surrounding the Covid-19 vaccines. The article goes on to day how 500 people developed a rare neurological condition called Guillain-Barre syndrome which left people in a coma and 25 died after the rollout of the Swine Flu vaccine in America in 1976 for a Swine Flu outbreak that never materialised. This article speaks openly of the lack of data and safety concerns. *'A further problem, he explained, was that flu vaccines are unique in that they are registered and approved before full scale clinical trials have taken place. Neither will the possible side effects be known on pregnant women or young children as Dr Marie Paul Kieny, director of vaccine research at the WHO explained. "It's not to say they would not be safe, they may be very safe but there is no data for the time being to demonstrate safety."* These open discussions of concerns of vaccine safety and efficacy contrasts to the messaging surrounding the Covid-19 vaccines where such concerns were not given the same consideration. Given the scale of the rollout we would ask the Inquiry to consider why the messaging surrounding the Covid-19 vaccine was so different to previous reporting of vaccine rollouts.

230. The Association of British Pharmaceutical Industries has a Code of Practice [CC/236 - INQ000413039]. It's states *"The Prescription Medicines Code of Practice Authority (PMCPA) was established by the Association of the British Pharmaceutical Industry (ABPI) in 1993 to operate the Code of Practice for the Pharmaceutical Industry independently of the Association itself".*

231. Forming part of this Code of Practice, is a section on how medicines and medical interventions can, and can't, be described by pharmaceutical companies. A supplement at the top of page 6 says "*Information and claims about adverse reactions must reflect available evidence or be capable of substantiation by clinical experience. It must not be stated that a product has no adverse reactions, toxic hazards or risks of addiction or dependency. The word "safe" must not be used without qualification".*

232. In an update on February 3rd 2021, AstraZeneca published an article [CC/237 - INQ000377556] on their website stating "*The primary analysis of the Phase III clinical trials from the UK, Brazil and South Africa, published as a preprint in The Lancet confirmed COVID-19 Vaccine AstraZeneca is safe and effective at preventing COVID-19, with no severe cases and no hospitalisations, more than 22 days after the first dose."*

233. UKCVFamily ask the Inquiry to investigate why this terminology was used so heavily in public messaging by government bodies and officials when Covid-19 vaccine trials were still underway and the vaccines were, and still are, under temporary use authorisation. We would also ask if Astrazeneca broke the PMCPA rules.

234. In April 2021, Matt Hancock claimed that the risk of a blood clot from the AstraZeneca vaccine was the 'same as a long-haul flight' [CC/238 -

INQ000377557]. At the time the MHRA stated they had 79 reports of clotting and 19 people had died after taking the AstraZeneca vaccine. To compare the risk of blood clots from the AstraZeneca vaccination in this context is in UKC Family's' opinion, very misleading. Deep Vein Thrombosis is very serious [CC/239 - INQ000377558] and indeed on many long haul flights you are reminded to regularly walk in the aisle or do exercises for your circulation, videos explaining this risk are sometimes played to passengers. People with known DVT risk are usually advised to take precautions such as blood thinning medications and to wear compression stockings. Members of the public who took the Astrazeneca vaccine were given no advice on how to minimise risk making this comparison a moot point. UKCVFamily would ask the Inquiry to investigate why the Secretary of State for Health and Social Care at the time, Matt Hancock, used this comparison when advising the general public on the risk of clotting with the Astrazeneca vaccine.

235. UKCVFamily would also like the Inquiry to examine whether more public messaging should've included alerting the public to the signs and symptoms of adverse reactions as soon as links were found between the vaccines and VITT, and other adverse reactions such as Myocarditis. With regards to VITT, there may have been added confusion as AstraZeneca was stopped for those under the age of 30, and subsequently 40, years in April, and May, 2021, respectively. At the time of these guidelines, published research suggested the average age of VITT patients was 46 years (range: 21-77 years) (Scully *et al.*, 2021, CC/240

- INQ000377560). This may have given those still receiving the AstraZeneca vaccine a false sense of security that VITT was not a potential side effect. Public messaging did not reflect this.

236. During Covid-19 vaccination roll out, the public were encouraged to get a vaccine to help reduce transmission though the Pharmaceutical companies had never conducted trials to prove this would be the case. In a .Gov press release titled "*People urged to get booster jabs to keep your family protected this Christmas*", it was repeatedly stated that vaccination would protect those you love from Coronavirus. [CC/241 - INQ000377561]

237. Paul Hunter, professor in medicine at the University of East Anglia said "*Most studies show if you got an infection after vaccination, compared with someone who got an infection without a vaccine, you were pretty much shedding roughly the same amount of virus"*, [CC/242 - INQ000377562] and one study by the Centre for Disease Control found that "*no difference in infectious virus titer between groups" who had been vaccinated and had not."* [CC/243 - INQ000377563].

238. UKCVFamily feel that public messaging should have included more open and transparent communication regarding adverse reactions and should've been more honest in explaining that some reactions may not yet be known as the vaccines were new. We ask the Inquiry to investigate why this wasn't addressed

in public messaging.

239. This is reinforced in the [CC/244 - INQ000377564] 'Strategy to Increase Uptake and Equity of Access to the COVID19 Vaccine Public Health England document' "*Communications need to be clear and credible, increasing knowledge and correcting misinformation. There should be open and transparent discussion about the safety, risks and benefits of vaccinations, including use of fact-checking resources and responding to misinformation. Dialogue about the vaccination programme needs to manage expectation"* UKCVFamily believe that the public messaging regarding the Covid-19 vaccines did not manage expectations. The vaccines were always referred to as 'safe and effective' and there were no public information campaigns to inform the public of what to do in the event of an adverse reaction. The Covid-19 vaccines were portrayed as the key to the ending of pandemic restrictions, and adverse reactions were not considered in public messaging.

240. The BBC have recently issued an apology regarding banners placed across the screen during a debate in Parliament. The debate, regarding Covid-19 vaccination was constantly captioned by the BBC [CC/246 - INQ000377566], many of the captions related to other vaccines and not the Covid-19 ones being discussed such as the DTP vaccine etc. A news article said [CC/245 - INQ000377565], *"A spokesman said: "We accept there was a lack of consistency in the use of our captions and that the number posted during the*

speech was not proportionate, nor always relevant which created the incorrect impression that there was an editorial approach in relation to the views expressed. "We apologise for this and are reviewing the way we use such captions during proceedings."

241. UKCVFamily ask the Inquiry to discover who controlled and decided on public messaging strategies during the Covid-19 vaccine roll out in particular whether it was discussed if potential adverse reactions should feature in advertising and whether ethical and moral implications were considered in those discussions.

COVID VACCINE PUBLIC MESSAGING: INVESTMENT

242. There appeared to have been significant resources invested in public messaging encouraging people to get the Covid vaccine, whereas investment into (i) public messaging about possible adverse reactions, and (ii) the care of the vaccine-injured appear to be lacking. The Inquiry may find it helpful to seek evidence of any investment that was made into public messaging about adverse reactions, and evidence of any discussions that were had around the potential investment into such public messaging about adverse reactions.

243. Examples of public messaging that may have taken considerable investment were part of the government's national campaign. This campaign was announced on a 26 April 2021 press release entitled *New campaign launches*

urging the public to get COVID-19 vaccine, [CC/247 - INQ000377567] and included:

a. " … *the vaccine programme's first ever TV advert showcases some of the tens of thousands of health and care workers and volunteers involved in the roll-out across the UK, as well as those who have received the vaccine. The advert will also run across radio, multicultural media, social media and out-of-home advertising like billboards in prominent locations across Manchester, Liverpool and London, including in Piccadilly Circus.*" It would be helpful to know how much this advertisement campaign cost, and whether any discussions regarding the acknowledgement of potential adverse reactions were included during its planning.

b. A campaign via Royal Mail: "*Royal Mail will apply a special postmark to stamped mail, which will run from 5 to 7 May.*" Again, it would be helpful to know how much this campaign cost, and whether discussions about adverse reactions were featured during its planning.

c. A social media campaign: "*Google and YouTube will feature vaccine messaging on their channels, and LinkedIn will be providing free advertising space on its platform …*" It would be helpful to see if there were any financial incentives made for these social media platforms to offer this messaging and free advertising space, and what were the details of the vaccine messaging that they were allowing on their platforms. Did they include any information about adverse reactions?

244. On 3 July 2021 the Department of Health and Social Care [CC/248 - INQ000377568] issued a press release entitled *Celebrities get back to the 'Rhythm of Life' in a new film supporting COVID-19 vaccination programme* [CC/249 - INQ000377569]. The press release describes the film: "*Celebrities including Jim Broadbent and David Walliams have joined forces to encourage everyone to get their coronavirus (COVID-19) vaccines in a new uplifting film released today (Saturday 3rd July).*" The film features a number of famous people performing a song and dance routine encouraging viewers to get vaccinated. There is no mention of adverse reactions during the song, and the press release doesn't indicate where the funding for the production originated nor whether any of the celebrities were paid. It would be helpful to know how the performers were briefed. Jim Broadbent — the main performer in the film, and the film's director, Josie Rourke, would perhaps be able to provide more information.

245. The NHS enlisted 'sensible' celebrities to encourage Covid-19 vaccination. An article in The Guardian [CC/250 - INQ000377571] said "*Health chiefs are particularly worried about the number of people who are still undecided, and about vaccine scepticism among NHS staff. "There will be a big national campaign [to drive take-up]," said one source with knowledge of the plans. "NHS England are looking for famous faces, people who are known and loved. It could be celebrities who are very sensible and have done sensible stuff during the pandemic."*

246. British Bake Off and MasterChef celebrities made films for the NHS encouraging Covid-19 vaccination in ethnic groups [CC/251 - INQ000377572]. The messaging clearly implied that getting vaccinated would mean that people could see family again and enjoy time together. UKCVFamily would ask the Inquiry whether this was an appropriate context in which to consider vaccination. Dr Saliha Mahmood Ahmed says in her advert "You must get the vaccine", [CC/252 - INQ000377573]. There is no mention of potential adverse reactions or what to do if you are having an adverse reaction to a Covid-19 vaccine in any of these adverts.

247. In August 2021, the government told the public that in order to be able to go 'clubbing' you would need to be fully Covid-19 vaccinated by September of that year. The clubbing industry joined in the public messaging campaign and brands such as Ministry of Sound and Heaven supported the vaccination drive 'by sharing vaccine messaging online and at their venues, along with Heaven hosting a vaccine event this Sunday (8 August), making it even easier to get vaccinated.' The .gov page stated "*A new campaign will roll out across social channels such as Facebook, Instagram, Twitter, Snapchat and TikTok, as well as on radio stations Kiss, Capital, Heart, Sunrise, and TalkSport, further continuing to help vaccine uptake in young adults. The 'Don't Miss Out' and 'Get Your Shot' campaign reinforces the messages of how simple it is to get both of your jabs and will help people get back to doing the things they love such as*

going travelling and going to big events such as clubbing." [CC/253 - INQ000377574].

248. Lohan Presencer, Executive Chairman of Ministry of Sound, said: "*It's incredible to welcome people back on to our dance floor after so long. We'll provide the music and the good times, people just need to get both their vaccines so we can all keep dancing together"* and Health and Social Care Secretary Sajid Javid said: *'Vaccines are saving lives, protecting people, and allowing us to regain some of the freedoms we've missed over the last 18 months – from visiting family abroad to dancing on a night out."* UKCVFamily ask the Inquiry to consider, from an ethical standpoint, whether this was appropriate advertising for a pharmaceutical product and whether potential adverse reactions were considered in this part of the public messaging campaign.

249. "*In collaboration with the NHS, YouTube has rolled out a video campaign with the tagline: 'Let's Not Go Back' to remind its core 18 to 34-year-old audience of the importance of being vaccinated through messaging that speaks to their personal experiences from a year in lockdown."* This advertising to encourage vaccination was supported by Health and Social Care Secretary, Matt Hancock MP saying,*" I am delighted that Snapchat, Reddit, TikTok and YouTube - some of the most influential social media platforms - are coming together to support the biggest and most successful vaccine effort in NHS history."* It was also supported by Oliver Dowden and Vaccines minister at the time, Nadhim Zahawi,

[CC/254 - INQ000377575].

250. UKCVFamily feel this was an unethical approach to encouraging Covid-19 vaccination, given that many young adults had suffered greatly with mental health issues due to lockdown restrictions. Professor Ellen Townsend wrote in an article, "*Young people are sacrificing so much socially, educationally and economically during this crisis, despite their infinitesimally small chance of their health being adversely affected by Covid-19.*" [CC/255 - INQ000377576). "*Data collected since the start of the pandemic demonstrates incontrovertibly that the overwhelming harm to young people has been to their mental health. Half of young people aged 16-25 report deteriorating mental health, with 1 in 4 feeling 'unable to cope' and the number likely to have clinically significant mental health problems has increased from 1 in 9 in 2017 to 1 in 6 in 2020 after the first English lockdown – that's 5 children in a class of 30 now likely to need clinical support.*"

251. Chapter 4 of the *COVID-19 mental health and wellbeing surveillance report* in relation to children and young people shows that studies found "*Evidence suggests that some children and young people's mental health and wellbeing has been substantially impacted during the pandemic.*" [CC/256 - INQ000377577] "Dr Antonis Kousoulis, Director at the Mental Health Foundation: "Our data reveal that millions of people in the UK are experiencing feelings of loneliness – which is a key risk factor for developing or worsening mental health problems. "The concern is that the longer the pandemic goes on,

the more feelings become long-term. The impact of long-term loneliness on mental health can be very hard to Manage." [CC/257 - INQ000377578] The advertising campaign 'Let's Not Go Back' clearly played on the suffering of young people living in the UK during the Covid-19 pandemic restrictions.

252. UKCVFamily ask the Inquiry to seek expert opinion on whether behavioural science methods used to target children and young adults for Covid-19 vaccination was, and is, ethically and morally correct, and whether the government had considered the ethical and moral implications fully. Professor Ellen Townsend, Dr Christian Buckland and Dr Antonis Kousoulis may be able to assist the Inquiry.

253. Other public messaging forums included the provision of pop-up clinics in "iconic locations" as described by NHS England on 29 July 2021 in their article, *Theme park joins NHS COVID vaccine drive*, which quoted Health and Social Care Secretary Sajid Javid as saying: "*From historic sites such as the British Science Museum, to huge entertainment events like Latitude Festival, we have worked to ensure the COVID-19 vaccine is easily accessible.*" The article continued, "*The NHS is continuing to encourage vaccine uptake by jabbing at convenient locations and popular destinations, including Goodwood races, London's Summer of Love Festival, Felixstowe seafront and Burnley FC's football ground, as well as community hubs including places of worships and shopping centres.*" and "*Last weekend, the NHS hosted walk ins at major events including Ascot*

races and Latitude Festival, jabbing thousands of people over the course of the weekend." [CC/258 - INQ000377579). There is no mention of adverse reactions in this news article and it is not clear whether they were considered during the planning of such pop-up clinics. Sajid Javid may be able to provide more information on how adverse reactions were considered.

254. According to the Department of Health and Social Care's press release of 16 August 2021 [CC/259 - INQ000377580], "*More of the country's leading businesses from a variety of industries have pledged their support for the UK's world-leading COVID-19 vaccination programme by offering incentives to vaccinated customers.*" Companies offering discounts or free services included Asda, lastminute.com, Better leisure centres, FREE NOW, Pizza Pilgrims, Vue, National Express Buses (Midlands), Uber, Bolt, and Deliveroo [CC/260 - INQ000377582]. Company representatives Zoe Matthews, Andrea Bertoli, Joseph Rham, Mariusz Zabrocki, and Chris Gibbens — quoted in the press release — offer support for anyone vaccinated but do not mention any support for those who experience adverse reactions. It would be helpful to know more from these company executives regarding the arrangement for this public messaging campaign, as well as from Sajid Javid and Nadhim Zahawi, also both quoted in the press release.

255. Dating apps Tinder, Match, Hinge, Bumble, Badoo, Plenty of Fish, OurTime and Muzmatch also collaborated to encourage their users to take the vaccine.

People that opted to display a virtual vaccinated badge, created by the apps, were given in-app boosts such as free 'super likes' on Tinder, free 'roses' on Hinge, complimentary credits on Bumble, and boosts on Match. These are normally paid for services which allow for more social interaction with an interested party.

256. "Vaccines Minister Nadhim Zahawi said: "I am thrilled that we are partnering up with dating apps to boost vaccine uptake across the country. This is another incredible asset to our vaccination programme – the biggest and most successful in our history." [CC/261 - INQ000377583 and CC/262 - INQ000377584].

257. We would like the Inquiry to consider this in the context of the pandemic, after a year or so of social distancing measures and lockdown/tiers. In a study by The Mental Health Foundation partnering with Prof Tine Van Bortel, Prof Ann John, Prof Alec Morton, Prof Gavin Davidson and YouGov. [CC/263 - INQ000377585], it was found that one in four adults (24%) in the UK has felt lonely because of COVID-19. UKCVFamily feel this was an unethical approach to encourage vaccination. Adverse reactions to Covid-19 vaccines were not considered when these kinds of psychological offers were made. Dr Christian Buckland and Prof Tine Van Bortel may be able to assist the Inquiry in understanding the psychological impact of these measures.

258. "Vaccine tents" were organised at festivals specifically targeting 16- and 17-year-olds. As reported by NHS England on 26 August 2021, "*Fans pitching up to see headliners Stormzy, Post Malone and Liam Gallagher can watch their favourite acts then rock up to get their jab at pop-up clinics on site available throughout the weekend including a vaccine bus at Reading.*" [CC/264 - INQ000377586]. How much was spent on this campaign and how much time and investment was allocated to potential adverse reactions? While examining this specific campaign, it cannot be ignored that, given the vast majority of young people at festivals tend to be drinking if not also taking drugs, was this an appropriate environment for the administering of a pharmaceutical product designed to provoke an immune response? Could any possible adverse reactions have been dismissed as being drug- or alcohol-induced and therefore not managed appropriately? (While the article stated that anyone under the influence of alcohol or drugs would not be given the vaccine, it did not state that anyone given the vaccine would be advised to refrain from consuming alcohol or drugs afterwards nor if the vaccinators had any checks in place to measure alcohol consumption of the vacinee).

259. The Inquiry may find that Dr Nikki Kanani, GP and Deputy Lead for NHS England's vaccination programme — quoted within the NHS England story about the vaccine tents would be best placed to answer questions about this particular public messaging campaign.

260. The NHS England story went on to mention "*Elsewhere in the country at over 2,000 sites, beachfronts, parks and football stadiums have transformed into vaccination centres …* " Again, how much was invested in this public messaging campaign, and how did the management of adverse reactions feature into this campaign?

261. In a 6 April 2022 article, the BBC reported [CC/265 - INQ000377587] on a "Covid vaccine festival" held in East London: "*The festival held between 30 July and 2 August 2021, included a stage with live performances and free food vouchers were handed out to festival goers as were first and second Pfizer jabs.*" The article reported that the event cost Tower Hamlets Council £237,000, and also reported that just 435 people were vaccinated at the event, leading to a cost of "*£535 per person jabbed.*" A spokesperson for the council was quoted in the article as saying, "*The vaccine event at Langdon Park, funded by Covid-19 grants from central government, was set up to help vaccinate young residents, where data was showing a low uptake in this group … Councils across the country have been actively encouraged to use funding to deliver vaccines in new and innovative ways, which is important in efforts to address vaccine hesitancy and low uptake in particular groups.*" It would be helpful for the Inquiry to examine how many grants were provided to local councils by the central government, the conditions under which those grants were made, and whether any provision was made for issues relating to adverse reactions.

262. On 14 January 2022, the government launched a "New advertising drive calling on young people to Get Boosted Now" described on its website as partnering " *… with leading social media giant Snapchat to launch a new filter to drive vaccine uptake amongst younger audiences. The 'I've been boosted' filter can be added to any photo or video on Snapchat. It celebrates those who have had their booster vaccine, and anyone who sees content with the booster filter can tap on a link to get more information about vaccines and where they can book their jab. Stephen Collins, Senior Director of International Public Policy at Snapchat, said: 'With Snapchat reaching 75% of 13 to 34 year olds in the UK, we believe we can play a unique role in helping young people access accurate and trusted information. We're delighted to continue our partnership with the UK government to support COVID-19 vaccine take up, following a successful vaccination awareness collaboration last summer. We hope our new Snapchat vaccine booster filter will encourage our community to protect themselves and others.'*" [CC/266 - INQ000377588]. Stephen Collins would be well-placed to provide the Inquiry with more information regarding whether there were any conditions imposed relating to the awareness collaborations Snapchat were party to, what financial investment was involved with the arrangement, and how any mention of adverse reactions was handled. Public messaging also included the use of sports professionals to encourage vaccination in younger people. "The young people we've spoken to are saying that we need to use social media channels. That maybe celebrities getting involved might be a route that they would listen to more." As part of England's vaccine drive, a film featuring rugby

stars - including Sam Underhill, Alex Goode and Dan Robson - will be played out at stadiums across the country from this weekend, urging young people to get their Covid vaccine". [CC/267 - INQ000377589]

263. We will talk in more detail about censorship of the vaccine-injured further in this document, but it is appropriate here to question why Snapchat, along with other social media platforms, such as Facebook, facilitated the creation of frames and filters relating to being vaccinated or boosted, whereas frames related to being vaccine-injured — used by the vaccine-injured themselves — were removed by Facebook. It may be helpful for the Inquiry to request information from a representative from Facebook regarding their policy about frames because other health-related frames — such as those relating to cancer — are available to use.

264. In general, we feel that the issue of investment into public messaging relating to adverse reactions — both financial investment and in terms of the time spent discussing the inclusion of adverse reactions in public messaging — needs further investigation. How much was invested? We ask the Inquiry why wasn't there anything invested into informing the public about adverse reactions and supporting those that had them?

265. "*To put all this in context, the Government spent £46 million on advertising "Get Ready for Brexit" in 2019 and at the time, this was apparently the biggest direct advertising spend by the Government since World War Two. Coronavirus*

spending has already topped £180 million and with the new contract for £320 million it will have spent, by the middle of 2022, £500 million on Coronavirus advertising." [CC/268 - INQ000377590].

266. In Scotland alone, "*Between 1 March 2020 and 31 January 2021, the Scottish Government public engagement spend has been £15,236,501. During this period 99.5% of the adult population (4.59m adults) has been reached over 510 times on average with multiple potential life-saving messages"* [CC/269 - INQ000377591].

267. "*Part of national drive for people to be vaccinated in fight against Omicron - An army of vaccine volunteers will help millions of people in hard-to-reach communities get jabbed, backed by £22.5 million of government funding."* The Community Vaccine Champions Scheme had £22.5 million allocated to it alone. [CC/270 - INQ000377593]

268. UKCVFamily as the Inquiry to investigate how much of this money was allocated to sign-posting people to support services if they did have an adverse reaction to a Covid-19 vaccine? How much public money was spent on advertising which includes potential adverse reaction awareness?

269. An article in The Guardian in February '22 said "*The vaccination drive has cost £8.3bn in the two years since the pandemic struck, the NAO said – the first time*

this figure has been disclosed. Of that, £4.6bn went to the taskforce, which it spent mostly on vaccines, and the other £3.7bn on the rollout." [CC/271 - INQ000377594]. Again UKCVFamily ask how much of this public money was spent on public messaging regarding potential adverse reactions or medical pathways for those who potentially had an adverse reaction?

270. In a .Gov publication *'Encouraging vaccination in younger people'* we see the use of behavioural science to capitalise 'peer influence', 'social media influencers', and 'financial incentives' for ways in which to encourage young adults to be Covid-19 vaccinated. [CC/272 - INQ000377595]

271. UKCVFamily would strongly urge the Inquiry to consider the ethics of offering financial incentives to students in exchange for agreeing to be vaccinated.

272. UKCVFamily would also strongly urge the Inquiry to consider the ethics of offering free food vouchers to individuals living in an area which its own council website describes as having " *… the highest rate of child poverty in the UK*" in exchange for receiving a pharmaceutical product. [CC/273 - INQ000377596]

WHAT DID THE PUBLIC MESSAGING INVOLVE?

273. UKCVFamily are concerned that adverts targeting children for Covid vaccination, may be misleading to the public. None of the Covid-19 vaccine

adverts we have found that target children mention adverse reactions. Iinstead some depict children in superhero costumes with the slogan 'Time to protect' [CC/274 - INQ000377597]. In the Information for Healthcare Professionals on COVID-19 Vaccine Pfizer/BioNTech (Regulation 174) Updated 5 September 2023 [CC/018 - INQ000377512] it clearly states that 'The safety and efficacy of COVID-19 mRNA Vaccine BNT162b2 in children under 12 years of age have not yet been established'. On the NHS England website Dr Nikki Kanani says: "*The vaccine is safe and effective – my 10-year old daughter will be getting hers this week – and I'd encourage all parents to read the information and consider booking their child in for a vaccination at the earliest opportunity."* [CC/275 - INQ000377598]

274. UKCVFamily would like the Inquiry to establish why children were being so heavily encouraged to take a Covid-19 vaccine when Pfizer has clearly stated that the safety and efficacy of their product in children is unknown and why parents were not told this.

275. Dr Sara Kayat said on ITV show This Morning on the 4th January 2021 that "*After 12 days from the first vaccination of the AstraZeneca vaccine you are 100 percent effective against hospitalisation and death*." This generated more than a hundred Ofcom complaints from viewers who insisted the claim was "scientifically untrue" and "deeply misleading" [CC/276 - INQ000377599]. No correction to this statement has ever been made by the show or Dr Kayat. The

show This Morning has an average viewership of 1.4 million people [CC/277 - INQ000377600]. UKCVFamily question why TV companies were allowed to make false claims such as this. Ofcom Chief Executive, Melanie Dawes may be able to assist the Inquiry with this matter.

276. Where adverse reactions are mentioned it is usually in relation to a 'sore arm' or 'flu-like' symptoms [CC/278 - INQ000377601]. They are referred to as *mild* and *self limiting* and the only advice given to those who may think they are suffering an adverse reaction is to report to the Yellow Card, which we know does not lead to any medical help or treatment. It is also sometimes mentioned to call 111 but as we will mention later on within this document, that doesn't always lead to medical help being provided with call handlers telling members to *"get a massage"* or to *"stop watching the news".*

277. However many times in official Covid-19 vaccine public messaging adverse reactions are not mentioned at all as we have already demonstrated.

WHAT SHOULD PUBLIC MESSAGING AROUND VACCINES & THERAPEUTICS INVOLVE?

278. According to legislation, The Human Medicines Regulation 2012 [CC/232 - INQ000377551], a clause was added to exempt vaccination advertising campaigns from having to comply with regulations that other Pharmaceutical

products must comply with "*287(4)(b) (material about effects of medicinal products) do not apply to an advertisement as part of a vaccination campaign that—a)relates to a medicinal product that is a vaccine or serum; and(b)has been approved by the Ministers.*" UKCVFamily ask the Inquiry to examine why this is the case and why the rules applied to other prescribed medication, don't apply to vaccinations.

WHAT DID THE PUBLIC MESSAGING NOT INVOLVE?

279. Public messaging regarding Covid-19 vaccination did not overtly include;

a. what to do if you suspected you'd had an adverse reaction

b. Signs and symptoms to be concerned about following vaccination and what to do if you were concerned

c. How to report a suspected adverse reaction

d. That the Covid-19 vaccines were authorised temporarily under emergency use.

e. That the manufacturer's were indemnified and what that means for the recipient

f. That some adverse reactions may develop over the coming days and weeks following vaccination

g. The active ingredient (per the Blue Guide)

280. This lack of transparency in public messaging led to many of the vaccine-injured to be ill informed of how to proceed when faced with the onset of their adverse reaction. In some cases, vaccine induced deaths may have been prevented if more information had been published in a timely manner regarding VITT, for example.

281. Members of UKCVFamily were largely unaware that vaccine manufacturers are not liable. Therefore, one learning point from the inquiry is communicating why this is the case, perhaps including it as part of informed consent to get vaccinated.

282. In addition, we request consideration into the potential harms of no fault liability schemes with regards to vaccinations, and whether there is a different way to support vaccine development with patient safety and support as a priority. Pulivel and Naik 2018, [CC/279 - INQ000377602] make a case that the combination of no-fault schemes plus changes in WHO criteria for determining causality with regard to adverse events following immunisation (which favour non-causality) created an environment in which vaccine manufacturers were more lax regarding adverse events: “As a result, manufacturers may be emboldened to be more reckless on vaccine safety issues".

283. As highlighted elsewhere in this document, the Vaccine Damage Payment Scheme is significantly inadequate; thus there seems to be little accountability for vaccine injuries. In other words, manufacturers are exempt from liability,

there are barriers to civil litigation and the Government does not offer meaningful nor appropriate support to victims, leaving our members stuck in a void. This void is not communicated to potential vaccinees; assuming they have heard of the VDPS, they may even be reassured that there is a safety net. Based on our experience, this reassurance is misleading, and therefore unethical.

MISINFORMATION ABOUT VACCINE ADVERSE REACTIONS

284. Misinformation is defined by the Collins English Dictionary as "*wrong information which is given to someone often in an attempt to make them believe something which is not true*".

285. NHS online information about the Covid vaccine states that, “Reports of serious side effects are very rare.” NICE guidelines define “very rare” side effects as occurring in “less than 1 in 10,000.” [CC/280 - INQ000377604]. By the end of 4 September 2022, 151,248,820 doses of a Covid vaccine had been administered to 50.7 million people in the UK. If the NICE guidelines refer to people as opposed to doses, serious side effects could currently be impacting up to 5,070 people. If the NICE guidelines refer to doses, we could be looking at up to 15,100. NHS Online’s estimate could therefore be between 5,000 and 15,000 people. Adverse reactions are seemingly underplayed in the media reporting them as "rare". Coincidentally, we have been unable to find any government statistics indicating the rate of adverse reactions to ANY drug.

286. For example the British Heart Foundation says "While reports of myocarditis following any Covid-19 vaccine are rare, cases are more common in young males aged 18 to 29 years following the second dose. Most people who have been affected have experienced a mild illness and recovered without medical treatment." [CC/215 - INQ000377532]

287. This language is never explained to the general public and contributes to the stigma that the vaccine-injured face. This in turn has a knock on effect as people who suffer adverse reactions are then labelled 'misinformation' themselves. While 'rare' reactions are readily recognised on paper, in reality it can be very different for those who've had a reaction to a vaccine.

288. If anything related to vaccine adverse reactions is labelled as misinformation then how are members of the public to know they are having one. Some UKCVFamily members didn't realise they were having an adverse reaction to a Covid-19 vaccine until they were informed by a medical professional. In the case of some of our bereaved families, they feel that had adverse reactions been discussed more openly, they would have heeded warning signs and symptoms that their loved ones displayed and would have sought medical attention much sooner.

MISINFORMATION ABOUT THE VACCINE'S SAFETY

289. On the 2nd of January 2021, the British Medical Journal wrote to the New York Times asking them to correct misinformation that had been published stating that it was safe to mix vaccine brands. "Fiona Godlee pointed out in her letter to the NYT that it was not a recommendation. She said the NYT's headline claiming UK guidelines say such substitutions "may happen" was "seriously misleading". [CC/281 - INQ000377605]

290. In a BBC article dated 20th September 2021, Dr Nikki Kanani, GP and deputy lead for the NHS Covid-19 vaccination programme, said: "*The vaccine is safe and effective and I would urge families to work closely with their schools based vaccination team to get their loved ones vaccinated when they are invited to protect themselves and their families ahead of the winter period.*" [CC/282 - INQ000377606]. Yet information taken from the government's own website states "*Paediatric population. The safety and efficacy of COVID-19 mRNA Vaccine BNT162b2 in children under 12 years of age have not yet been established.*" and later on "*There are no data on a booster dose administered to individuals less than 18 years old.*" [CC/018 - INQ000377512]

CENSORSHIP AROUND VACCINE INJURY

291. Censorship is defined by the Oxford Reference as *'Any regime or context in which the content of what is publicly expressed, exhibited, published, broadcast, or otherwise distributed is regulated or in which the circulation of information is*

controlled. The official grounds for such control at a national level are variously political (e.g. national security), moral (e.g. likelihood of causing offence or moral harm, especially in relation to issues of obscenity), social (e.g. whether violent content might have harmful effects on behaviour), or religious (e.g. blasphemy, heresy). Some rulings may be merely to avoid embarrassment (especially for governments). "2. A regulatory system for vetting, editing, and prohibiting particular forms of public expression, presided over by a censor: an official given a mandate by a governmental, legislative, or commercial body to review specific kinds of material according to pre-defined criteria. Criteria relating to public attitudes—notably on issues of 'taste and decency'—can quickly become out-of-step." "3. The practice and process of suppression or any particular instance of this. This may involve the partial or total suppression of any text or the entire output of an individual or organisation on a limited or permanent basis."

292. Those of us who experienced our adverse reactions in the early months of the rollout found it impossible to access information about vaccine injuries in the mainstream media, leading to an increased sense of fear and isolation and more likelihood of being disbelieved. Adverse reactions to the Covid vaccines were not discussed in mainstream media for the main part of the rollout. When they were eventually covered, stories were very much cushioned by a focus on the rarity of the reaction, the safety of the vaccine, and the millions of lives it had saved. And the people being interviewed by mainstream media had to agree to censor themselves or had their words censored in editing.

293. UKCVFamily member Gareth Eve, husband of the late Lisa Shaw, BBC presenter, who tragically died due to an adverse reaction to the Astrazeneca vaccination was interviewed by the BBC on the 15th of July 2021 [CC/283 - INQ000377607]. Gareth recall's that while the reporter was very sympathetic to his situation, conversation had to be 'steered' a certain way, that the BBC editorial team had only cleared what they deemed 'acceptable' to talk about and that the reporter's questions were guided that way. At the end of the interview the reporter ended by speaking about the safety and effectiveness of the vaccine, she told Gareth '*that's what I had to say*'. Gareth also remembers talking to another well known broadcaster who when deliberating whether or not he could cover the story said he was struggling to work out how to tell it without it *'being hijacked by the conspiracy theorists'.* One of Gareth's family members approached ITVs' This Morning show to see if they would interview Gareth but the response was that *'It was deemed not in the public interest at the time when the vaccine programme needed to be rolled out.'*

294. Mainstream media reporters themselves spoke to myself and Ms Pover about the censorship they themselves were facing. One mainstream media representative spoke to us in their car, for fear of repercussions from work colleagues for speaking to us about Covid-19 vaccine adverse reactions. Prior to the pandemic Ms Pover had been in contact with mainstream media reporters due to her voluntary and entrepreneurial work. Ms Pover contacted those

reporters in 2021, regarding her adverse reaction and was informed that they weren't allowed to report on Covid-19 vaccine adverse reactions. UKCVFamily emailed over 100 reporters in early 2022 and we only had two replies.

295. The Telegraph newspaper claims to have received a threatening phone call from a senior official at the MHRA in March 2021 after publishing an article highlighting a causal link between the Astrazeneca vaccine and blood clots. According to the Telegraph they were told they "would be banned from future briefings and press releases" if they "didn't soften the news" [CC/284 - INQ000377608]. Sarah Knapman, Science Editor at the Telegraph may be able to assist the Inquiry regarding this interaction.

296. UKCVFamily would like the Inquiry to investigate what editorial policies were put into place that made journalists so reluctant to talk about Covid-19 vaccine adverse reactions, was there any pressure from government or MHRA officials and if so, what form did that pressure consist of?

297. When our members attempted to post about their adverse reactions on social media, their posts were assigned warnings or removed altogether, with some people getting banned completely from using platforms such as Facebook. Online support groups set up by the vaccine-injured for the vaccine-injured, were frequently shut down, leading the injured to develop code words and styles of communicating that would not flag up their individual or group pages. Words like

"carrot," "Maxine," and "ice-cream," are used instead of the word "vaccine" itself so that the injured can safely share information about their symptoms and experiences in the hope of finding the solutions that the healthcare system is failing to provide. A BBC reporter exposed the coded communication resulting in one of the Facebook support groups being shut down [CC/285 - INQ000377609]. There is a world of difference between a genuine vaccine-injury support group and a group set up purely to discuss the vaccines themselves. Unfortunately, social media doesn't recognise this. UKCVFamily for example keep discussion in the group support focused to aid the well being of its members. There is always the worry that what are deemed lifelines for many will be lost when a group is shut down. Society would never consider it reasonable to shut down a cancer support group.

298. A poll of UKCVFamily members revealed that 74% had been censored when talking or posting about their adverse reaction to a Covid-19 vaccination on social media. All UKCVFamily members have to self censor, which we will talk more about later in this section.

299. UKCVFamily members have had their Facebook accounts restricted when posting about their adverse reaction, they have been prohibited from commenting or posting for a set amount of time,or they have been 'shadowbanned' [CC/286a - INQ000377610, CC/286b - INQ000377611, CC/286c - INQ000377612, CC/286d - INQ000377613, CC/286e -

INQ000377614, CC/286f - INQ000377615, CC/286g - INQ000377616, CC/286h - INQ000377617, CC/286i - INQ000377618, CC/286j - INQ000377619, CC/286k- INQ000377620, CC/286l - INQ000377621, CC/286m - INQ000377622, CC/286n - INQ000377623, CC/286o INQ000377624, and CC/286p - INQ000377625).

300. Shadow banning is where a social media account is made invisible to other users by limiting the reach and engagement of content posted. The user is not notified of the ban thus the term 'shadow ban' has been coined. In the case of the vaccine-injured, it can be an extremely alienating experience, cutting them off, virtually, from their only source of support.

301. Although social media giants such as Facebook, Instagram and Tik Tok deny that Shadow banning is real, many other people have experienced it. An article in the Washington Post says "Shadowbanning is real. While the term may be imprecise and sometimes misused, most social media companies now employ moderation techniques that limit people's megaphones without telling them, including suppressing what companies call "borderline" content." [CC/287 - INQ000377626]. Many other people have experienced shadow banning on social media including women's health advocates who have been subjected to it for using the words 'period' and 'vulva', LGBTQ artist, Michael Kerschner, and users posting content supporting the black lives matter movement. [CC/288 - INQ000377627, CC/289 - INQ000377628, and CC/290 - INQ000377630]

302. Many UKCVFamily members are bed or housebound so social media can be their only form of interaction with others. It is extremely distressing for our members to have restrictions placed on their social media accounts for talking about their adverse reaction and related health conditions.

303. Social media posts by our members mentioning their adverse reaction, that were deemed acceptable, were then subjected to 'banners'. These banners were placed on the content regularly.

304. A BBC article from March 2021 [CC/291 - INQ000377631] Anti-Covid vaccine tweets face five-strikes ban policy describes how users were to face locks on their accounts.Twitter introduced a five strikes and then permanent ban policy. Twitter also said it would begin applying labels to tweets that it believes "may contain misleading information" about Covid-19 vaccines that it has not deemed to be serious enough to warrant removal. The article goes on to explain how Twitter 'will label those that only contain misleading information about the safety of the treatments, or that make other debunked claims about adverse impacts'. Many of our members experienced this first hand only for the adverse reactions to be fully acknowledged later.

305. An article in the Guardian titled 'Facebook bans misinformation about all vaccines after years of controversy' [CC/292 - INQ000377632] confirmed a change in approach by social media companies clamping down on anyone who

was critical of the Covid 19 vaccine program.Those who spoke about their experiences of their own vaccine injury or bereavement on social were faced with bans for spreading 'misinformation'.

306. In 2021, a video was produced by people who had suffered adverse reactions, around the world which you can still watch [CC/293 - INQ000377633]. It was a desperate plea for help, many of us had been suffering with little to no help with our symptoms. The video starts with the words "We are a growing group of thousands of people who have been injured by the Covid 19 vaccine. We did our part to support and protect our families, friends, communities…you ..Now we need your help."

307. The video has a banner placed under it by YouTube, which when clicked on, redirects the viewer to the NHS page for information about Covid-19 services but nowhere on that page does it explain what to do if you think you've had, or are having, an adverse reaction.to a Covid vaccine [CC/294 - INQ000377634]. UKCVFamily would like the Inquiry to ask why banners used on social media posts relating to adverse reactions didn't include information to signpost the viewer for help or more information about adverse reactions.

308. Account restrictions on social media can also be in the form of time limited restrictions such as disallowing comments or posts for a set time period and UKCVFamily members have also faced such restrictions. Sometimes an 'Account Warning' is given which means if the account holder 'offends' again

then they will face a more permanent ban from the site [CC/286a - INQ000377610 and CC/286h - INQ000377617]. While UKCVFamily realise that social media needs to be regulated, it is apparent that the algorithms and methods used to do so at this time are unfairly censoring vulnerable and marginalised groups of people.

309. In November '21 a UKCVFamily member posted an article written by the British Medical Journal [CC/295 - INQ000377635] and within a few hours, UKCVFamily Facebook page had a warning placed on it by Meta claiming that we had violated Facebook's fact checking service [CC/296 - INQ000377636]. The BMJ had many warnings about this and subsequently wrote an open letter to Mark Zuckerberg about the censorship of their article raising 'serious concerns'. In this letter the BMJ said "*The BMJ commissioned an investigative reporter to write up the story for our journal. The article was published on 2 November, following legal review, external peer review and subject to The BMJ's usual high level editorial oversight and review."* The letter goes on to say "*But from November 10, readers began reporting a variety of problems when trying to share our article. Some reported being unable to share it. Many others reported having their posts flagged with a warning about "Missing context ... Independent fact-checkers say this information could mislead people." Those trying to post the article were informed by Facebook that people who repeatedly share "false information" might have their posts moved lower in Facebook's News Feed. Group administrators where the article was shared received messages from Facebook informing them that such posts were "partly false."* The letter

concluded with "*We hope you will act swiftly: specifically to correct the error relating to The BMJ's article and to review the processes that led to the error; and generally to reconsider your investment in and approach to fact checking overall."* [CC/297 - INQ000377637]

310. A UKCVFamily video, created specifically to support our members entitled "Kindness" [CC/298 - INQ000377638] was removed by YouTube for citing 'medical misinformation', [CC/299 - INQ000377639], it was a conversation between Ms Crichton and Suzanna Newell. Both of whom have been clinically diagnosed with "Adverse reaction to a Covid-19 vaccine". In the conversation they talk about how being kind to others is important and their symptoms at that time. After an appeal it was reinstated but upon reading YouTube's policies on medical misinformation we found contradictory terms; "We do not allow content that denies the existence of specific health conditions." So, in effect YouTube broke their own rules by removing the content.

311. A parliamentary rapid response dated 26th April 2021 [CC/300 - INQ000377642] stated "Social media often amplifies misinformation and allows it to spread quickly to a large number of people, with studies showing that misinformation spreads much faster than factual information online." The response goes on to say "The main public health concern around vaccine misinformation is the risk of it leading to a reduction in vaccine uptake." The rapid response mentions nothing about signposting people to information regarding adverse reactions to

a Covid-19 vaccine, nor in the event of suffering from one, what they should then do.

312. The rapid response article goes on to explain how social media companies are tackling misinformation:

"*More recently, some social media companies have taken specific action to counter vaccine misinformation, for example: In February 2021, as part of its wider policies on coronavirus misinformation, Facebook announced that it would expand its efforts to remove false information about COVID-19 vaccines (and vaccines more broadly). The company said it would label posts that discuss COVID-19 vaccines with additional information from the WHO. It also said it would signpost its users to information on where and when they can get vaccinated. Facebook is applying similar measures on Instagram.*

In March 2021, Twitter began applying labels to tweets that may contain misinformation about COVID-19 vaccines. It also introduced a 'strike' policy under which users that violate its COVID-19 misinformation policy five or more times will have their account permanently suspended.

YouTube announced a specific ban on COVID-19 anti-vaccination videos in October 2020. It committed to removing any videos that contradict official information about the vaccine from the World Health Organization. In March, the company said it had removed more than 30,000 misleading videos about the COVID-19 vaccine since the ban was introduced."

313. UKCVFamily members have been subjected to being labelled as 'misinformation' as you can clearly see from these strategies undertaken by the government in conjunction with social media executives. UKCVFamily ask the Inquiry to investigate whether 'misinformation' and fact checking policies that are put in place to safeguard the public are actually harming the public in some cases, especially marginalised groups of people such as the vaccine-injured and bereaved, LGBTQ and BAME communities.

314. On the 8th of November 2020, the government agreed on a 'package of measures to reduce vaccine misinformation' and on the .gov website it is reported that "*Digital Secretary Oliver Dowden and Health Secretary Matt Hancock have agreed with social media platforms new measures to limit the spread of vaccine misinformation and disinformation and help people find the information they need about any COVID-19 vaccine.*" [CC/301 - INQ000377643] Yet nowhere does it seem to have been recommended that genuine vaccine adverse reactions should be recognised as legitimate by social media companies nor do Oliver Dowden MP nor Matt Hancock MP discuss how social media should signpost members of the public who may have had, or be having, an adverse reaction to a Covid-19 vaccine.

315. Rebecca Stimson, Facebook's Head of UK Public Policy, said in this.Gov article [CC/301 - INQ000377643] :

"*We're working closely with governments and health authorities to stop*

harmful misinformation from spreading on our platforms. Ads that include vaccine hoaxes or discourage people from getting a vaccine are banned, we remove harmful misinformation about Covid-19 and put warning labels over posts marked as false by third party fact checkers. We're also connecting people to accurate information about vaccines and Covid-19 whenever they search for these topics. In the first months of the pandemic we directed more than 3.5 million visits to official advice from the NHS and UK government and we're pleased to continue to support public health efforts."

316. UKCVFamily feel the Inquiry would benefit from seeking information from Oliver Dowden MP, Matt Hancock MP and Rebecca Stimson regarding how social media policy around adverse reactions to a Covid 19 vaccination were discussed at these meetings to ascertain how these policies would affect those who may suffer or had suffered an adverse reaction. If sign-posting to medical advice for those suffering a suspected adverse reaction to a Covid 19 vaccination wasn't included in discussions, we would like the Inquiry to ask why.

317. An article featuring Ms Pover by The Express titled "Compensation denied to hundreds of Covid vaccine victims suffering severe side effects' [CC/500 - INQ000377887, CC/302b - INQ000377645, CC/302c - INQ000377646, CC/302d - INQ000377647, and CC/302e - INQ000377648] was shared by Ms Pover herself and Facebook subsequently gave her an account warning. Ms Pover was not given an option to dispute the decision and her account shadow

banned for some time after. This can be not only isolating as mentioned previously but can also affect that person's business, in Ms Pover's case, her Facebook account is linked to her pickle business which is her households main source of income.

318. Continuing the description of 'Censorship' on the Oxford Reference website says "*4. Self-censorship is self-regulation by an individual author or publisher, or by 'the industry'. Media industries frequently remind their members that if they do not regulate themselves they will be regulated by the state. Self-censorship on the individual level includes the internal regulation of what one decides to express publicly, often attributable to conformism.*"

319. UKCVFamily members self censor for fear of repercussions. Members have become used to self censorship and often it is so ingrained now that I receive emails from members that are still written in code. And vaccine injury support groups aren't the only groups self censoring on social media. An epilepsy support group was closed due to its members talking about vaccine adverse reactions they'd experienced [CC/303 - INQ000377649]. The UK Migraine group uses code words too instead of the word vaccine and many other groups for varying health conditions will not permit members to talk about vaccines at all.

320. Self censorship can be imposed due to hate speech and online bullying as well. Many UKCVFamily members have been subjected to cruel and hateful attacks

by others for speaking about their adverse reaction or bereavement both publicly, on social media and through private messaging. These attacks may only be in words but can be extremely upsetting especially when you are acutely unwell with frightening symptoms.

321. Comments and messages made to members of our group when talking about their Covid vaccine adverse reaction symptoms range from calling the vaccine-injured and bereaved liars and asking us to show our medical records to prove our illness, through to those who tell us we've been experimented on and that we are going to die. Recently Ms Pover had a message telling her to make a will as she will only have a few years to live, adding that she now has Aids. Videos are also sent to us, telling us about how our bodies are now damaged beyond repair and that we are going to die [CC/304 - INQ000377650]. I'd like to remind the Inquiry that vaccine injury isn't well researched and many doctors can't help us with these frightening symptoms. Many of the vaccine injured have gone to sleep at night with terrifying symptoms, not knowing if they would wake the next day and doctors can't tell us exactly what is happening. These videos compound that trauma.In other cases members have been told that by talking about their adverse reaction they are 'putting people off' from being vaccinated. The vaccine injured are often asked to produce their medical records to prove the cause of their illness. Instead of responding in a kind way, many people react in a very inappropriate, emotionally detached way when connecting with someone who is vaccine-injured or bereaved. The impact this has on the psychological well-being of someone suffering an adverse reaction is detrimental and many times those

running UKCVFamily receive messages from distraught members after being subjected to such behaviour.

322. Other examples of this include one of our members' teenage child who reached out on a post about vaccines, looking for some sort of help or support regarding their mum's sudden illness due to an adverse reaction to a Covid 19 vaccination. Our member (their mum) said they were 'harshly cut down' and as a result they don't discuss their mum's disability now, not even with friends. Another example is UKCVFamily member, Simon Clark who has been awarded the Vaccine Damage Payment Scheme. He was attacked online about his award from the scheme with comments such as *"I'd prefer you to stop defrauding the good people of this country and taking their hard earned tax money… you fraud!"* [CC/305a - INQ000377651 and CC/305b - INQ000377652).

323. One symptom that is particularly frightening that some of our members have or had, especially early on in their illness, are tremors. These tremors can come on suddenly and violently and be particularly frightening for the person suffering them. When some of the vaccine-injured community posted videos of these tremor episodes online, a targeted bullying campaign trended with influencers and well-known brands such as Duolingo mocking the vaccine-injured [CC/306a - INQ000377653, CC/306b - INQ000377654, CC/306c - INQ000377655, CC/306d - INQ000377656, CC/306e - INQ000377657, CC/306f - INQ000377658, CC/306g - INQ000377659, and CC/306h - INQ000377660].

The Duolingo post alone amassed 10.2 million views [CC/307a - INQ000377661 and CC/307b - INQ000377662] and has yet to be removed by the company nor have they offered any apology. Videos of items and people shaking were posted with the hashtag #ThanksPfizer, ridiculing the tremors experienced by the vaccine-injured. Many of these cruel videos are still visible on Twitter, Facebook, Tik Tok and Instagram. BuzzFeed, an online magazine stated "*The TikTok has amassed more than 7.6 million views and nearly 690,000 comments like*: "*I'm in agony every day, ever since I got my booster shot I can't stop doing the cha cha slide*." "*I got mine and I can't stop twerking. Please pray for me*." "Since Covid vaccine, everyday I'm shuffling." *"I got mine and now I can't stop doing the worm. " life's a nightmare." "I'm so glad people are finally talking about this. I haven't been the same since I got da jabby jabby, now I only do the stankiest of legs. "The jokes are endless."* [CC/308 - INQ000377663]

324. UKCVFamily ask the Inquiry to investigate why it was deemed acceptable by social media companies to allow a targeted bullying campaign of marginalised, disabled and unwell people, would this be permitted in any other similar situation?

a. Censorship of vaccine injuries extends to the culture within the NHS as a workplace and patient as we have mentioned previously in this document. Dr Steve James, consultant anaesthetist at Kings College Hospital, felt compelled to speak when interviewed by Sajid Javid MP in January 2022 [CC/309 -

INQ000377664). He said he didn't want to take the Covid 19 vaccination and listed reasons why. He was subsequently fact checked by a number of mainstream media articles and labelled *"The poster boy for the anti-vax movement"* by The Daily Mail [CC/310 - INQ000377666]. This was a doctor who had worked during the pandemic on the frontline, who had genuine concerns. UKCVFamily believe that legitimate concerns should not be labelled as being *'anti'* anything, dialogue should be encouraged to elicit proper informed consent. Dr Steve James may be able to assist the Inquiry to learn more about the concerns of NHS staff regarding vaccination and how they were handled internally and also by the media.

325. An NHS occupational therapist that spoke confidentiality to UKCVFamily said that she had been escorted from the hospital where she had worked for speaking with a patient about their adverse reaction. UKCVFamily would like the Inquiry to investigate the possibility that NHS staff were being actively discouraged to talk to patients regarding adverse reactions to a Covid-19 vaccination. Was this at ground staffing level or managerial? How were conversations around vaccine damage managed within the NHS?

326. Another NHS worker spoke to UKCVFamily and had been subjected to a disciplinary investigation because they had raised concerns about how the vaccine-injured were being treated during a meeting about the spring booster campaign.

327. UKCVFamily members have told us that nurses have readily admitted that 'they are seeing a lot of us' and that while some doctors and consultants are very helpful within their remit (as there are no NHS pathways that remit can be very limited) they often won't put the diagnosis in writing and just say it verbally. UKCVFamily members have spoken of doctors speaking in hushed tones about their diagnosis. UKCVFamily members have also found that they have had to have their medical records corrected as they have been wrongly diagnosed on paper with "Post Covid Syndrome" when they were previously verbally diagnosed with an adverse reaction to a Covid vaccine.

328. Wherever the vaccine-injured turn they feel they are faced with censorship. One such example is the National Covid Memorial Wall in London representing those who lost their lives during the pandemic. Those in our vaccine bereaved community painted purple hearts on an empty area on the wall to respectfully remember their loved ones lost to the vaccine. The organisers of the wall removed the purple hearts and any mention of the vaccine was quite literally wiped away [CC/311a - INQ000377667 and CC/311a INQ000377668). UKCVFamily feel that those who lost their lives to the vaccine should be respected as we would any other death during the pandemic. This level of censorship does incredible harm to those already in the midst of such terrible grief.

329. Vaccine injury censorship poses significant risks to public health and transparency. When information related to vaccine injuries is suppressed or censored, it undermines trust in the healthcare system and discourages open dialogue. This lack of transparency can make it difficult for individuals to make informed decisions about their health.

330. If the NHS isn't able to provide us adequate support and healthcare professionals feel unable to speak about vaccine adverse reactions, the vaccine-injured are vulnerable to other forms of misinformation and are left open to abuse in other ways. The Covid-19 vaccine injured have been left susceptible to fraudsters, many 'treatments' costing hundreds of pounds each. UKCVFamily had to post some informal safeguarding advice to its members in early 2022 with regards to testing and treatments after a suspicious testing facility was offered to its members [CC/312 - INQ000377669]. This shows the desperate need for proper support and research for the vaccine-injured in the UK.

331. UKCVFamily urge the Inquiry to question the involvement of the Government's Counter Disinformation Unit in the censorship of its members and the wider vaccine-injured and bereaved community.

332. The Covid-19 vaccine-injured and bereaved throughout the world have found each other online, and established country-specific and international groups through which members share practical information and emotional support. Facing

social stigma for talking about their symptoms, for some members these groups are the only places where they feel safe enough to speak freely.

ROLLOUT IMPLEMENTATION

333. When examining rollout implementation we will look at who was targeted to receive the vaccine, who and how many actually received a vaccine at each stage of the rollout, what exactly they received and how this was communicated to them, who administered the vaccines, and how the vaccines were administered. Matt Hancock MP said: "*This vaccine will not be used for children. It hasn't been tested on children. And the reason is that the likelihood of children having significant detriment if they catch Covid-19 is very, very low. So, this is an adult vaccine, for the adult population."* [CC/313a - INQ000377670]

334. It should be noted that planning for potential adverse reactions to Covid-19 vaccines, is silent in the document, 'Investigations into preparations for potential COVID-19 vaccines' produced by the National Audit Office [CC/313b - INQ000283340].

335. The government website's article entitled "*COVID-19 vaccination first phase priority groups*" (updated 23 April 2021, CC/314 - INQ000377672), listed those targeted by the vaccine rollout in the following order:

a. Residents in a care home for older adults and staff working in care homes

for older adults

b. All those 80 years of age and over and frontline health and social care workers

c. All those 75 years of age and over

d. All those 70 years of age and over and clinically extremely vulnerable individuals (not including pregnant women and those under 16 years of age)

e. All those 65 years of age and over

f. Adults aged 16 to 65 years in an at-risk group (see clinical conditions below)

g. All those 60 years of age and over

h. All those 55 years of age and over

i. All those 50 years of age and over

j. Rest of the population (to be determined)

336. By summer that year, rollout implementation included all adults. By spring 2022, rollout implementation included all children from the age of 5 years, and later included all children from the age of six months.

337. Guidance has changed throughout the rollout, regarding the period of time necessary between vaccinations. A representative of the Joint Committee on Vaccination and Immunisation (JCVI) could provide the Inquiry with more

information regarding the changes in recommendations for the timings of vaccinations, what the reasons for the changes in recommendations were, and whether there is any relevance to adverse reactions.

338. The JCVI could also provide more information on the justification for their recommendations on eligibility and prioritisation, the ethics of prioritisation decisions, and the impact that vaccination ultimately has on particular groups such as those with comorbidities.

339. According to the UK government website updated on 6 April 2023, uptake in the UK was as follows:

a. 53,813,491 people had a first dose,

b. 50,762,968 had a second dose

340. Those numbers were reported up to 11 September 2022. That leaves 3,050,523 who stopped after the first — 6% of those who received the first vaccine. Over three million people in the UK didn't come forward for the second part of what was clearly marketed as a two-part vaccine course. One of our members conducted an informal survey within their social network and concluded that 85% of their acquaintances who did not receive the second did so because of how they felt after the first. However, we have been unable to find any reliable information regarding why over three million people, who were willing to take the first dose, were not willing to take the second. This is something that we believe requires urgently investigating. [CC/315 - INQ000377673]

341. We are concerned about — as the rollout continued to be implemented — how many people went on to have further vaccines despite having become unwell after a previous one. Many UKCVFamily members report being urged by healthcare practitioners to have further vaccines, despite already experiencing adverse reactions. A survey we ran of our members showed that of those who had a further vaccine, despite already having symptoms indicating a possible adverse reaction, 99% reported getting worse. Did the rollout implementation include guidance to healthcare providers on how to handle patients who were showing signs of ongoing illness and/or were concerned about how any previous vaccines may have affected their health? Or was the focus solely on getting as many vaccines out as possible? More information regarding rollout guidance to healthcare staff is required to get answers to these questions.

342. In examining the number of people who participated in the rollout, it may be useful to acknowledge that in a population of around 67 million, around 13 million people did not have any Covid-19 vaccines at all (just over 19%, or one in five people chose not to be vaccinated against Covid-19).

343. An ONS survey *Coronavirus vaccine hesitancy in younger adults: June 2021* found the reasons for people aged 16–29 choosing not to have the Covid vaccine included distrust of the vaccine (safety and content), distrust of government and authorities encouraging take up, concern about side effects

(including on fertility), and the belief that the vaccine was unnecessary for those at low risk of harm from the virus. [CC/316 - INQ000377674]

344. As we have discussed previously in this document, the government's way of attempting to implement the rollout appears to have been promoting fear and/or guilt, and offering freebies (even food) and discounted goods and services. We are concerned that this method of encouraging vaccination may well have contributed to the general public's increased lack of trust in the government and other institutions. More information on the body in charge of promoting the vaccine rollout would be useful here.

345. UKCVFamily ask if the Covid-19 vaccine rollout implementation included an intention to inform those getting vaccinated exactly what they were getting vaccinated with? Were the individual ingredients discussed so that the public could make an informed decision, for example in the AstraZeneca vaccine:

a. Polysorbate 80 (E 433), which Naimi et al [CC/317 - INQ000377675] researched in their paper, *Direct impact of commonly used dietary emulsifiers on human gut microbiota* published in the *Microbiome* journal on 22 March 2021. The paper stated, "*Two synthetic emulsifiers in particular, carboxymethylcellulose and polysorbate 80, profoundly impact intestinal microbiota in a manner that promotes gut inflammation and associated disease states*." Did the rollout of Covid-19 vaccines include having specific conversations with those with gut issues about the potential

for those issues to be impacted by one of the vaccine's ingredients?

b. Ethanol. Did the rollout implementation include having specific conversations with alcoholics so that they were aware of the alcohol content, however minimal?

c. Disodium edetate dihydrate (EDTA). EDTA is listed on the pharmaceutical information website drugs.com as having multiple drug interactions and can cause increased symptoms for those with cardiovascular or renal dysfunction, or seizures amongst others. We have seen all three of these specific symptoms within the vaccine-injured community.

d. Polyethylene glycol. Some of our members have been found to be allergic to PEG. An article in Science Mag [CC/318 - INQ000377676] commenting on the relationship between the Pfizer and Moderna vaccines and PEG said "*PEG has never been used before in an approved vaccine, but it is found in many drugs that have occasionally triggered anaphylaxis—a potentially life-threatening reaction that can cause rashes, a plummeting blood pressure, shortness of breath, and a fast heartbeat. Some allergists and immunologists believe a small number of people previously exposed to PEG may have high levels of antibodies against PEG, putting them at risk of an anaphylactic reaction to the vaccine.*"

346. UKCVFamily are concerned that the above ingredients — plus others that may not have been listed on any published information — may not have been adequately communicated to the public during rollout implementation.

Representatives of the vaccine manufacturers should be able to produce for the Inquiry a detailed and comprehensive list of all ingredients — however minimal — so that any possible connections with adverse reactions can be fully investigated.

347. Continuing questions about what efforts were made to fully inform the public about the vaccines as a concerted part of the rollout implementation, AstraZeneca stated that its vaccine was "*Produced in genetically modified human embryonic kidney (HEK) 293 cells.*" Was this something that was effectively communicated to the general public? [CC/319 - INQ000377677]

348. The Department of Health's *Reference guide to consent for examination of treatment* (second edition published 2009, original edition published 2001) "*... provides a guide to the legal framework that all health professionals need to take account of in obtaining valid consent for any examination, treatment or care that they propose to undertake.*" [CC/320 - INQ000377679]. In the context of the Covid vaccine rollout implementation, it is worth noting the following:

a. "*A healthcare professional (or other healthcare staff) who does not respect this principle may be liable both to legal action by the patient and to action by their professional body. Employing bodies may also be liable for the actions of their staff.*"

b. "*Further, if healthcare professionals (or other healthcare staff) fail to obtain proper consent and the patient subsequently suffers harm as a result of treatment, this may be a factor in a claim of negligence against the*

healthcare professional involved."

c. "*Poor handling of the consent process may also result in complaints from patients through the NHS complaints procedure or to professional bodies.*"

d. "*Where a patient has the capacity to make decisions about treatment, they have the right to refuse treatment – even when the consequences of such decisions could lead to their death.*"

e. *"Chester v Afshar. The House of Lords judgement held that a failure to warn a patient of a risk of injury inherent in surgery, however small the probability of the risk occurring, denies the patient the chance to make a fully informed decision. The judgement held that it is advisable that health practitioners give information about all significant possible adverse outcomes and make a record of the information given.*"

f. "*A person is entitled to make a decision which may be perceived by others to be unwise or irrational, as long as they have the capacity to do so.*"

g. "*To be valid, consent must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment. Such pressure can come from partners or family members, as well as health or care practitioners.*" See points raised in Public Messaging (above) regarding the fear, guilt, and free food and discounts offered in exchange for vaccination.

h. "*… threats such as withdrawal of any privileges, loss of remission of sentence for refusing consent or using such matters to induce consent may well invalidate the consent given, and are not acceptable.*"

i. In Chester v Afshar, a majority of the House of Lords held that a neurosurgeon who failed to warn a patient of the small risk of injury inherent in surgery, even if properly performed, was liable to the patient when that risk materialised, even though the risk was not increased by the failure to warn and the patient had not shown that she would never have had an operation carrying the same risk.The Lords departed from the traditional 'but for' test of causation on the basis that, exceptionally, policy and justice required a modification to causation principles. The fundamental principle underlying the decision was the right of a patient to make an informed choice as to whether – and if so, when and by whom – to be operated on."

i. "*The GMC provides guidance on the type of information that patients may need to know before making a decision, and recommends that doctors should do their best to find out about patients' individual needs and priorities when providing information about treatment options. It advises that discussions should focus on the patient's 'individual situation and risk to them' and sets out the importance of providing the information about the procedure and associated risks in a balanced way and checking that patients have understood the information given".*

j. "The same legal principles apply when seeking consent from a person for research purposes as when seeking consent for investigations or treatment. GMC guidance advises that patients 'should be told how the proposed treatment differs from the usual methods, why it is being offered,

and if there are any additional risks or uncertainties'. Clinical trials are covered by the Medicines for Human Use (Clinical Trial Regulations) 2004.26 40. If the treatment being offered is of an experimental nature, but not actually but not actually part of a research trial, this fact must be clearly explained to a person with capacity before their consent is sought, along with information about standard alternatives. It is good practice to give a person information about the evidence to date of the effectiveness of the new treatment, both at national/international levels and in the practitioner's own experience, including information about known possible side-effects".

349. The rollout implementation was not conducted according to the aforementioned reference guide. We understand that, given that all involved in the rollout implementation — the government, manufacturers, vaccinators, prescribers, and doctors — were granted the statutory immunity for a vaccine given temporary emergency authorisation (Reg 345 of the Human Medicines Regulations 2012, CC/232 - INQ000377551). Clinical trials were still being undertaken when the Covid-19 vaccines were rolled out to the public. We are concerned that this immunity led to a complete lack of effort in obtaining informed consent.

350. The author of the reference guide — Marjorie Thorburn of the Health, Science and Bioethics Division — may be able to provide input into how much the rollout

implementation may or may not have made appropriate effort to obtain consent, and perhaps give some insight into the ethics of removing the necessity for gaining informed consent. Another expert that may be able to assist is Dr David Townend who was a member of the Emerging Science and Bioethics Advisory Committee until the parliamentary committee closed in 2014.

351. UKCVFamily are concerned that those involved in the rollout were not kept up to speed with the adverse reactions that were becoming apparent as the rollout implementation continued. For example, in January 2022, one of our members visited their local vaccination centre, and asked the vaccinators about possible adverse reactions. The vaccinator handed them a leaflet but couldn't answer any questions. When offered information, the vaccinator said, "I don't want to know" and later "We're only allowed to say what's on our screen."

352. Patient Information Leaflets for Covid vaccines have changed since the rollout began. For example, according to *Regulation 174 Information for UK recipients package leaflet: Information for the recipient,* published on the government website, the number of words as of 3rd March 2021 listed on the AstraZeneca leaflet and related to possible side effects was 231. Exactly one year later, on 3rd March 2022, the same leaflet contained approximately six times more (1408) words relating to possible side effects. Significant differences are as follows:

a. **2021:** No reference to possible allergies to active substances or ingredients. **2022:** Individual instructed NOT to have the vaccine *"If you*

are allergic to any of the active substances or any of the other ingredients listed ...”

b. **2021:** No references to blood clots, platelets, or thrombosis with thrombocytopenia syndrome. **2022:** Individual instructed NOT to have the vaccine “*If you have had a blood clot occurring at the same time as having low levels of blood platelets (thrombosis with thrombocytopenia syndrome, TTS) after receiving the vaccine*.”

c. **2021:** No references to capillary leak syndrome. **2022:** Individual instructed NOT to have the vaccine “*If you have a previous diagnosis of capillary leak syndrome.”*

d. **2021:** No wording instructing anyone to NOT have the vaccine, for any reason. **2022:** Three specific circumstances (see above) listed where individuals are instructed NOT to have the vaccine.

e. **2021:** Individual instructed to tell doctor/pharmacist/nurse before vaccination *“If you have ever had a severe allergic reaction after any other vaccine injection.*” **2022:** Sentence expanded so that individual is instructed to tell doctor/pharmacist/nurse before vaccination “*If you have ever had a severe allergic reaction after any other vaccine injection or after you were given COVID-19 Vaccine AstraZeneca in the past.”* The leaflet then goes on to explain what the signs of an allergic reaction may be: *“itchy skin rash, shortness of breath and swelling of the face or tongue,*” and is followed with instructions, “*Contact your doctor or healthcare professional immediately or go to the nearest hospital emergency room right away if*

you have an allergic reaction. It can be life-threatening."

f. **2021:** No reference to heparin-induced thrombocytopenia and thrombosis or a blood clot in the sinus veins in the brain. **2022:** Individual instructed to tell doctor/pharmacist/nurse before vaccination *"If you have ever had a condition known as heparin-induced thrombocytopenia and thrombosis (HITT or HIT type 2), or a blood clot in the sinus veins in the brain ..."*

g. **2021:** No reference to Guillain-Barré syndrome. **2022:** Individual instructed to tell doctor/pharmacist/nurse before vaccination *"If you previously had Guillain-Barré syndrome (temporary loss of feeling and movement) after being given COVID-19 Vaccine AstraZeneca."*

i.**2021:** No reference to blood disorders. **2022:** 300 words on *"Blood disorders*," including mention of excessive clotting, excessive bleeding, life-threatening or fatal outcomes, brain clots, severe headaches, blurred vision, confusion, difficulty with speech, weakness, drowsiness or seizures (fits), rashes, bruises, shortness of breath, chest pain, leg swelling, leg pain or persistent abdominal (tummy) pain.

h. **2021:** No reference to capillary leak syndrome. **2022:** 74 words on "*capillary leak syndrome,"* including mention of rapid swelling of the arms and legs, sudden weight gain, and feeling faint (low blood pressure).

i. **2021:** No reference to neurological events. **2022:** 52 words on "*neurological events,"* including mention of weakness and paralysis.

j. **2021:** No reference to symptoms of a severe allergic reaction. **2022:** Explanation of what may indicate a severe allergic reaction: feeling faint or

light-headed; changes in your heartbeat; shortness of breath or wheezing; swelling of your lips, face, or throat; hives or rash; nausea or vomiting; stomach pain.

k. **2021:** No reference to side effects after the first or second doses. **2022:** "*In clinical studies with the vaccine, fewer side effects were reported after the second dose and those that were reported were milder in nature when compared to after the first dose.*"

l. **2021:** "*Very common,*" "*Common,*" and "*Uncommon*" side effects listed. 107 words total. **2022:** "*Very common,*" "*Common,*" "*Uncommon,*" "*Rare,*" "*Very rare,*" *and "Not known"* side effects listed. 425 words total.

353. UKCVFamily are concerned about what has happened to the people who were vaccinated before those changes were made to the Patient Information Leaflets. The new information reflected in the updated leaflets needs to be used to support the treatment of those that are still suffering from vaccines administered before the leaflets were updated. We believe that anyone who has experienced any of the symptoms listed in the updated leaflets should:

a. at least have vaccination considered as a possible cause,

b. have thorough testing for the conditions that have now come to light as being related to vaccination,

c. have immediate treatment for their symptoms, and

d. have assistance from a medical professional in filing a Yellow Card report.

354. UKCVFamily are concerned that Patient Information Leaflets were not distributed according to The Human Medicines Regulations 2012 legislation. Only 19% of UKCVFamily members polled received a Patient Information Leaflet prior to Covid-19 vaccination, 33% were given it after they'd be given a Covid-19 vaccination and 48% were not given a Patient Information leaflet at all during the Covid-19 vaccination process.

355. UKCVFamily are concerned about how any storage problems during the rollout implementation may have affected the likelihood of the recipient suffering from an adverse reaction. On 8 December 2020 NHS England stated "*The life-saving vaccine is typically delivered by a simple injection in the shoulder but there is a complex logistical challenge to deliver from the manufacturers to patients. It needs to be stored at -70C before being thawed out and can only be moved four times within that cold chain ahead of use*" [CC/321 - INQ000377680]. It may be useful to examine records from the busiest vaccination sites in the UK, regarding how exactly they adhered to storage regulations, and what steps were taken when those regulations were inadvertently not adhered to.

356. It would also be helpful to know exactly in what ways the vaccine would have been affected if it were not stored correctly, and whether the vaccines would have had an increased chance of contributing to any possible adverse reactions. The manufacturers' records on how they developed their storage guidelines would be useful to the Inquiries' investigation of this matter and whether these

guidelines were strictly adhered to and/or what happened if things went wrong during storage.

357. Conditions of authorisation for the Covid-19 vaccines state: *"Any importation or manufacturing facilities located within the UK are authorised by the MHRA to handle Regulation 174 products."* *"All drug substance and drug product manufacture are in accordance with EU GMP and the Human Medicines Regulations 2012 (as amended) in facilities with current EU GMP certificates or other acceptable and suitable authorisation to MHRA."* [CC/322 - INQ000377681]

358. UKCVFamily are concerned that due to the pandemic and the 'flexibilities' allowed because of it, that there may have been no actual physical inspections of the facilities used to manufacture the vaccines. Did inspections of these facilities ever take place physically or were they all virtual. Virtual inspections are dictated by the company being inspected, not the inspectors. Do the MHRA have inspection reports to make sure there was compliance? What were the observations?

359. Taken from the Conditions for Authorisation for emergency supply under Regulation 174 for COVID-19 Vaccine AstraZeneca (Exhibit 333) "AstraZeneca are not only responsible for compliance with the conditions expressly applied to AstraZeneca in this authorisation but also, where the conditions apply legislation

or guidance that confers responsibilities on marketing authorisation holders, for compliance with any responsibility however worded that applies to a marketing authorisation holder in the applied legislation or guidance."

360. Good Manufacturing & Distribution Practice (GMDP) applied to the AstraZeneca conditional authorisation. The vaccination centres carried out Good Distribution Practice activities, UKCVFamily ask if they were licensed to do so? Or were changes made in light of the pandemic that exempted them and if so, did this have a negative effect on quality? Did they have a Wholesale Dealer's Licence (WDA(H)) to ensure they could safely import the vaccines and do the inventory control activities (such as stock records, re-labeling part finished vials etc). Was there a quality management system in place, with standard operating procedures? Did staff undertaking this have the necessary training, skills and expertise?

361. Referring to the 'UK Covid 19 vaccines delivery plan' [CC/334 - INQ000377683] "*In the United Kingdom, the vaccines will be delivered to designated NHS bodies or NHS contractors that have capacity to hold the vaccines. Thereafter, the NHS arrangements for the onward and (if different) final distribution of the products, and their final deployment, are still being developed, but the bodies responsible under NHS arrangements in each of the four countries for any aspect of the distribution or final deployment of the vaccine, and the relevant bodies in the Crown Dependencies and the United Kingdom's Overseas Territories, must*

comply, as conditions of this authorisation, with the conditions that are applicable to that aspect of the distribution or final deployment in this authorisation." Usually pre-pandemic, vaccines have been delivered to pharmacies by wholesale distributors that hold appropriate licences to do so. UKCVFamily are concerned that these wholesalers weren't used and instead the NHS took over this aspect when they had never done so before. Did they have the correct skills to deliver the vaccines correctly and were the conditions adhered to?

362. UKCVFamily are concerned about any potential role that specific batches may have in relation to adverse reactions. The World Health Organisation's *Covid-19 Vaccines: Safety Surveillance Manual on Monitoring and Responding to Adverse Events Following Immunization (AEFIS)*, published in 2020, [CC/221 - INQ000377539] states, "*For COVID-19 immunization-related AEFIs, in addition to standard information, it is important to record the brand name, the manufacturer, as well as the batch numbers*."

363. The MHRA's response published on 27 March 2023, *Freedom of Information request on specific batch numbers on the adverse reactions reported following the COVID-19 vaccinations (FOI 22/661)*, provided "*... details of the batch numbers that appear most often in the Adverse Drug Reaction (ADR) reports, including those with a fatal outcome, reported to the Yellow Card scheme in association with the COVID-19 Pfizer/BioNTech Vaccine, COVID-19 Vaccine AstraZeneca and COVID-19 Vaccine Moderna.*" [CC/336 - INQ000377685] We

would like to know whether:

a. there have been any concerns regarding specific batch numbers,

b. the MHRA have conducted any investigations into specific batch numbers, and

c. There have been any campaigns encouraging anyone who received those batches to notify their doctor or the Yellow Card System (much in the same way that the Food Standards Agency and food manufacturers are obliged to inform the public if there are any concerns).

364. On 11th March 2021, it was reported in The Guardian newspaper that "*Denmark, Norway and Iceland announced they were temporarily halting all AstraZeneca vaccinations to investigate the cases. Italy followed Austria, Estonia, Latvia, Luxembourg and Lithuania in banning inoculations with one particular batch of 1m doses that was sent to 17 countries."* [CC/337 - INQ000377686]. Although we have discussed batches elsewhere in this document, it's worth noting that the article goes on to say "*Italy's health authority said it was banning the use of the suspect batch after being notified of "some serious adverse effects", but stressed the move was precautionary and no link had been established with the vaccine."* And that "*Austria stopped using the batch on Monday when a 49-year-old nurse died of "severe blood coagulation problems" days after receiving an anti-Covid shot."* UKCVFamily would like the Inquiry to investigate if the UK administered any vaccinations from this particular batch and to identify this batch number.

365. UKCVFamily are concerned about who actually administered the vaccines during the rollout, whether the general public was aware that there were non-medical professionals administering them, how they were trained, what the likelihood of administration error was, and whether that may have contributed to any possible adverse reactions. As mentioned in the Introduction, Ms Crichton volunteered at a local mass vaccination centre and completed the online training to become a vaccinator. This training took a few hours online and then there was a practical half a day course which she never completed as she decided not to after becoming unwell and took a different voluntary role. Some of the other vaccinators that volunteered were NHS admin staff who had been trained in this way and had never vaccinated before.

366. Until January 2021, NHS Professionals National Bank™ (NHSP) were welcoming applications from anyone with a Level 3 NVQ in any subject (non-medical accepted) in order to participate in the rollout implementation. NHSP provided 20,000 vaccinators for the Covid vaccine rollout, and were partners in the mobile vaccination programme. Stephen J Collier was NHSP Chair during this period and would perhaps be able to provide more information regarding hiring and training of Covid vaccinators on behalf of the NHS.

367. According to the NHS Specialist Pharmacy Service *Information and guidance from across SPS on pharmaceutical aspects of COVID-19 vaccines' use*, the

following people were also permitted to vaccinate:

a. Non-registered HCPs (Healthcare Professionals);

b. Optometrists, opticians, non-registered and student optical professionals.

c. Osteopaths and Chiropractors.

d. Dentists.

368. The specific method by which the vaccines were delivered may provide some insight into possible reasons for adverse reactions, as indicated by Rzymski and Fal's research documented in their paper, *To aspirate or not to aspirate? Considerations for the COVID-19 vaccines*, published in PubMed 23 March 2022 [CC/338 - INQ000377687]. Their abstract states, "*Syringe aspiration when vaccinating intramuscularly was not recommended before the pandemic due to the lack of conclusive evidence that it provides any benefit. However, in vivo evidence suggests that intravenous injection of mRNA vaccine can potentially lead to myocarditis, while introducing adenoviral vector to bloodstream can possibly result in thrombocytopenia and coagulopathy. These rare reactions were recorded in humans following the administration of the COVID-19 vaccines. Although the syringe aspiration may increase the level of pain at the injection site, it represents a simple technique to decrease the risk of vaccine introduction into the vascular system and potentially decrease the risk of severe reactions to mRNA and adenoviral vaccines.*" UKCVFamily are concerned that the omission of aspiration during rollout implementation may have contributed to

adverse reactions and consider this to be worth further investigation.

369. Finally, when considering aspects of the rollout implementation, we need to examine the financial incentives that were offered to doctors for administering the vaccines, and the ethics involved in this practice. According to a letter dated 14 July 2021 to all GP practices from Dr Nikita Kanani (NHS England Deputy Senior Responsible Officer, COVID-19 Vaccination Programme and Medical Director for Primary Care) and Caroline Temmink (NHS England Director of Primary Care Vaccinations), payments were offered as follows:

"*… a payment of £12.58 will be made to the lead practice for the PCN grouping for administration of each vaccination to each patient. In addition, a payment of £10 shall be made to GP practices:*

For administration of each vaccination to each patient where that patient is:

- *resident in and receives the vaccination at a Care Home or other residential setting; or*
- *employed or engaged by a Care Home and receives the vaccination at that Care Home or other residential setting;*

For administration of each vaccination to each housebound patient.

If the vaccination is delivered in a hostel/hotel accommodation for the homeless, where it would not be possible for these patients to attend vaccination sites then

the £10 supplement can be claimed. Further additional reasonable costs funding will be available to PCN groupings delivering COVID-19 vaccinations in phase 3. Further guidance will be issued shortly, but the arrangements will be similar to the arrangements for phases 1 and 2. Additional reasonable costs funding will also be available to general practices delivering flu vaccination in 2021/22. [CC/339 - INQ000377688]

370. UKCVFamily are concerned that by offering GP practices incentives for administering Covid vaccines, that there may be a conflict of interests in their ability to provide medical advice with their patients' best interests at heart. This financial motivation may also contribute to a lack of motivation amongst GPs to acknowledge possible adverse reactions, to keep up to date with the latest research regarding possible adverse reactions, and to maintain a curious and sympathetic culture within their workforce.

371. GP practices are private businesses contracted to provide specific NHS services — the Covid vaccine rollout was a revenue source for these private businesses. We would like to look at how much GP practices earned from providing a service that was aggressively promoted by the government and the mainstream media, and about which any questioning was actively discouraged. We would also like to know how much of that revenue was set aside for dealing with those who suffered adverse reactions. We recommend gaining further information from the GP practices who facilitated the highest number of vaccinations in the UK.

372. UKCVFamily are also concerned that the financial incentives offered to GP practices as part of rollout implementation may have impacted the ability for employees to make a fully informed choice regarding their own vaccination. We will examine the topic of vaccination as a condition of employment or deployment in the next section.

VACCINATION AS A CONDITION OF DEPLOYMENT/EMPLOYMENT

373. 30% of our members cited work as being a reason they received the vaccine. We specifically consulted with members for whom their employers, managers, and in some cases colleagues, made it clear to them that — should they not be fully vaccinated against Covid — their job was at risk. In the case studies we have submitted as part of this document, several of our members mention the role that their employment had in their decision to be vaccinated.

374. A letter dated 6 December 2021 from NHS England — signed by NHS Chief People Officer Prerana Isaar, National Medical Director Professor Stephen Powis, Chief Nursing Officer for England Ruth May, Deputy SRO, COVID-19 Vaccination Deployment Programme & Medical Director for Primary Care Dr Nikki Kanani, and Chief Allied Health Professions Officer Suzanne Rastrick — stated that, "… *individuals undertaking CQC* [Care Quality Commission] *regulated activities in England must be fully vaccinated against COVID-19 no later than 1 April 2022 to protect patients, regardless of their employer, including secondary and primary*

care. The regulations will apply equally across the public (NHS) and independent health sector" and continued, "*The guidance reiterates the importance of continuing to have supportive 1:1 conversations with colleagues and supports employers in ensuring the best protection for vulnerable patients and staff in healthcare settings. Also attached is a supporting document curating useful tools to help increase vaccination uptake.*" [CC/340 - INQ000377690] Those who signed this letter could provide more information to the Inquiry regarding how anyone choosing not to be vaccinated should be treated in a non-discriminatory way.

375. The topic of mandatory Covid-19 vaccination as a condition of employment was debated in parliament after a petition raised 232,534 signatures in 2021 Parliamentary privilege

Parliamentary privilege

Parliamentary privilege

376.

Parliamentary privilege

377. Care home workers had already been required to be fully vaccinated by November 2021. A number of UKCVFamily members were part of this workforce.

378. On 27 January 2022 the BBC reported [CC/343 - INQ000377693] on *Covid vaccines: The unvaccinated NHS workers facing the sack*, stating that "*... around 80,000 unvaccinated NHS staff in England* [were] *being told if they work with patients and don't get a jab by next week they could be moved to a different role or even sacked.*" We would like to suggest that the experiences of the NHS staff who chose not to be vaccinated may be helpful to the Inquiry, in particular the campaigning group NHS 100k and Ryan Karter who started the above petition.

379. On 31st of January 2022, Sajid Javid, the then Secretary of State for Health and Social Care retracted the government's position on mandatory vaccination but not without first praising those NHS workers who had been vaccinated saying *"Since we launched the consultation on vaccination as a condition of deployment in the NHS and wider social care settings in September, there has been a net increase of 127,000 people working across the NHS who have done the right thing and got jabbed, becoming part of the 19 out of 20 NHS workers who have done their professional duty. "* Mr Javid then went on to say *"I have asked the NHS to review its policies on the hiring of new staff and deployment of existing staff, taking into account their vaccination status".* [CC/344 - INQ000377694]

380. The guidance for both care home workers and all CQC-regulated staff was withdrawn on 15 March 2022, although as of October 2023, the NHS website still states that "*NHS England and NHS Improvement are clear that colleagues have a professional duty to get vaccinated and that it remains the best line of defence against COVID-19.*"

381. Covid-19 vaccination as a condition of employment was a matter of individual policy for private institutions and companies.

382. Many UKCVFamily 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.

383. The NHS England guidance mentioned above, "*... reiterates the importance of continuing to have supportive 1:1 conversations with colleagues …*" however the experiences of some of our members cause grave concern. Methods by which employers communicated with employees about Covid vaccination were neither

supportive nor on a one-to-one basis, and could be construed as bullying, threatening, and intimidating. Our members describe treatment from their seniors as "*harassment*" and speak about feeling "*violated*" post-vaccine. We believe that the method by which employers communicated with their staff about Covid vaccination needs serious investigation.

384. According to UKCVFamily members, this method of pressuring employees began in October 2020, when the flu vaccine was "*aggressively*" pushed to care home staff who had never had a flu vaccine before. There was a general atmosphere of assumption that all staff would be getting a Covid vaccine in the following December, and very little room for discussion. Questions about the Covid vaccine were not encouraged, and senior staff did not seem to be well-informed about what the Covid vaccine entailed. There existed a general environment where everyone had to get a Covid vaccine as soon as possible. Allergic reactions to previous vaccines and lifetime advice not to take further ones were ignored, staff were made to watch videos about how they were expected to take all vaccines that were offered to them, and the constantly changing regulations created an atmosphere of panic and confusion amongst a workforce for whom their patients were incredibly important.

385. Those who chose not to take the Covid-19 vaccine received regular emails questioning their decision, and were requested to attend meetings on the pretext of helping their managers to understand the reasons behind their choice. These meetings became opportunities for senior staff to bully employees and suggest

that their future employment was at risk. One member recounts being in tears during these meetings and eventually giving in to what they considered to be serious pressure. One member in the private sector received weekly phone calls asking when they were going to be vaccinated so they could return to the workforce. They were told that they would not be offered further work until they were fully vaccinated. UKCVFamily ask the Inquiry if these behaviours at work due to Covid-19, would be classed as harassment and victimisation under the Equality Act 2010 [CC/345 - INQ000377695].

386. Pressure was put on people to be vaccinated even if they were hired post-rollout, despite the condition of vaccination never having been discussed during the interviewing process. For one of our members, managers regularly asked all staff to provide proof of their vaccination status, which contributed to a hostile environment that she had not been expecting when hired. It became easier to give in to the pressure.

387. In cases where people experienced ill health post-vaccine, employers continued to make it clear that they expected their employees to continue with vaccination until they were considered fully vaccinated. One of our members with 24 years of experience working in a private sector industry experienced pericarditis after a first vaccine, and the employer stopped offering any contract work and has not made any contact since. Lawyers have so far refused to get involved with this case.

388. The Inquiry has expressed interest in how these policies may have impacted vaccine uptake in general. While Covid vaccination was not legally mandated in the UK, the BBC article on 5 December 2021, *Mandatory vaccinations: Three reasons for and against*, [CC/346 - INQ000377696] provides an analysis of the impact on vaccine uptake. The article stated the following as reasons against mandatory:

a. "*... whatever a government does, it will face opposition ...*" stating that there will always be people who oppose anything a government makes compulsory, and quoting Vageesh Jain, a public health doctor at the Institute for Global Health at University College London, who stated that choosing not to vaccinate was an "*emotive response.*" The article did not acknowledge that there were a number of logical reasons — specifically relating to their individual health concerns — why people might choose not to vaccinate.

b. "'*For those who are afraid, who have no trust, for those whose assessment of risk is low — for them it is important that they are listened to and that their concerns are taken seriously,' Barbara Juen, a health psychologist at the University of Innsbruck…* " Our members who chose not to vaccinate due to what they considered employer pressure, did not feel that they were being listened to, and having got vaccinated anyway and suffered from an adverse reaction for which they have received no support, now have diminished trust in the healthcare system.

c. "*It could prove counterproductive.*" For some, vaccination as a condition of

employment has negatively impacted not just the rollout, but also vaccination in general, and even the whole healthcare system.

389. It should be noted that the BBC article introduces the topic of mandatory vaccinations from a position of instilling fear: "*If you are a French doctor, a New Zealand teacher or a Canadian government employee, getting your shots is essential to go to work. Indonesia can deny benefits to people who refuse jabs. Greece is making them compulsory for the over-60s. Austria is set to go further still, with a plan to introduce mandatory vaccinations for all by February. This would not mean Austrians being forcibly injected. There will be medical and religious exemptions. But the bulk of the remaining unvaccinated population face fines for not getting their shots.*" and does not mention adverse reactions at all, either in the past or the future, to the recipient or anyone close to them, as being a possible reason for anyone to be reluctant or unwilling to be vaccinated.

390. 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?

391. We have found that employers were not sympathetic or supportive to

UKCVFamily members who experienced adverse reactions as a result of choosing to have the Covid-19 vaccine in order to improve their work environment or to be able to continue to work.

a. Requests for reasonable adjustments to the work environment were denied resulting in reluctant and distressing resignations from people who loved their jobs, whereas government guidance states that "*Employers must make reasonable adjustments to make sure workers with disabilities, or physical or mental health conditions, are not substantially disadvantaged when doing their jobs.*"

b. The vaccine-injured have been dismissed on grounds of long-term ill-health or incapacity.

c. Another was instructed not to disclose to colleagues that they had experienced an adverse reaction.

d. For one of our members, it took a full year before the employer offered any kind of support for a vaccine-injured employee.

392. We believe that anyone who chooses to receive a vaccine or any other medical intervention as a result of instructions from their employer should be entitled to receive compensation in the same way that those who suffer from work-related injuries do.

393. UKCVFamily members are not alone in facing work place discrimination due to issues relating to Covid-19. A report from the TUC [CC/347 - INQ000377697]

found that 52% of people polled that suffered from Long Covid had suffered some form of discrimination or disadvantage because of their condition. The TUC are calling for Long Covid to be recognised as a disability under the Disabilities Act. Section 6 of the Equality Act 2010 outlines that a person has a *'disability'* if they have (i) a physical or mental impairment and (ii) which has a *'substantial'* and 'long-term' adverse effect on the ability to carry out normal day-to-day activities.

394. When looking at the criteria of section 6 of the Disabilities Act [CC/348 - INQ000377698] UKCVFamily believe that a severe ongoing adverse reaction to a Covid-19 vaccine should also be classed as a disability. This would give those suffering many more rights within the workplace and more chance that they may be able to resume their careers.

395. Government, NHS, and private company policies regarding vaccination have changed since the rollout began. UKCVFamily would like to know why those policies have changed and what measures have been implemented to support those who were:

a. harmed but continued to work,

b. harmed and resigned due to being unable to work,

c. harmed and had their employment terminated as result of being unable to work, or

d. terminated due to not adhering to those policies.

The policies have changed but there are people who are still living with the damage that those policies caused. This needs addressing.

396. We hope that the Inquiry will seriously consider ways of ensuring that employers support those who are harmed by their policies, but also consider the ethics of vaccination policies as a condition of employment in the first place.

NHS PREPAREDNESS TO MANAGE ADVERSE REACTIONS

397. We asked our members to rate how they felt the NHS — from a purely medical perspective — had treated them since they experienced an adverse reaction to the Covid vaccine. We asked them to rate on a scale of 0–10, with zero being extremely dissatisfied, and 10 being extremely satisfied. 90% gave a score of 5 or below, with 42% choosing zero (extremely dissatisfied). 8% said that they were extremely satisfied, and 2% did not seek help from the NHS. It is safe to say that almost all of our members have been shocked at how they have been treated by the NHS and its inability and unwillingness to acknowledge and support patients in managing an adverse reaction to the Covid-19 vaccine. It is also safe to say that the way that the NHS has responded to our conditions has made those conditions worse, and our ability to deal with them much more challenging than they already are.

398. Adverse reactions to pharmaceutical products are recognised in the UK by the Medicines and Healthcare products Regulatory Agency (MHRA). According to the MHRA's document [CC/349 - INQ000377699] Guidance on Adverse Drug Reactions: "*An adverse drug reaction (ADR) is a response to a medicinal product which is noxious and unintended. Response in this context means that a causal relationship between a medicinal product and an adverse event is at least a reasonable possibility. The reaction may be a known side effect of the drug or it may be new and previously unrecognised.*" Given that the Covid-19 vaccines were a pharmaceutical product that was newly introduced to the population, were NHS staff warned to:

a. specifically look out for new, unexpected side effects or adverse reactions, and

b. maintain the attitude that it was "*at least a reasonable possibility*" that any unexpected ill-health experienced post-vaccination may have been related to the vaccine?

Or were MHRA guidelines not part of the information conveyed to NHS staff during the rollout?

399. MHRA guidance goes on to explain that some adverse reactions are expected, and some are novel; some continue for an extended period of time, and some become apparent after a delayed period of time. MHRA guidance also states that, "*adverse drug reactions account for 1 in 16 hospital admissions, and for 4% of hospital bed capacity …*" Are hospital staff specifically trained to consider

that there is a 6.25% chance of any hospital admissions being due to adverse reactions, and as part of the rollout of the Covid-19 vaccines, were hospital staff specifically trained to consider that a mass vaccination campaign may contribute to admissions during the period that the Inquiry is considering? Steve Barclay, Secretary of State for Health and Social Care may be able to provide insight into if and what training was provided to prepare hospital staff for patients with potential adverse reactions to Covid-19 vaccination.

400. The MHRA also acknowledges the impact adverse reactions have on both patients as individuals and the healthcare system as a whole: "*It is clear that adverse drug reactions adversely affect patients' quality of life and can also cause patients to lose confidence in the healthcare system. There is a significant impact through increase costs of patient care and the potential to lengthen hospital stays. Adverse drug reactions may also mimic disease, resulting in unnecessary investigations and delays in treatment.*"

401. It is clear from the MHRA document that adverse reactions and the impact they can have on the NHS as well as the individuals concerned are formally recognised on paper. How this recognition and guidance form part of the real-life NHS procedures appears to be extremely inadequate and virtually neglected during the rollout period — arguably a time when NHS vigilance toward and training regarding potential adverse reactions should have been a priority. UKCVFamily members are still today often subjected to disbelief from NHS staff regarding their post-

vaccine symptoms. Whilst many factors likely contribute to this, it is partly due to inadequate healthcare practitioner training.

402. Current guidelines to the Covid vaccines only briefly discuss adverse reactions, and focus on temporary reactions such as fatigue or pain at injection site. Well-recognised serious adverse events — such as previous anaphylaxis, known allergies to the vaccine ingredients, thrombosis and thrombocytopenia syndrome (TSS), Guillain Barre syndrome, myo/pericarditis, and capillary leak syndrome — are mentioned, with a link to the Green Book (Exhibit 350) for [CC/350 - INQ000508050] further information. However, the Green Book does not discuss less well-recognised adverse reactions nor provide guidance on further information sources.

403. Current training refers to possible implications for those who have experienced past adverse reactions, however these cautionary words appear to be ignored by NHS staff. Many UKCVFamily members report being urged by healthcare practitioners to have further vaccines, despite already experiencing adverse reactions. We believe this is due to a severe lack of adequate training in this country. As mentioned in a previous section, a survey we ran showed that of the 90 patients who had a further vaccine, 99% reported getting worse.

404. Some UKCVFamily members did indeed go on to take a second or third Covid-19 vaccine on the advice of their doctor, having already suffered an adverse

reaction to the first or/and second. Unfortunately, this has resulted unfavourably for those members who then experienced yet more damage.

405. UKCVFamily members have repeatedly been sent text reminders and letters inviting them to take more Covid-19 vaccines. One of our members had, in the space of two days; a letter, two texts and an email to remind them to book a booster vaccine. Some members tried to block the text messages but texts were them sent from a different number. This causes great distress to our members and adds to the trauma they are already going through. Some members have described this as 'harassment' and 'upsetting'. Many have sought exemption certificates so they no longer receive such invitations but exemptions have been very difficult for our members to acquire. Some of our members still received Covid-19 vaccine text reminders even though they had exemptions in 2021. UKCVFamily would like the Inquiry to ask why those who have suffered an adverse reaction to a Covid-19 vaccine have been urged to take further Covid-19 vaccines and if it is considered appropriate to send repeated text messages and letters at the frequency they were being sent. UKCVFamily believe that in the future, those who suffer an adverse reaction should be taken off NHS lists that send text reminders and letters for further vaccinations.

406. Current guidelines to the Covid vaccines do not mention that adverse reactions as yet unknown may occur, giving the impression that all adverse events are known. This provides rationale for healthcare professionals to dismiss patients,

which has implications for patient management, and vaccine safety tracking.

407. Vaccinators are required to read the government guidelines, but vaccinators are only likely to deal with immediate adverse reactions such as anaphylaxis. Only 8% of our members experienced symptoms while in the presence of a vaccinator. 39% of our members experienced symptoms within hours of vaccination, 39% within days, and 14% within weeks; all beyond the scope of the vaccinators and instead dealt with by paramedics, GPs, or those working in A&E or on the 111 helpline. While encouraged, these staff are not actually required to read the government guidelines on adverse reactions, so the clinical staff dealing with most adverse reactions are unlikely to have read the latest guidelines on how to deal with them. UKCVFamily members have experienced even well-recognised adverse events like myocarditis taking over a year to diagnose because of clinicians' lack of awareness of the symptoms and the link to the vaccine as a cause

408. According to the National Academy of Medicine (in the US) [CC/069 INQ000377701], understanding pathophysiology provides strong evidence of causality when determining vaccine risks; it is therefore a medical practitioners' duty to ensure rapid and thorough investigation. We have guidelines for other conditions; atypical vaccine adverse events should not be an exception.

409. The lack of adequate training and support for NHS staff to recognise potential

adverse reactions also means that new pharmaceutical products are missing potential safety signals, as indicated by current NICE guidelines on *Adverse reactions to drugs* (not specific to Covid vaccines*), "Only limited information is available from clinical trials on the safety of new medicines. Further understanding about the safety of medicines depends on the availability of information from routine clinical practice."* [CC/352 - INQ000377702]

410. Those non-specific NICE guidelines provide information in the *Established drugs and vaccines* section that — had NHS staff been required to read them pre-rollout — could potentially have led to the NHS being better able to manage those dealing with possible adverse reactions. For example:

a. *"Healthcare professionals and coroners are asked to report all suspected reactions to … vaccines that are serious, medically significant, or result in harm. Serious reactions include those that are fatal, life-threatening, disabling, incapacitating, or which result in or prolong hospitalisation, or a congenital abnormality; they should be reported even if the effect is well recognised. Examples include anaphylaxis, blood disorders, endocrine disturbances, effects on fertility, haemorrhage from any site, renal impairment, jaundice, ophthalmic disorders, severe CNS [central nervous system] effects, severe skin reactions, reactions in pregnant women, and any drug interactions." 83% of our members experienced at least one of these symptoms whereas in the majority of cases, their healthcare professionals did not report them as per these NICE guidelines.*

b. *"Some reactions (e.g. cancers, chloroquine retinopathy, and retroperitoneal fibrosis) may become manifest months or years after exposure. Any suspicion of such an association should be reported directly to the MHRA through the Yellow Card Scheme." The guidelines appear to be open to the possibility of pharmaceutical products causing reactions significantly later after administration, whereas our members have discovered that even symptoms experienced in days after vaccination have been dismissed as being unrelated.*

c. *"When an infant is born with a congenital abnormality or there is a malformed aborted fetus doctors are asked to consider whether this might be an adverse reaction to a drug and to report all drugs (including self-medication) taken during pregnancy." Have those working in maternity and neonatal departments been reminded of this during the rollout? NHS England's Chief Midwifery Officer, Kate Brintworth would be best placed to provide more information regarding training conducted specifically to encourage such awareness amongst NHS staff.*

d. *"with a new drug, be particularly alert for adverse reactions or unexpected events" As mentioned above, were NHS non-vaccinating staff actively encouraged to be aware?*

411. The section entitled *Drug allergy (suspected or confirmed)* is also especially of interest due to the specific details regarding timing that are given, as follows:

a. "*Immediate, rapidly-evolving reactions (onset usually less than 1 hour after*

drug exposure) … Anaphylaxis, with erythema, urticaria or angioedema, and hypotension and/or bronchospasm; Urticaria or angioedema without systemic features; Exacerbation of asthma"

b. "*Non-immediate reactions, without systemic involvement (onset usually 6–10 days after first drug exposure or 3 days after second exposure) … Cutaneous reactions, e.g. widespread red macules and/or papules, or, fixed drug eruption*"

c. "*Non-immediate reactions, with systemic involvement (onset may be variable, usually 3 days to 6 weeks after first drug exposure, depending on features, or 3 days after second exposure) … Cutaneous reactions with systemic features, e.g. drug reaction with eosinophilia and systemic signs (DRESS) or drug hypersensitivity syndrome (DHS), characterised by widespread red macules, papules or erythroderma, fever, lymphadenopathy, liver dysfunction or eosinophilia; Toxic epidermal necrolysis or Stevens–Johnson syndrome; Acute generalised exanthematous pustulosis (AGEP)*".

412. The above guidance confirms UKCVFamily members' experiences that those NHS staff who were most likely to witness possible adverse reactions were staff seeing patients within hours, days, or weeks of vaccination, as opposed to within minutes. How were non-vaccinating staff reminded to be vigilant of possible adverse reactions?

413. The guidance also states, "*Suspected drug allergy information should be clearly*

and accurately documented in clinical notes and prescriptions, and shared among all healthcare professionals. Patients should be given information about which drugs and drug-classes to avoid and encouraged to share their drug allergy status." Our members have not been encouraged by their healthcare professionals to share their adverse reaction status, and in fact, when attempting to do so, have often experienced discrimination from other healthcare professionals, as well as society in general (including social media, which censors those who speak about adverse reactions to the Covid vaccines). One of UKCVFamilys NHS-employed members was specifically told not to speak about their adverse reaction with their colleagues.

414. In contradiction to the above guidance, 59% of the vaccine-injured struggle to have their symptoms included on their records as suspected adverse reactions. A UKCVFamily survey showed that 41% have written confirmation from an NHS-approved healthcare professional that the health problems they were experiencing were likely or certainly due to the Covid vaccine, 30% have verbal confirmation but the practitioner would not put this in writing, and 29% have no confirmation — written or verbal. UKCVFamily are concerned not just about 59% struggling to have their symptoms appropriately acknowledged, but that practitioners are so unwilling to put their medical concerns in writing. It would be useful for the Inquiry to see what specific information was sent to NHS staff regarding the recording of suspected adverse reactions as part of the rollout.

415. One of our members who worked in the NHS found there was a reluctance from doctors to acknowledge vaccine injuries, alluding to a fear of being perceived as "anti vax" or discouraging vaccination. Once they had the emerging research explained to them, they seemed to be more open to the possibility of such reactions. Intuitive denial of (unrecognised) vaccine injuries goes against GMC guidelines [CC/353 - INQ000377703] which state:

a. *make the care of your patient your first concern*

b. *be competent and keep your professional knowledge and skills up to date*

c. *take prompt action if you think patient safety is being compromised*

d. *establish and maintain good partnerships with your patients and colleagues*

e. *maintain trust in you and the profession by being open, honest and acting with integrity*.

By denying a vaccine reaction to begin with, many of our members (as discussed above) were recommended to get further vaccines, which often ended in symptomatic worsening. This is also an added barrier in terms of accurate vaccine adverse event tracking (as diagnoses are not made), and providing evidence for causality (for VDPS claims). We would like the Inquiry to investigate what cultural changes need to be made within the NHS so that clinicians are basing clinical decisions on evidence, not intuition or concerns regarding how their comments might be perceived.

416. Special mention needs to be made regarding the training, information, and support that NHS staff were given regards the identification and treatment of VITT (vaccine-induced thrombocytopenia and thrombosis, CC/354 - INQ000377704), "*a new, rare condition that has been identified after COVID-19 vaccination*" (NHS England). 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.

417. UKCVFamily are concerned not just with the NHS's neglect in the area of practical preparedness but also in the area of empathetic preparedness, and have found that the NHS seems to nurture a toxic culture toward vaccine-related adverse reactions, which is not just damaging to patients but to staff, who may feel unable to communicate worries about any adverse reactions they may have experienced themselves. On a scale of zero to ten (with zero being extremely dissatisfied, and ten being extremely satisfied) 96% of our members choose five or below when asked how they felt about the compassion shown to them by NHS staff. 44% chose zero: extremely dissatisfied. This is extremely concerning — it is one thing to be unable to provide medical care; it is another thing entirely to be unable to provide human compassion.

418. Vaccine adverse reactions is more than a "taboo" topic within the NHS — this is a situation where NHS staff look over their shoulder before acknowledging to a patient that their symptoms may be related to vaccination — this is the development of a culture of fear-based medical treatment. As mentioned above, 30% of UKCVFamily members have healthcare practitioners who are unwilling to put their suspicions in writing. We need to establish why NHS staff are so unwilling to show compassion when compassion itself is listed in the NHS Constitution [CC/355 - INQ000377705], "*We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. We do not wait to be asked, because we care.*" The vast majority of the vaccine-injured have not found this to be the case.

419. It is understandable that Covid vaccine-specific guidance may have taken time to be developed, as in the case of VITT guidelines. However, the general guidance for the management of suspected adverse reactions to pharmaceutical products — as quoted above — already existed. The NHS had guidelines to follow as it treated those who could have been suspected of having adverse reactions. The reality of what happened to the vaccine-injured community — and continues to happen — clearly indicates that those guidelines were — and still are — ignored.

420. The vaccine rollout began during lockdown, which in itself created the first barrier to the vaccine-injured in accessing the NHS. This was a period where people found it difficult to access their doctors, were reluctant to call ambulances, and afraid to go to hospitals. This in itself may impact the actual numbers of people we are aware of as having experienced symptoms in the days, weeks, or months post-vaccination; and affect any administrative records that may provide evidence as to the seriousness of symptoms.

421. NHS111 may therefore have been the main resource that members of the public turned to in order to discuss concerns about their health post-vaccination. It is proving difficult to obtain statistics regarding the number of calls made to NHS111 post March 2021, in order to compare them to statistics that are available until March 2021 (*NHS 111 Minimum Data Set, England, March 2021, CC/356 - INQ000377706*). These statistics may be helpful to the Inquiry, along with 999 call statistics.

422. UKCVFamily members experienced a wide array of responses to their own calls to NHS111, sometimes sympathetic and concerned that the patient should be urgently seen, and sometimes dismissive with the distinctly non-medical advice to stop watching television. It would be useful to find out what instructions NHS111

a. call-handlers were given with respect to:

b. callers specifically concerned about possible post-vaccination symptoms,

c. callers with unusual symptoms but when questioned, had had a Covid vaccine in the weeks prior to onset.

423. For those UKCVFamily members who were able to access face-to-face medical assistance, 88% felt discriminated against because of having experienced an adverse reaction to a Covid-19 vaccine. Some of us have found that we can have better access to healthcare if we do not mention vaccination, and one member even visited A&E giving a false name and address as an attempt to access better care. Our symptoms are dominated by the debate over whether they are relevant to the Covid vaccine or not, and if we suspect they might be, access to healthcare seems to become problematic. The possibility of our symptoms being related to a Covid vaccine should not be a barrier to healthcare being provided to diagnose, treat, or manage those symptoms.

424. Many UKCVFamily members have not even had the most basic of tests ordered by their GPs. Those who have had basic tests done, which often produce non-concerning results, are then not allowed further testing despite experiencing debilitating symptoms. In some cases, if GPs request further testing, those requests are being refused by labs. GPs are restricted on what tests they can order to help inform clinical decisions and referrals. And test availability in the NHS depends on regions, which goes against General Medical Council guidance on equitable care.

425. One reason that our members are also being denied access to further testing is because our basic tests are not indicating a need for further testing — "everything is normal." Yet the life-changing symptoms persist, and we spend our life-savings on more thorough testing, in some cases revealing permanent damage that, had it been discovered earlier, would have been treatable.

426. If our complicated symptoms are not matching any existing conditions within NHS guidelines then it is assumed that we are suffering from a mental health condition. While there is no doubt that living with a chronic, taboo health condition that many medical professionals and society in general dismiss can bring about serious mental health challenges, an adverse reaction to a pharmaceutical product is not a mental health condition and should not be treated as such. Such medical gaslighting only exacerbates any psychological distress already experienced, promotes distrust in the NHS, and fails to take advantage of the opportunity to learn what could be vital information about the pharmaceutical product concerned. And the patient remains undiagnosed and untreated. This lack of knowledge by doctors means many vaccine-injured are turned away with a diagnosis of anxiety only to later find out they in fact have a physical health condition that needed urgent attention.

427. Some UKCVFamily members have been diagnosed with a functional disorder (e.g. functional neurological disorder, functional weakness, CC/357 -

INQ000377707) (hereafter: FND). The treatment for FND is predominantly based on psychotherapy (e.g. cognitive behavioural therapy, CC/358 - INQ000377708) and neurorehabilitation. In our experience, once this diagnosis has been made, all symptoms thereafter are attributed to FND. As a result, further testing is halted, and for some patients has even been refused on the grounds that it would be "*harmful*". If UKCVFamily patients had accepted this diagnosis and had not advocated themselves for further testing, diagnoses as serious as Guillain Barre syndrome (an autoimmune disease), pulmonary emboli (blood clots), endocrine (hormone) disorders, and postural orthostatic tachycardia syndrome (a neurological disease) would have been missed. Importantly, these conditions all have treatments, which means the FND diagnosis was actively preventing patients from improving; some of these diagnoses can be fatal if not treated (indeed, one UKCVFamily member did nearly die due to lack of investigation because of the FND label). At the lack of support from the medical community, one of our members wrote a letter to the Editor of the *Journal of the Royal College of Physicians Edinburgh* to try and raise awareness of the potential pathologies that could be missed by diagnosing a patient solely on rule-in FND markers (Carroll & Deans, 2022, CC/359 - INQ000377709 pg4). UKCVFamily would be interested in understanding how many vaccine injured patients have been diagnosed with FND without proper investigation for other pathologies, and we would appreciate support in getting such patients more comprehensive medical help.

428. The NHS website lists "*serious health problems*" as one of four possible causes of post-traumatic stress disorder (PTSD), and the condition has been recognised by the Vaccine Damage Payment Scheme (VDPS) as being related to the Covid vaccine. At this point, we are unaware of any specific research into the development of PTSD post-vaccination, however, some of our members have been diagnosed with, or have many symptoms of, since experiencing an adverse reaction. PTSD symptoms amongst our members vary, and include symptoms that are specifically related to dealing with healthcare professionals or being in healthcare environments, to the extent that we have felt it necessary to issue "Medical Trauma Cards" [CC/360 - INQ000377711] to any members of UKCVFamily who feel they need them to hand to medical staff when attending appointments or emergency visits.

429. Those UKCVFamily members who have managed to get appropriate medical care in some cases privately and not always in the UK — have been diagnosed with a number of conditions listed at the beginning of this document. Some of these conditions are life-threatening if left untreated and some of us have been left untreated for almost three years. All of these conditions are life-altering. Some of our members have multiple diagnoses. Some of us have spent thousands of pounds on testing — both in the UK and overseas — that has resulted in these diagnoses. Had our symptoms been taken seriously from the beginning, these diagnoses would have been obtained via the NHS, in some cases via those referrals that were rejected.

430. There seems to be a general consensus amongst the sympathetic NHS staff, who frequently say, "We don't know what to do with you." There is nowhere they seem able to turn to for specialist advice, and nowhere they seem able to direct us so that we may be researched. NHS staff need support in order to be able to support us.

431. UKCVFamily are concerned that there appear to be no specialists coming forward within the NHS who are able to care for the complicated health conditions that have arisen post-vaccination. The few that are, seem to be seeing us alongside their usual patients and don't appear to have any special funding or pathway for us. We are concerned that the government does not appear interested in encouraging such professionals to come forward or funding any clinic time specifically for the vaccine-injured. We are aware of individual practitioners in both traditional and modern fields of medicine who are attempting to provide some relief to those suffering from adverse reactions — some of whom have given presentations to our members. But fear of professional repercussions means that these practitioners tend to be discreet about their support for the vaccine-injured, even if they have been treating vaccine-injured patients for many years before the Covid-19 vaccine rollout.

432. It needs to be noted that this lack of NHS specialists willing/able/encouraged to work with the vaccine-injured has led to our community becoming extremely

vulnerable to individuals and organisations, both in the UK and overseas, with unsubstantiated claims of being able to "cure" us. In desperation, some of our members have paid significant amounts of money to access products or practitioners, only for their conditions to worsen afterwards.

433. One option for some vaccine-injured patients has been the Long Covid clinics although there is inconsistency regarding which clinics accept those whose symptoms are due to the vaccine and not due to the virus. Even if GPs have provided referrals, some of our members have found that they were rejected from Long Covid clinics because they hadn't actually had Covid, we attach a small sample of examples of this in the Appendices (CC/361a - INQ000377712, CC/361b - INQ000377713, CC/361c - INQ000377714, CC/361d - INQ000377715, CC/361e INQ000377716, CC/361f - INQ000377717, CC/361g - INQ000377718, CC/361h - INQ000377719, CC/361i - INQ000377720, CC/361j - INQ000377721, CC/361k - INQ000377722, CC/361l - INQ000377723, and CC/361m INQ000377724). Note: some of our members have been misdiagnosed as having Long Covid, despite never having had Covid (one of our members has twice had her medical records changed to Long Covid without her knowledge or any consultation).

434. 26% of UKCVFamily members who responded to a recent poll said that they had attended a Long Covid clinic. Others had asked for referrals, but were rejected because they had never had Covid before becoming unwell, or were

outright told that they were vaccine-damaged. Of those who did attend, 81% said they were unhelpful, and 19% said they were helpful.

435. According to the *British Medical Journal* article *What happens inside a long covid clinic?* [CC/362 - INQ000377725] published 7 September 2023, "*By July 2022, there were 90 post-covid services that had seen 60,000 patients and received £194m of funding between October 2020 and March 2023.*" Each of those services on average received over two million pounds, yet no provision appears to have been made for investing in services to support the vaccine-injured. Sir Simon Stevens, NHS Chief Executive may be able to provide the Inquiry with more information as to whether the vaccine-injured were/are considered in the development of these services and why there is an inconsistent approach as to whether vaccine injured people are eligible for treatment under Long Covid services.

436. On the topic of Long Covid clinics, it is worth noting that there is a growing community of people within the UK — and not just the vaccine-injured — who would prefer to get Covid than another vaccine, even though they may have compromised immune systems and be advised by the NHS that they are at risk of serious illness if they catch Covid. Their reason being is they feel that if they get Covid or Long Covid or even the flu the medical profession (including Long Covid clinics) will treat them but they won't treat an adverse reaction to a vaccine. And they will be stigmatised if they claim the vaccine made them ill.

The non-injured public is aware of how the injured are treated. Detailed research and analysis into the public's attitudes towards the Covid-19 vaccines and vaccines in general post-Covid, would be beneficial to better understand the impact that the Covid-19 rollout has had on healthcare and related attitudes. We have included what limited information we could find in the section "The Covid Vaccine's Impact on Immunisation in the UK" toward the end of this document.

437. Not only are there no specialists that the NHS can refer patients suspected to be vaccine-injured, but there is no research being conducted into our conditions and experiences. As made clear in previous sections, the MHRA are not researching us, the vaccine manufacturers are not researching us, and the NHS are not researching us. Not one of our members is being researched, and we are not aware of any research being conducted in the UK. UKCVFamily would like the Inquiry to ascertain why research into Covid vaccine adverse reactions wasn't prioritised, and still isn't now, within the context of a mass vaccination campaign and novel vaccinations.

438. International research in conditions occurring post-vaccination are discovering a variety of possible explanations, one of which is microclotting. Microvascular damage is extremely difficult to detect with the standard testing procedures available in the UK, particularly in the early stages of disease progression, and microclot damage has not been seen before. More sensitive tests are often needed to show damage, particularly if the patient has been symptomatic for

several months. The vast majority of UK scientists and medical professionals seem unaware of international research that is being conducted into Covid-19 vaccine injuries.

439. Some of our members have travelled overseas in order to access clinics or professionals willing to speak openly to, research, and treat the vaccine-injured, such as to South Africa, Germany, Cyprus, or the USA. These services tend to be part of healthcare facilities dedicated to Long Covid, but are willing to accept and treat the vaccine-injured. We are aware of just two clinics entirely dedicated to supporting the medical needs of the vaccine-injured, one in Taiwan and another in Germany.

440. Taiwan: Taipei Medical University Hospital established a telemedical outpatient clinic in September 2021, entirely dedicated to supporting anyone concerned about side effects or adverse reactions. Following a telephone or video consultation, patients are then referred on to specialists within the hospital for examinations. Medical equipment such as heart monitors are provided to patients so they can monitor their own conditions, and are even provided to people considered to be at risk of an adverse reaction to wear for 14 days post-vaccine. Patients suffering with continuous chest tightness, dizziness, headache, extensive skin redness or rashes, rapid heartbeat, or a fever are always advised to seek immediate medical attention, and anyone with an irregular heart rhythm can get urgent access to the clinic. The hospital publicly acknowledged in the *Taipei Times*

that as the number of vaccines administered increased, so were the number of suspected adverse reactions [CC/363 - INQ000377726].

441. Germany: University Hospital Marburg. In the beginning of 2022, Germany established a post-vaccine clinic in the University Hospital Marburg for the purpose of treating anyone dealing with serious or ongoing health problems since vaccination, *regardless of whether the cause has been determined to be the Covid vaccine.* In the first six months, the clinic had treated 250 people and had a waiting list of 3000. Health Minister Karl Lauterbach has publicly committed to helping people with long-term consequences of Covid vaccination, pledging to ensure vaccine injury is recognized more quickly, and planning research on "Post-Vac Syndrome" [CC/364 - INQ000377727 and CC/365 - INQ000377728].

442. The complete failure of the UK to:

a. provide adequate training for NHS staff in the identification of suspected adverse reactions,

b. create a culture of compassion amongst NHS staff regarding the topic of vaccine injuries,

c. listen and learn from the vaccine-injured themselves during NHS consultations,

d. provide immediate and thorough testing as a matter of urgency,

e. invest in specialists, researchers, and a clinic specifically dedicated to the needs of the vaccine-injured, and

f. be aware of international healthcare systems' efforts to support the vaccine-injured, has led to an even greater impact on the NHS, which continues now. Local services have been unnecessarily burdened simply because there was no preplanned pathway nor willingness to think "out of the box" for the vaccine-injured.

g. The NHS Constitution states: *"The NHS belongs to the people. It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most."*

443. UKCVFamily would urge the Inquiry to examine the failure of the NHS to support the medical treatment of those suffering an adverse reaction to a Covid-19 vaccine, in full, to prevent future harm to patients.

444. Amanda Pritchard Chief Executive Officer (CEO) of NHS England, Matt Hancock and Sajid Javid,-Secretaries of State for Health and Social Care during the time period 30 Jan 2020 to 28 Jun 2022, may be best placed to comment

on the NHS' treatment of those suffering adverse reactions due to a Covid-19 vaccination.

OTHER NEW & EXISTING THERAPEUTICS AND/OR MEDICATIONS

445. Many of the vaccine-injured have given up trying to get answers from the NHS, or waiting for this country to provide treatments that may alleviate symptoms. Some no longer trust the NHS or the pharmaceutical industry in general. When surveyed, 100% of UKCVFamily members who responded stated that they will not be having any more Covid vaccines, and this understandably leaves some being vulnerable to infection. 22% were issued with an exemption or have it on their medical records that they should not have any more Covid vaccines, a further 20% applied for an exemption but were denied one and this also leaves some being vulnerable to infection. Some of our members are immunocompromised — 12% were immunocompromised before vaccination and 50% have become immunocompromised since vaccination. 74% have tested positive for Covid since vaccination, and it is well known that being vaccinated does not prevent infection. New or existing therapeutics and/or medications are not just relevant to what arguably should have been drawn upon in addition or as an alternative to vaccination during the early stages of the pandemic; they are also very relevant now.

446. Many of us have been extremely proactive in exploring new and existing

therapeutics and/or medications, including those offered by traditional healthcare systems. Our knowledge may be useful for the medical and the scientific communities, if only representatives from them were willing to listen to us. Our knowledge is specifically related to and may be of interest to professionals working within these three areas:

a. managing acute infection,

b. managing chronic symptoms, and

c. disease prevention (including generally maintaining good health).

447. What follows are some of the therapeutics and medications that our members are having success with, some of which have scientific research to support their use, some of which indicate suggest that scientific research may be beneficial, some of which are "common sense" ways of managing one's own healthcare that would benefit from investment into promotion amongst the general public. Our community has found that pharmaceuticals are not the only answer to healthcare. Existing or new research in these therapeutics or medications may well have saved lives.

448. Copper: numerous scientific studies have shown the use of copper in relation to Covid. On 2 February 2022, the University of Southampton published an article, *Using copper to fight COVID-19: Biological Sciences and Health Sciences are showing how copper can provide a permanent defence against the spread of*

Coronavirus on surfaces in just one minute, with details of the work conducted by Professor Bill Keevil and Dr Sandra Wilks. The article said, "*Bill first published a paper in 2015 investigating how Human Coronavirus 229E, which is closely related to the COVID-19 virus, remains infectious on common touch surface materials such as stainless steel compared to how it can be rapidly inactivated on a range of copper ones.*" It also said, "*Their findings have already led to the installation of antimicrobial surfaces globally in hospitals, supermarkets, public transport and airports. They have informed regulatory standards for products and healthcare facilities and helped government agencies.*" [CC/366 - INQ000377729]. It may be useful to establish what part, if any, Professor Keevil played into government decisions regarding ways of preventing disease and managing acute infection.

449. Further mention of the potential use of copper against Covid was published in the following:

a. *Medical Hypotheses* journal (September 2020): *Is copper beneficial for COVID-19 patients?* [CC/367 - INQ000377730]

b. *Diagnostic Microbiology and Infectious Disease* journal (December 2020): *The use of copper to help prevent transmission of SARS-coronavirus and influenza viruses. A general review* [CC/368 - INQ000377731]

c. *Frontiers in Medicine* journal (12 March 2021): *COVID-19 Therapy: Could a Copper Derivative of Chlorophyll a Be Used to Treat Lymphopenia Associated With Severe Symptoms of SARS-CoV-2 Infection?* [CC/369 -

INQ000377732]

d. *Nutrients* journal (31 May 2021): *Relation of Serum Copper Status to Survival in COVID-19* [CC/370 - INQ000377734]

e. *BioMetals* journal (16 August 2021): *Antiviral properties of copper and its alloys to inactivate covid-19 virus: a review* [CC/371 - INQ000377735]

f. *BioMetals* journal (7 December 2022): *Efficacy of copper blend coatings in reducing SARS-CoV-2 contamination* [CC/372 - INQ000377736]

450. Furthermore, as early as 10 February 2021, the United States Environmental Protection Agency (EPA) issued the statement, *EPA Registers Copper Surfaces for Residual Use Against Coronavirus*, which said, "*... certain copper alloys provide long-term effectiveness against viruses, including SARS-CoV-2, the virus that causes COVID-19. As a result of EPA's approval, products containing these copper alloys can now be sold and distributed with claims that they kill certain viruses that come into contact with them. This is the first product with residual claims against viruses to be registered for use nationwide.*" [CC/373 - INQ000377737]. It would be worth exploring how the UK's equivalent body responded to this statement.

451. Nicotine: Some of our members have had success in managing acute and chronic symptoms through the use of nicotine products. The BBC reported on 23 April 2020 that, according to French research, fewer smokers were amongst those admitted to hospital for severe symptoms of Covid-19 when compared to the

general population. The Centre for Evidence-Based Medicine at the University of Oxford published an article on 26 May 2020 concluded, "*There are biologically plausible pathways through which nicotine may impact SARS-CoV-2, but the clinical significance of these is entirely unclear.*" [CC/374 - INQ000377738]. The authors, Jamie Hartmann-Boyce and Nicola Lindson, would be best placed to provide an update on the research into the relationship between nicotine and Covid.

452. The Daily Mail's article on 15 April 2020, entitled *Does smoking PROTECT against Coronavirus?* [CC/375 - INQ000377739], stated the following:

a. "*... data from multiple Chinese studies shows that COVID-19 hospital patients contained a smaller proportion of smokers than the general population (6.5 per cent compared to 26.6 per cent), suggesting they were less likely to end up in hospital.*"

b. "*Another study, by America's Centers for Disease Control of over 7,000 people who tested positive for coronavirus, found that just 1.3 per cent of them were smokers - against the 14 percent of all Americans that the CDC says smoke. The study also found that the smokers stood no greater chance of ending up in hospital or an ICU.*"

c. "*A study published earlier this month by scientists in New York and Athens claims the opposite. It looked at 13 Chinese studies that had registered smoking as a precondition and found that the number of smokers across the whole sample of 5,300 patients was 6.5 per cent. An astonishingly*

small number in a country where half of all men still smoke."

453. The *Daily Mail* article explained the relationship between nicotine and ACE-2 receptors, and ACE-2 receptors and coronavirus, and mentioned a number of

a. UK-based professionals who were knowledgeable in this field. These may be able to provide information regarding further research and the role such research has played into the government's development of therapeutics or medications relating to tackling Covid-19:

b. Professor Marco Leitzke

c. Professor Jamie Brown, addiction researcher at University College London, Professor Paul Hunter, medicine lecturer at the University of East Anglia.

454. Vitamins C, D, K2, B1, B3 (niacin), B12. Our members have had success in the management of both acute and chronic symptoms through supplementation or infusion of specific vitamins, or by increasing foods containing high levels of those vitamins.

455. Numerous studies on the role of Vitamin C in preventing and treating Covid-19 were conducted prior to vaccination rollout. Some of our members have had success with high doses of Vitamin C during both acute and chronic phases of illness. It would be helpful to learn more about how Vitamin C was considered by the government as a possible tool for managing Covid-19.

a. "*Many patients with severe COVID-19 have elevated levels of the mediators interleukin-6 and endothelin-1 ... There is clear evidence that vitamin C in high doses can reduce these mediators. Vitamin C is cheap and safe. Hence, using a relatively low dose of vitamin C as prophylaxis, and in cases of severe COVID-19, an (intravenous) high-dose regimen may be beneficial.*" Nutrition journal, 25 July 2020, *Vitamin C as prophylaxis and adjunctive medical treatment for COVID-19?* [CC/376 - INQ000377740]

b. "*Due to the excellent safety profile, low cost, and potential for rapid upscaling of production, administration of vitamin C to patients with hypovitaminosis C and severe respiratory infections, e.g., COVID-19, appears warranted.*" Nutrient journal, 27 October 2020, *The Emerging Role of Vitamin C in the Prevention and Treatment of COVID-19* [CC/377 - INQ000377741]

c. "*Vitamin C is an essential, inexpensive nutrient. Due to the severe clinical course of COVID-19 pneumonia, even moderate benefits may be worthwhile. However, the excellent safety profile of vitamin C and the necessity of ICU treatment for a high proportion of COVID-19 patients may justify consideration of clinical application of vitamin C, even before the results of large clinical trials are available.*" Frontiers in Medicine journal,

18 January 2021, *Vitamin C and COVID-19* [CC/378 - INQ000377742]

d. "*Based on the theoretical background presented in this article, and some preliminary encouraging studies, the role of vitamin C in the treatment of patients with SARS-CoV-2 infection should be further investigated.*" Nutrients journal, 1 April 2021, *Vitamin C in the Treatment of COVID-19* [CC/379 - INQ000377743]

e. "*... vitamin C possesses positive impacts on curing of infection and this may play a protective role in the current COVID-19 pandemic through boosting the immune system … to develop strong immunity against COVID-19 infection, a regular administration of vitamin C is required … high-dose vitamin C has been shown to reduce inflammation, improve oxygen support status, and reduce mortality in COVID-19 patients, all without causing any negative side effects. Additionally, it may be beneficial for specific subgroups of patients with severe and critical condition, as well as for older individuals. High-dose vitamin C may prove to be an effective treatment for COVID-19. Furthermore, there is an urgent need to investigate the direct relationship between serum/plasma nutritional C levels and the incidence and severity of COVID-19 infection.*" AIMS Microbiology, 20 March 2022, *Role of vitamin C in preventing of COVID-19 infection, progression and severity* [CC/380 - INQ000377745].

456. Our members have also had success with Vitamin D supplementation, which is supported by some research, for example:

a. "*Older adults with vitamin D deficiency and COVID-19 may demonstrate worse morbidity outcomes. Vitamin D status may be a useful prognosticator.*" Postgraduate Medical Journal, 27 August 2020, *Vitamin D status and outcomes for hospitalised older patients with COVID-19* [CC/381 - INQ000377746]

b. *"The evidence supports recommending 2,000 IU (50 mcg) vitamin D daily for at-risk teens and adults, which is well within safe limits and might dramatically reduce COVID-19 fatalities."* Frontiers in Public Health, 10 September 2020, *A Basic Review of the Preliminary Evidence That COVID-19 Risk and Severity Is Increased in Vitamin D Deficiency* [CC/382 - INQ000377747]

c. *"... it is recommended that improving vitamin D status in the general population and in particular hospitalized patients has a potential benefit in reducing the severity of morbidities and mortality associated with acquiring COVID-19.*" PLOS One Journal, 25 September 2020, *Vitamin D sufficiency, a serum 25-hydroxyvitamin D at least 30 ng/mL reduced risk for adverse clinical outcomes in patients with COVID-19 infection* [CC/383

- INQ000377748]

d. "*COVID-19 risk increased among Black individuals with vitamin D level less than 40 ng/mL compared with those with 40 ng/mL or greater and decreased with increasing levels among individuals with levels greater than 30 ng/mL. No significant associations were noted for White individuals. Randomized clinical trials should examine whether increasing vitamin D level to greater than 40 ng/mL affects COVID-19 risk.*" Journal of the American Medical Association, 19 March 2021, *Association of Vitamin D Levels, Race/Ethnicity, and Clinical Characteristics With COVID-19 Test Results* [CC/384 - INQ000377749]

457. Our members have also had success with B vitamins, specifically vitamins B1 (thiamine), B3 (niacin), and B12, which are supported by research and academics:

a. "*Vitamin B not only helps to build and maintain a healthy immune system but it could potentially prevent or reduce COVID-19 symptoms or treat SARS-CoV-2 infection … In particular, vitamin B modulates immune response by downregulating pro-inflammatory cytokines and inflammation, reducing breathing difficulty and gastrointestinal problems, preventing hypercoagulability, potentially improving outcomes and reducing the length of stay in the hospital for COVID-19 patients.*"

Maturitas journal, 14 August 2020, *Be well: A potential role for vitamin B in COVID-19* [CC/385 - INQ000377750]

b. "*Since inflammation increases the utilization of the active form of vitamin B6 (PLP) and leads to its depletion, COVID-19 patients experiencing inflammation would become acutely depleted of PLP … So PLP repletion may help to balance the immune response, allowing the control of viral replication without the cytokine storm.*" *Kaitlyn Rose, PharmD, CTNC* quoted in VeryWellHealth, 5 September 2020, *B Vitamins May Help Improve COVID-19 Outcomes, Researchers Say.* [CC/386 - INQ000377751]

c. "*The evaluation of parameters that determine the deficiency or subclinical levels of vitamin B12 deficiency can be an ally in treating patients affected by COVID-19 or in persistent symptoms of the disease, given the important functions of this vitamin in the skeletal muscle–gut–brain axis. Vitamin B12 plays an important role in viral infections. The consumption of a healthy diet containing vitamin B12 sources, and especially supplementation with methylcobalamin and cyanocobalamin, are promising alternatives as adjuvants in the treatment of COVID-19, especially in patients with B12 deficiency or deficiency risk. However, establishing doses, intervention times, and mechanisms of action of vitamin B12 against COVID-19 can be a great challenge. Researchers are*

encouraged to identify whether the subclinical deficiency or deficiency itself of this vitamin is a risk factor for COVID-19 complications, and it is necessary to carry out intervention studies with vitamin B12 supplementation in both the adjuvant treatment of mild, moderate, and severe COVID-19 and post–COVID-19, with a focus on minimizing symptoms related to the muscle–gut–brain axis." Nutrition Reviews, 13 November 2021, *The role of vitamin B12 in viral infections: a comprehensive review of its relationship with the muscle–gut–brain axis and implications for SARS-CoV-2 infection* [CC/387 - INQ000377752]

d. "*It was documented that thiamine plays a significant role in eliminating the SARS-CoV-2 virus by triggering humoral and cell-mediated immunity. Hence, sufficient levels of thiamine help in building immunity against SARS-CoV-2 patients … Riboflavin with UV light causes irreversible damage to nucleic acids leading to inhibition of replication of pathogens. Hence, it can be used to reduce pathogens in the blood plasma of COVID-19 patients to reduce the risk of transfusion–transmission of COVID-19 … Considering the therapeutic features of niacin, it can be used as an adjunct in the therapy of COVID-19 patients … A recent study revealed that pyridoxine supplement helps to relieve COVID-19 symptoms by improving immune responses, reducing pro-inflammatory cytokines, supporting endothelial integrity, and preventing hypercoagulability … A recent study determined that folic acid inhibits the furin, an enzyme*

responsible for bacterial and viral infections, and blocks the binding of SARS-CoV-2 spike protein. Therefore in the early stages, folic acid could be useful for controlling COVID-19-associated respiratory disease … While considering the health benefit and risk ratio, vitamin and micronutrients are probably justifiable with negligible risks. This is in contrast with the risk associated with novel drugs and some vaccines. Therefore, nutrient supplementations seem to be a promising approach towards SARS-CoV infection." Inflammopharmacology, 10 June 2021, *Role of vitamins and minerals as immunity boosters in COVID-19.* [CC/388 - INQ000377753]

458. Anticoagulants: Our members have had success with pharmaceutical anticoagulants such as aspirin, Clopidogrel, and Apixaban; and also enzymes such as Lumbrokinase, Serrapeptase, and Nattokinase. Research supports the use of anticoagulants in the treatment of acute and chronic Covid-related illness:

a. "*Therapeutic enoxaparin improves gas exchange and decreases the need for mechanical ventilation in severe COVID-19.*" Thrombosis Research, 20 September 2020, *Therapeutic versus prophylactic anticoagulation for severe COVID-19: A randomized phase II clinical trial (HESACOVID)* [CC/389 - INQ000377754]

b. "*In noncritically ill patients with Covid-19, an initial strategy of therapeutic-*

dose anticoagulation with heparin increased the probability of survival to hospital discharge with reduced use of cardiovascular or respiratory organ support as compared with usual-care thromboprophylaxis." New England Journal of Medicine, 4 August 2021, *Therapeutic Anticoagulation with Heparin in Noncritically Ill Patients with Covid-19* [CC/390 - INQ000377756)

c. "*... nattokinase and natto extracts have potential effects on the inhibition of SARS-CoV-2 host cell entry via S protein degradation.*" Molecules, 24 August 2022, *Degradative Effect of Nattokinase on Spike Protein of SARS-CoV-2* [CC/391 - INQ000377757]

d. "*Hospitalized, moderately ill COVID-19 patients may benefit from therapeutic-dose anticoagulation, while critically ill patients may not.*" Thrombosis Research, 7 September 2022, *Anticoagulation in COVID-19 patients – An updated systematic review and meta-analysis* [CC/392 - INQ000377758].

459. Ivermectin: The use of Ivermectin in relation to acute and chronic Covid-related illness has been accompanied by media campaigns both for and against its use, which have made it challenging for our community to determine whether it is a treatment they would like to try, in addition to the difficulties in obtaining the

product in the UK. Only a very small number of our members have tried it, with varying results — 40% said that it helped them, 28% said they experienced no difference, and 31% said it made them feel worse.

460. Low Dose Naltrexone (LDN): used to treat autoimmune conditions, cancer, ME, CFS, chronic pain, Crohn's disease, fibromyalgia, Gulf War syndrome, and multiple sclerosis; some of our members have had success with LDN, and research is available to support its use:

a. "*LDN alone or as an adjuvant therapy with hydroxychloroquine or an antiviral agent may give physicians more time to provide supportive treatment for patients with COVID-19.*" Journal of Biomolecular Structure and Dynamics, 15 September 2020, *Naltrexone a potential therapeutic candidate for COVID-19* [CC/393 - INQ000377759]

b. "*Through its effects on TLR signalling, pathogenic autoantibody production, and platelet/immune-mediated thrombosis, LDN could be particularly beneficial in that it counteracts several of the pathogenic drivers of COVID-19.*" European Heart Journal, 18 February 2022, *Repurposing low-dose naltrexone for the prevention and treatment of immunothrombosis in COVID-19* [CC/ 394 - INQ000377760]

c. "*Low dose naltrexone (LDN) is safe to use in patients with long covid (LC).*

In patients with LC for a median 11 months, LDN reduced symptoms at 2 months. In this cohort, LDN also improved well-being in 6 of 7 parameters at 2 months." Brain, Behavior, & Immunity, 3 July 2022, *Safety and efficacy of low dose naltrexone in a long covid cohort; an interventional pre-post study* [CC/395 - INQ000377761]

461. IVIG or Intravenous Immunoglobulin Therapy has been helpful for some of our members and we are aware of many in the US that are receiving it for Covid-19 vaccine-injury. Unfortunately, in the UK it seems to be very difficult to receive this treatment and in UKCVFamily we have only seen members who have had Chronic Demyelinating Polyneuropathy or Guillain Barre Syndrome diagnosed, receive it. Those with Peripheral Neuropathy or Small Fibre Neuropathy in our group haven't been able to access this treatment due to the strict NHS guidance around its use [CC/396 - INQ000377762]. UKCVFamily would ask the Inquiry to investigate why this treatment isn't available for those with other neuropathies due to a Covid-19 vaccine adverse reaction. The NHS England Immunoglobulin Expert Working Group would be best placed to advise the Inquiry regarding use of this treatment.

462. Plasmapheresis seems to help some of the vaccine-injured internationally. Plasmapheresis works by removing plasma of the patient and replacing it with donor plasma or human albumin. In the UK we have plasmapheresis treatment readily available but unfortunately like IVIG, this treatment has been rarely given

to our members. UKCVFamily would like the Inquiry to investigate why these treatments haven't been considered for the Covid-19 vaccine injured. The British Society for Haematology who developed guidelines for plasma exchange therapy would be best placed to assist the Inquiry here. [CC/397 - INQ000377763]

463. Covid-19 antivirals. Many of our members have been told they shouldn't have any more Covid-19 vaccinations, some are prescribed immunosuppressive treatment for their adverse reactions. This means they now feel vulnerable to Covid-19 infection yet having an adverse reaction doesn't automatically qualify the patient to be offered Covid-19 antivirals should they become infected. UKCVFamily believe that those who have suffered a severe adverse reaction to a Covid-19 vaccination should qualify for these medications if they so wish to take them.

464. Our members have had success with other therapeutics for tackling acute and/or chronic phases of Covid-related illness, as follows:

a. Acupuncture. Acupuncture is available on the NHS, with NICE guidelines recommending acupuncture for chronic pain, chronic tension-type headaches, and migraines, all three of which are now affecting many of our members. On 19 April 2021, Briefings in Bioinformatics published the article, *Is acupuncture effective in the treatment of COVID-19 related symptoms? Based on bioinformatics/network topology strategy*, which

found, "*For the first time, candidate targets and underlying mechanisms of the acupuncture treatment against COVID-19 were identified. This research proposed a method to study the therapeutic mechanism of acupuncture. The comprehensive research based on bioinformatics/network topology methods may clarify the multifunctional synergy mechanisms of acupuncture in the treatment of COVID-19. This research provided ideas for formulating relevant intervention measures for acupuncture treatment of COVID-19.*" [CC/398 - INQ000377764] Pia Huber, Chair of The British Acupuncture Council, may be able to provide further information about the use of acupuncture in Covid-related illness.

b. Diet/Nutrition. Many of our members have made significant dietary changes as a means of managing illness. According to the Association of UK Dieticians (BDA), "*Dietitians interpret the science of nutrition to improve health and treat diseases and conditions by educating and giving practical advice to clients, patients, carers and colleagues. They advise and help to maintain nutritional status when individuals want to trial dietary interventions such as exclusion diets, nutritional supplementation or dietary interventions in areas such as autism for which evidence is still emerging.*" Diet and nutrition experts could be well-placed in providing support not only for the maintenance of good health and disease prevention, but also in the management of ongoing symptoms. They may also be knowledgeable about the latest research about diet and Covid-

related illness. Dieticians are available on the NHS. Caroline Bovey, Chair of the BDA, may be able to provide more information about the role of nutrition in Covid-related illness.

c. Fasting. In December 2022, BMJ Nutrition, Prevention & Health published *Association of periodic fasting with lower severity of COVID-19 outcomes in the SARS-CoV-2 prevaccine era: an observational cohort from the INSPIRE registry*, and concluded, "*Routine periodic fasting was associated with a lower risk of hospitalisation or mortality in patients with COVID-19.*" [CC/399 - INQ000377765]

d. Herbal Medicine. On 16 October 2021, Metabolism Open published *Herbal medicine use for the management of COVID-19: A review article*, which concluded "*The use of herbal medicine is a potential platform for answering various types of COVID-19 virus management. An antiviral drug that is primarily approved by WHO for emergency management was remdesivir. Herbal medicine and its bioactive fractions are potentially beneficial in preventive COVID-19 and as supportive measures. Different valuable herbal medicine can interfere with COVID-19 pathogenesis by inhibiting SARS-CoV-2 replication and entry to its host cells. Different components of plants biochemicals are the most desirable herbal drink or fruit that can be introduced as effective adjuvant components in COVID-19 management; and also, to reduce fever and cough as the most*

common complication of COVID-19 via their anti-inflammatory effect." [CC/400 - INQ000377768) Robyn Soma, President of the National Institute of Medical Herbalists, may be able to provide more information on the potential benefits of herbal medicine in the management of Covid-related illness. Herbal medicine is not available on the NHS, although the NHS website advises patients that they can *"... find THR-registered products in your local health shop, pharmacy or supermarket"* and THR (traditional herbal registration) is available through the government website.

e. Homeopathy. Homeopathy was available on the NHS until 2017, some of our members have found it to be helpful. Corinne Stuart, Chief Executive Director of the Society of Homeopaths may be able to provide information on homeopathy and its potential uses in Covid-related illness.

f. Hyperbaric Oxygen Therapy (HBOT). According to the British Hyperbaric Association, "*Hyperbaric oxygen therapy is a treatment which significantly increases the amount of oxygen available to the body's tissues, thereby creating an environment that is more conducive to healing certain conditions.*" HBOT is available on the NHS for certain conditions. Perhaps Dr Doug Watts, Chair of the British Hyperbaric Association, could provide information regarding HBOT and its potential uses in Covid-related illness.

g. Ozone Therapy. On 25 October 2020, Virus Research published *Ozone therapy in COVID-19: A narrative review*, and concluded, "*Systemic ozone therapy has several positive effects, such as control of inflammation, stimulation of immunity, low antiviral activity and protection from acute coronary syndromes and ischaemia reperfusion damage. This therapy could be a new method of immune therapy, so its use in combination with other antiviral drugs in COVID-19-positive patients may be justified, helpful and synergic.*" [CC/401 - INQ000377769] Steven Karim, Founder and CEO of the Ozone Society, may be best placed to provide more information regarding ozone therapy and its potential benefits for Covid-related illness. Ozone therapy is not available on the NHS.

h. Reflexology. On 18 June 2021, Cambridge University Press published a study into *Reducing fatigue-related symptoms in Long COVID-19: finding an intervention that works*, including massage, and concluded that "*Our findings indicate that this intervention based on massage and mobility exercises significantly reduced fatigue related to Long COVID. It may be that early intervention and supportive treatments at the end of the acute phase of COVID-19 can help overcome acute phase symptoms and prevent them becoming chronic/enduring.*" [CC/402 - INQ000377770] Deborah Cook, Chair of The Association of Reflexologists, may be able to provide more information about the benefits of reflexology for Covid-

related illness. Reflexology is available on the NHS.

i. Mouthwash/nasal sprays: In 2021 a small (n = 41) triple-blinded randomised controlled trial demonstrated that an adjunct mouthwash may reduce acute COVID-19 severity in severe unvaccinated cases, reducing hospitalisation by 3 days, with no ICU stays (versus 30 % of the placebo group going to ICU). More recently, a systematic review has reported reduced viral load with mouthwash use and "There is also the possibility that the use of mouthwash containing cetylpyridinium chloride in SARS-CoV-2 positive subjects could reduce transmissibility and severity of COVID-19.". NHS Salisbury took note of the emerging evidence and advised patients with COVID-19 to mouthwash regularly to reduce viral load. Similarly, NHS Barts Health and Queen Mary University of London researchers showed efficacy in using nasal sprays in 2022. We ask why such a simple and safe measure was not emphasised by public health bodies?

a. In addition, therapeutics and medications that are already known to have success in treating the conditions that some of our members have been diagnosed with, could perhaps be drawn upon without the long periods of time that our members are experiencing with delayed diagnoses. These conditions include Postural Orthostatic Tachycardia, Peripheral Neuropathy, Myalgic Encephomyelitis, Myocarditis/ Pericarditis, Post Traumatic Stress Disorder,

Stroke, Chronic Inflammatory Demyelinating Polyneuropathy, Thrombocytopenia/Thrombosis, Migraine, and Allergies; all of which have treatment pathways and guidelines within the NHS.While most of our diagnoses have no cure, multiple treatments available through the NHS that can at least alleviate symptoms and improve quality of life for patients. Considering the safety profile of some of those treatments and the length of time our community has now been suffering, we need to urgently start at least trying some treatments, even if we do not have the test results to warrant them.

465. Other pharmaceutical products that have helped vaccine induced illness include amitriptyline, antihistamines, beta blockers, bisoprolol, blood pressure controlling medications, bumetanide, capsaicin, carbamazepine, colchicine, corticosteroids, dabigatran, dapagliflozin, diazepam, eye drops, fenofibrate, fludrocortisone, gabapentin, immunosuppressants, Inspra, ivabradine, IVIG, maraviroc, mast cell stabilisers, melatonin mestinon, methylene blue, mirtazapine, morphine, mycophenolate mofetil, pregabalin, quetiapine, and sertraline. Often these have been used on a trial and error basis, and it is unclear whether any research is being conducted into the effects on Covid-related illness. More research is necessary.

466. Other therapeutics that have helped vaccine induced illness include Creative Kinesiology, deep salt therapy, goldic, infrared light therapy, massage, photobiomodulation, psychedelic therapy, saline infusions, therapeutic

phlebotomy, reiki, and vagus nerve stimulation. Other minerals and supplements that have helped include Co Enzyme Q10, electrolytes, glutathione, iron, l-serine, luteolin, N-acetylcysteine (NAC), slow sodium, and tauroursodeoxycholic acid (TUDCA). Again, more research into these fields is needed.

467. In 2021 (though originally published in 2020 as a preprint), a study found several drugs to be associated with significantly reduced odds for COVID-19 hospitalisation. These included: ubiquinone (also known as CoEnzyme Q10), ezetimibe (a cholesterol-lowering drug), rosuvastatin (another cholesterol-lowering drug), flecainide (an antiarrhythmic drug), and vitamin D (Israel et al., 2021). Some of these have continued to have some research in them, for example, statins have not been shown to be effective in reducing mortality or hospital stay in acute COVID-19 (Ren et al., 2023); however, others have not been further studied so we do not know whether or not they have therapeutic potential. These, and other agents (which have been used for many years, with a greater awareness of adverse reactions), may have efficacy in reducing COVID-19 severity and chronic outcomes, thus reducing the reliance on vaccines. For example, metformin has recently been shown to reduce long COVID risk by 41 % (Bramante et al., 2023), which is similar or greater than many estimates for the effects of vaccines on long COVID risk (Ayoubkhani et al., 2022; Byambasuren et al., 2023); why has it taken three years to find this? How long will it take for metformin to be included in clinical guidelines and available for wider use

(considering unmitigated spread of COVID-19)? What other pharmaceuticals and/or supplements have such effects?

468. SARS-CoV-2 is an airborne virus which causes COVID-19. It is spread via aerosols, and can linger in the air for several hours. Therefore, clean air initiatives have a fourfold benefit with regards to vaccine injuries:

a. Many vaccine injured patients report symptom worsening after infections (including COVID-19)
b. Since vaccine injured patients have been advised not to, or do not want to, get further vaccines, their risk of severe COVID-19 is elevated
c. Many vaccine injured live with others who have to go to work or school which can be high risk areas and can bring home diseases.
d. Reduction in the transmission of pathogens potentially means a lower need for vaccinations overall, which means fewer vaccine injuries, whilst still mitigating disease spread.

469. Clean air can be achieved through many mechanisms. Whilst surgical masks offer some protection when widely used, respiratory protective equipment (RPE), such as face-fitted FFP3s can offer up to 100 % protection against infection even in high-risk settings (Banholzer et al., 2023 CC/403 - INQ000377771; Ferris et al., 2021, CC/404 INQ000377772; Royal Society, 2023). There are several limitations to these, including cost, fit checks, breathing difficulties (e.g. for patients with respiratory problems), and the need

to remove them for certain medical procedures.

470. Therefore, a multitargeted approach is warranted to support clean air, such as ventilation or filtration (Alwan et al., 2020; Banholzer et al., 2023; Morris et al., 2022, CC/405 - INQ000377773). Unlike vaccination, RPE, filtration, and ventilation remain effective even in the face of viral mutations. Clean air initiatives can effectively be implemented by the government, making it safer for vaccine injured patients, and others, to do basic activities and attend medical appointments more safely. These measures have a greater impact in terms of mitigating spread and reducing the risk of illness, and are supported by The Lancet COVID-19 Commission Task Force on Safe Work, Safe School, and Safe Travel (2022) and the World Health Organization (2021). UKCVFamily would like the Inquiry to investigate why clear air initiatives weren't and haven't been initiated as a therapeutic in the context of the COVID-19 pandemic.

471. Self-help lifestyle changes that our members feel have been beneficial to them include a general commitment toward maintaining good health: eating fresh and unprocessed food, time spent outdoors, hot/cold water therapy to promote circulation, detoxing, breathing exercise, physical exercise but only at a level that will not bring about relapses, and pacing. Such health-focused lifestyle changes during lockdown may have been challenging for many to maintain, and, according to Gavi: The Vaccine Alliance, this in itself may have damaged our immune systems, "*For nearly a year, a sizable chunk of the world's*

population has spent a significant amount of time shuttered inside their homes, venturing outdoors only for essential supplies or certain types of work. Staying at home is a good way of limiting our exposure to coronavirus, but it could leave us more vulnerable to other infections if we don't take steps to reduce stress, protect our sleep, and ensure we're getting the nutrients and exercise we need to stay healthy." (*Why lockdown can be bad for your immune system - and what to do about it*, 13 January 2021)

472. We are concerned that, the government did not pay enough attention to ensuring that UK residents were focused on the aforementioned components of maintaining good health, and instead were living in a fear-based environment, which also negatively impacts the immune system, as documented in the Mayo Clinic Proceedings article published November 2020, *Stress and Fear: Clinical Implications for Providers and Patients (in the Time of COVID-19 and Beyond)* [CC/406 - INQ000377774], which concluded "*The physiological and psychological consequences of the worldwide COVID-19 pandemic on both patients and caregivers are well documented, but the link between physiology, pathophysiology, and psychology in this milieu is underappreciated. We have provided a brief overview of the physiologic consequences of stress and fear; better understanding of these relationships can inform care of both patients and providers. Diligent attention to stress management and human interactions can have a rapid and positive influence on patient outcomes. The approaches recommended in this paper can be implemented immediately to reduce*

suffering imposed by this pandemic and beyond." It would be useful to know not only what steps were in place to ensure that — during a health crises access to fresh, nutritious food was facilitated; but also what steps the government put in place both during and after lockdowns, to actively support citizens in managing the potential negative impact of living in a state of fear.

473. Many of our members have spent a significant amount of time living in fear — fear for their health, fear of dying, fear of leaving children alone, fear of the future in general. Some are still learning to manage the psychological impact of having an adverse reaction (as detailed earlier in this document), and many of us have drawn upon specific therapeutics to support our mental health as well as our physical health, such as cognitive behavioural therapy, counselling, meditation, praying, private coaching for holistic wellbeing, sound baths, spiritual/emotional self help, and tapping. Some of these forms of mental health support are available on the NHS but members only seem able to access them when in crisis. More investment into preventative measures is needed.

474. The above therapeutics are used by our members, and experts in their fields would be best placed to provide further information to the Inquiry regarding the possible benefits of these therapeutics that could have been explored at various points during the pandemic, could potentially be useful for patients currently requiring treatment, and may be useful for future health crises. Some of these treatments are available through the NHS, but most are privately available.

Funding needs to be made available — along with a more open-minded and solution-focused approach — so that a variety of treatments are more widely known about and accessible to the public, as well as to the NHS itself.

475. We are concerned that the amount of and attitude toward investment into vaccine development as the sole way of dealing with a health crisis may cost people their health and their lives — both the people affected before a vaccine was available, and the people who become affected afterwards through adverse reactions. We are concerned that new and existing therapeutics and medications were not given enough attention or investment. We are concerned that the government actively discouraged non-vaccine-related products or modalities that potentially could have helped.

476. Our community has found help from a wide variety of products and modalities, albeit usually at our own financial cost. We are concerned that funding has still not been made available on a national, regional, and individual level. Many of our members have established their own healing protocols at entirely their own cost and financial support is urgently required in order to maintain this.

477. Currently the vaccine-injured themselves are initiating most of the research into their adverse reactions. React19.org in collaboration with UKCVFamily and other international advocacy groups have just launched the largest survey of vaccine adverse reactions that we know of with the University of Maryland.

478. UKCVFamily founder Ms Charlet Crichton, alongside one of UKCVFamily's members, Dr Harriet Carroll set up a collaboration between the University of Oxford, University of Kent, and Hamburg University to understand the vaccine injury experience, with the hope to improve healthcare and guide Vaccine Damage Payment Scheme reform.

479. Additionally, Dr Harriet Carroll, also ran a survey in 2022 to characterise vaccine injuries; has written letters to the Editor at academic journals about published papers misrepresenting vaccine injury; has written up a case study of her and another patient; is working on a long COVID biomarkers paper with UK clinicians to ensure vaccine injury gets fair representation; has help set up and run a patient-led collaboration to understand underlying pathophysiology in vaccine injuries and related diseases like long COVID; and is working with a US group to understand COVID-19 vaccine risks, all without pay. Dr Harriet Caroll would be best placed to advise the Inquiry regarding current Covid-19 vaccine injury research.

480. UKCVFamily feel it shouldn't be left to patients that are ill to investigate adverse reactions themselves, the government should want to understand why and how they are caused. UKCVFamily members have spent a vast amount of money and time on trying different medication, testing and treatments, simply because there hasn't been adequate medical support for them.

481. We are very concerned that researchers appear disinterested in learning about our experiences of these new and existing therapeutics and medications. A vast body of knowledge is being developed within the vaccine-injured community that could benefit others, but it is being ignored. This should have been a time for learning and research for the medical community.

VACCINE DAMAGE PAYMENT SCHEME

482. In the UK, the Vaccine Damage Payments Act 1979 [CC/ 407 - INQ000377775], was introduced in response to campaigning efforts by advocacy groups, including the Association of Parents of Vaccine Damaged Children, and MPs supporting them [CC/408 - INQ000377776].

483. This Association was founded by two women, Rosemary Fox MBE and Rene Lennon, who's daughters Helen and Joanne, had suffered severe brain damage following polio vaccination in the 1960s. Rt. Hon. Lord Ashley of Stoke, became the honorary secretary of the association and recalls *'Just imagine that in 1962 you have been blessed with a happy, healthy baby daughter and that overnight she is transformed into one that could never be normal and who suffers permanent mental handicap and convulsions. Then as you sought explanations and challenged the Government's refusal of compensation, you were warned that you were damaging the vaccine programme and told to keep quiet. How, in*

that deferential age, would any woman react? Rosemary Fox refused to condone this lamentable ethos, defied convention and began a campaign for compensation.' (Foreword by Rt. Hon. Lord Ashley of Stoke; Fox,Helen's Story)

484. In 1973, the campaign gained traction and a piece was published in the British Medical Journal [CC/409 - INQ000377777] *'The moral justification for compensation … is based on the social contract. National immunisation programmes not only aim to protect the individual but also to protect society. … If individuals are asked to accept a risk (even a very small one) partly for the benefit of society then it seems equitable that society should compensate the victims of occasional unlucky mishaps'.*The two main aims of the Association were to 'establish the reality of vaccine damage' and to demand compensation for those affected' (Fox, Helens story p28).

485. In 1974, a peer reviewed paper was published by Wilson [CC/410 - INQ000377779], Kulenkampff and Schwartzman, three doctors from Great Ormond Street hospital who found a potential causal link between brain-damaged children and the whooping cough vaccine. The Associations' campaign carried on and gathered media and public attention. There were concerns made that this attention was damaging the uptake of the Pertussis vaccination.

486. Members of Parliament raised questions and debates in the Houses of

Parliament until in 1977, the then Labour government agreed to introduce the Vaccine Damage Payment Act. The details of the scheme could not be settled until the Report of the Royal Commission on Civil Liability and Compensation for Personal Injury was received, otherwise known as the 'Pearson Report'. The Royal Commission recommended, first, that there 'should be strict liability in tort for severe damage suffered by anyone as a result of any vaccination which has been recommended in the interests of the community'. The Vaccine Damage Payment Scheme was originally created as an interim scheme. It has been suggested that a permanent solution should be found as soon as possible [CC/411 - INQ000377780].

487. The scheme has remained an interim payment 'to ease the burden' for families affected and never became a form of compensation as it was intended. Again, the temporary nature of the scheme has been reiterated. [CC/412 - INQ000377781] However, the temporary scheme became permanent and it is still in force today. At the time the payment of £10,000, (roughly equivalent to three years average wages) was recognised as being much less than what would potentially be received by a claimant pursuing civil litigation but that receiving the payment wouldn't preclude a claimant from taking such action. However, a clause was put into place allowing an adjustment in any such proceeds to detract the VDPS sum from any winning awards received through civil action. It was noted by campaigners at the time that the amount of money awarded by the Vaccine Damage Payment would certainly not cover the costs

of looking after a disabled child for life.

488. In order to receive the vaccine damage payment of £10,000 claimants originally had to be assessed as being 80% disabled on the balance of probability by vaccination and that all cases were to be dealt with sympathetically. [CC/413 - INQ000377782]

489. Claimants have six years to make a claim from the date of vaccination. Cases were and still are assessed regarding disability percentage, based on Industrial Injuries and War pensions schemes from prior to the second world war.

490. Throughout the years, there have been other patient advocacy campaigning groups, looking to seek adjustments to the Vaccine Damage Payment Act.

491. In 2007, after 20 years of campaign work, Olivia Price, was awarded an MBE for her advocacy efforts following her daughter's disability post vaccination. The group she represented, the Vaccine Victims Support Group lobbied parliament many times [CC/414 - INQ000377783].

492. From the initial amount of £10,000 in 1979, the sum increased to £20,000 in 1985, £30,000 in 1991 and £40,000 in 1998. In June 2000 Alistair Darling, the then Secretary of State, announced that the Payment would be increased to a total of £100,000 and would cover disability 60% and over [CC/415 -

INQ000377784].

493. The Vaccine Damage Payment Scheme was also discussed at the time, 28th June 2000, in the House of Lords by Lord Ashley of Stoke, Lord Brennan and Lord Clement-Jones. The increase in payment and the drop in the eligibility criteria was well received, however, the Peers were keen to point out the length of time it had taken to reach that point. [CC/416 - INQ000377785]

494. The campaigning group, JABS (Justice, Awareness and Basic Support) is another such patient led advocacy group and was formed in 1993 by Jackie Fletcher, who's son Robert was severely damaged after his MMR vaccination. After 18 years of her and her husband appealing for the Vaccine Damage Payment on behalf of their son, they were finally awarded, £90,000 [CC/417 - INQ000377786). This amount of time is unacceptable for a payment which is meant to help families affected, not distress them further. The media coverage at the time referred to the payment as '*compensation*', which we know the Vaccine Damage Payment Scheme is not, leading the public to believe that the parents were fully compensated.

495. It seems throughout history, change to the Vaccine Damage Payment Scheme and indeed its inception has arisen by patient led advocacy groups and their supportive MPs. It is an uncomfortable topic, one which has been controversial and is weighted by the fear of vaccine hesitancy. Many times throughout the

history of the scheme, MPs and ministers have justified the reasoning behind the payments as a tool to reduce public fear around vaccination. Nonetheless, vaccine-injured and bereaved patients do exist and so do Members of Parliament that are compassionate towards us.

496. In June '21, Sir Christopher Chope OBE MP presented the first version of his Private Members Bill to Parliament. This was "*A Bill to place a duty on the Secretary of State to make provision about financial assistance to persons who have suffered disablement following vaccination against Covid-19 and to the next of kin of persons who have died shortly after vaccination against Covid-19; to require the Secretary of State to report to Parliament on the merits of a no-fault compensation scheme to provide such financial assistance, on whether there should be any upper limit on the financial assistance available, on the criteria for eligibility and on whether payment should be made in all cases where there is no other reasonable cause for the death or disablement suffered; and for connected purposes."* [CC/418 - INQ000377787]

497. Sir Christopher then secured several debates thereafter on this topic, the first being on 10th September 2021. During this debate Sir Christopher called for "*a judge-led inquiry into the issues raised" based on a petition "to improve support for those harmed by covid-19 vaccine*s" that had gained over the 10,000 signatures required to be debated in Parliament [CC/419 - INQ000377788].

498. **Parliamentary privilege**

499. UKCVFamily have found that even when a consultant has linked our members' condition to having a causal link to Covid-19 vaccination, the VDPS medical assessors disagree and we have many members with the same diagnoses. UKCVFamily feel that claims should be more weighted in favour of the claimant as was originally proposed in 1978.

500. In March 2022, Caroline Pover, founding member of UKCVFamily started to converse with Sir Christopher Chope OBE MP, with regards to the issues faced by UKCVFamily members as part of our MP campaign. Sir Christopher was to organise an All Party Parliamentary Group on Covid-19 Vaccine Damage and indeed in July '22, this transpired. UKCVFamily try to have a representative at all the meetings of Sir Christophers' APPG.

501. Following on from that inaugural meeting, Sir Christopher Chope has taken part in several more debates, the latest being in October 2023. Parliamentary privilege

Parliamentary privilege

Parliamentary privilege

502. Parliamentary privilege

503. As outlined elsewhere in this document, UKCVFamily has a number of MPs both supporting the group as a whole and their individual vaccine-injured or bereaved constituents.

504. While the UK has led the way in the development and rollout of Covid-19 vaccines, that is not the case in terms of financial provision under the VDPS when compared with 37 other national compensation schemes, analysed by the Centre for Socio-Legal Studies, University of Oxford and Dr Sonia McCloed. [CC/505 - INQ000508043, CC/506 - INQ000508044, CC/507 - INQ000508045, CC/508 - INQ000508046, CC/509 - INQ000508047, and CC/510 - INQ000508048].

505. The UK VDPS is one of only 12 out of 38 national schemes that pays ONLY for

permanent injuries. Countries that pay for temporary vaccine injuries include Australia, Austria, China, Denmark, France, Germany, Hong Kong, New Zealand, Norway, Singapore, South Africa, Sweden, and Switzerland.

506. The 60% disability threshold in the UK compares unfavourably with, for example, South Africa which has a 5% threshold for permanent impairment and 25% for temporary, and Norway where the threshold for significant injury is 15% disablement.

507. 15 national schemes provide some form of compensation for loss of earnings which the UK VDPS does not.

508. 19 national schemes provide a level of cover for expenses on an individual basis which the UK VDPS does not.

509. 14 national schemes provide a level of cover for funeral expenses which the UK VDPS does not.

510. 13 national schemes pay compensation to dependents which the UK VDPS does not.

511. In a poll taken by UKCVFamily members 91% thought that the Vaccine Damage Payment Scheme was inadequate, the remaining 9% hadn't heard of the

scheme at all.

512. So far, as of 9 September 2024, 14,844 claims have been made to the VDPS. Of the total number of claimants, 7,028 have been notified of an outcome. 1,078 claims were received more than 12 months ago and have not yet reached an outcome. Of these 1,078 claims, 256 claims were received more than 18 months ago and have not yet reached an outcome. As of 3 September 2024, 186 claimants have been notified that they are entitled to a Vaccine Damage Payment. Of the 186 claims, fewer than five were Pfizer and Moderna and the remaining claims were AstraZeneca. 6,845 claims have been rejected entirely [CC/422 - INQ000377792]. The latest figures show us that most VDPS applicants are not receiving a payment under the scheme. Many of our members that have applied, have waited over a year for a decision, sometimes in dire financial circumstances. The delays to payments have been extensively covered by the media including The Telegraph [CC/423 - INQ000377793].

513. A few UKCVFamily members have been awarded the payment but the majority are either still waiting for a decision, have been rejected or have decided not to claim. One of the main reasons our members give for not claiming is that they don't want to put themselves through rejection and the emotional stress that will cause, having witnessed other members being rejected. Many of our members are already struggling with acceptance of now being physically disabled or chronically unwell for almost three years post vaccination. The rejection letters

can be harsh, inaccurate and very impersonal, making the applicant feel belittled, undermined and totally abandoned by the system. Unfortunately, members have felt suicidal after receiving the Vaccine Damage Payment rejection letter.

514. Despite some of our members having their adverse reaction clearly documented within their permanent medical records, many are denied the payment on causation. The current number of applications denied overall due to causation reflect this (3,128 claims).

515. The VDPS is primarily based on the Green Book and Brighton Collaboration. The assessors therefore do not assess the actual likelihood of the reaction being causal to the vaccine. For some conditions, such as myalgic encephalomyelitis, there is virtually no published research. However, charities and patient groups know very well that vaccines can cause it (e.g. ME Association, 2021, CC/424 - INQ000377794). The VDPS has used absence of evidence to infer evidence of absence. As discussed above regarding causal inference, there are other ways to assess causality, and assessors should be utilising these, particularly in the cases of currently unrecognised reactions. This is particularly pertinent due to the length of time it is taking for our members to get a diagnosis, meaning if there is going to be a population signal, this will potentially take decades to be established.

516. VDPS medical assessors should take into account the opinion of doctors who have treated the patient. If there is a good record that the treating clinicians believe an injury is legitimately from the vaccine, the assessors (who do not physically assess the patient) should not have powers to decide otherwise. In the case where the treating medical team do not strongly suspect a link to the vaccine, the assessors should use pathophysiological evidence and mixed methods of causal inference to make their assessment, not just based on currently recognised reactions.

517. Of the UKCVFamily members that have applied and causation has been accepted, many are then rejected due not meeting the 60% disability criteria. parliamentary privilege

Parliamentary privilege

Parliamentary privilege The current figures for the rejection reflect UKCVFamily members experience and are not represented truly by the suggestion made by Maria Caulfield MP. At the time of writing this, of the claims made, 3,128 were rejected on causation and 243 were rejected on percentage of disability.

518. The guidelines for what levels of disability actually mean should be completely transparent. The current guidelines are based on wartime injuries and similar. Equally some symptoms may seem relatively benign, but can be incredibly debilitating. For example, tinnitus has driven people to suicide (Lugo et al., 2019, CC/426 - INQ000377796). Such nuance does not seem reflected in the

Vaccine Damage Payment Scheme.

519. Many UKCVFamily members are now on medications, likely for life, because of the adverse reactions suffered. Even the safest medications come with risks of side effects, especially with long term use. However, some medications are highly risky, for example, fludrocortisone (often used for postural orthostatic tachycardia syndrome) is an immunosuppressant with a warning about severe psychiatric side effects. Direct oral anticoagulants carry a risk of internal bleeding which can be fatal and some of our members are on these long term. Even if these drugs meant we were fully functioning again (which they don't), our lives would still be centred around reducing the risks that come with such medications (e.g. avoiding falls/risk of bleeding). The risk that we carry with these medications is not taken into account with VDPS assessments. Equally, if for example, someone had a fatal bleed due to anticoagulant use, this would not be logged as related to the Covid-19 vaccine, even though they were only taking the medication due to their adverse reaction.

520. The process can be demoralising and when acutely unwell, traumatic. UKCVFamily believe the eligibility in the criteria for the Vaccine Damage Payment should be removed completely in cases where there is a clear medical diagnosis of an adverse reaction or a bereavement caused by one, to address these issues more compassionately. Furthermore, UKCVFamily believe that in cases where there is a medical diagnosis or bereavement clearly determined

as caused by vaccination (such as a coroner's report), payment of damages to be issued within 28 days of that diagnosis or report.

521. In a recent Freedom Of Information request, it is revealed that most applications to the scheme are of working age people, with 6,011 claimants under the age of 66. Yet out of those only 129 have been awarded. 29 of those claimants who are not yet awarded are 0-17 years old, no under 18s had been awarded as of the 13/10/23 [CC/427 - INQ000377797].

522. UKCVFamily believe that a financial contribution should be made toward any healthcare expenses/funeral costs incurred after a person has suffered an adverse reaction to a government recommended vaccine or died because of one. Families should not be left out of pocket because they took a vaccine that was highly recommended by the government and NHS.

523. At the start of the Covid-19 vaccine roll out there were just 4 members of staff assessing claims for the VDPS. This was later addressed nearly a year after the roll out, once it was apparent that the department couldn't cope with the amount of applications in an efficient way. The Department of Work and Pensions transferred the processing of applications to the NHSBSA in November '21. In May '22 Crawford and Co., a third party company were also contracted and started to process applications. Staff increased from 4 to 80 [CC/428 - INQ000377798].

524. UKCVFamily are concerned with how the Vaccine Damage Payment Scheme is managed. Specifically, it is run by the NHS Business Service Authority (NHS BSA), who outsource to Crawford & Company. On TrustPilot, Crawford & Company have a rating of 1.2 stars (out of 5), this is rated as "bad". Of 211 reviews, 96 % rated this company 1 star, 0 % 2 stars, < 1 % 3 stars, < ! % 4 stars, and 3 % 1 star [CC/429 - INQ000377799]. We would like the inquiry to investigate why Crawford & Company were chosen to do this vital public service, whether they have appropriate expertise, and why the NHS have not done this themselves. We would like Crawford & Company to be fully audited and assessed in terms of their performance relating to the Vaccine Damage Payment Scheme.

525. In addition, a FOI request in May 2023 asked NHS BSA the qualifications of VDPS assessors, to which they replied "*the information you requested is not held by the NHS Business Services Authority. This is because this is managed by the independent medical assessor supplier…All claims are assessed on a case-by-case basis by an independent medical assessor. Medical assessors are General Medical Council (GMC) registered doctors with a licence to practise and at least 5 years' experience*" [CC/430 - INQ000377801]. The Information Commissioner (2023) have reported that individual assessors' qualifications would breach data protection if given to a claimant [CC/431 - INQ000377802), however UKCVFamily do not think it is reasonable that the NHS BA do not even

hold information regarding who is doing the assessments. UKCVFamily ask the inquiry to investigate whether it is appropriate for anonymous assessors with no known identity to NHS BA to be completing these assessments. UKCVFamily feel it pertinent for the Inquiry to examine how the assessors are employed, and what qualifications or experience they have specifically relating to vaccine injuries.

526. UKCVFamily question whether assessors are truly informed about the pathophysiology of vaccine injuries, for example, that certain symptoms might have a slow onset over several months. As such, we also ask whether assessors should be engaging with scientists, whose work often takes time to publish and be accepted as likely true, to help identify whether a case is likely a true vaccine injury.

527. As per the VDPS medical assessor's handbook **[CC/432 - INQ000508090]** claims are denied because a connection is not made with a particular diagnosis and the vaccination in the Green Book but without research no additional conditions will be added to the Green Book. Adverse reactions to a Covid-19 vaccination need more urgent research in the UK.

528. UKCVFamily would like assessors to be aware of the significant limitations within our medical records. Many of our members have found significant inaccuracies or omissions. Some have been rejected for the payment because

of those inaccuracies. Assessors seem to weigh medical records as a more reliable version of events than the lived patient experience. We have seen cases where certain symptoms have not been recorded on medical records, and the VDPS determined that meant the symptom was no longer a problem, for example. As disabled patients, it is impossible to correct every inaccuracy on our record, and our voice should be taken as the most accurate version of events, corroborated by medical records (which are based on our account of events anyway).

529. Doctors also need to understand the relevance of their consultation write-ups, for example, writing faux reassurances about the patient improving can be misconstrued as the disability is not permanent. As above, inaccuracies and omissions can impact our assessment. Writing that a reaction is definitely not from the vaccine may work against our claim, when in reality the doctor does not know that for certain.

530. UKCVFamily would like the Inquiry to investigate how assessors have determined that cases of VITT, which is uniquely caused by viral vector vaccines, has been determined non-causal to the vaccine. This highlights the significant flaws in the system [CC/433 - INQ000377804].

531.

Parliamentary privilege

Parliamentary privilege

532. Prior to the Covid vaccine rollout, the VDPS was managing an average of 76 claims per year (or 1.5 per week). These claims were entirely paper-based and the scheme had no room for expansion. As it currently stands, there have been 7,544 claims as of 20th October 2023.

533. The pre-rollout assessment states that 670 claims were expected (based on the number of claimants for the H1N1 vaccine — 759), which, at the pre-Covid rate of processing, the VDPS would have taken almost nine years to process [CC/434 - INQ000292597].

534. In addition, the DWP had a backlog of claims from other (non-Covid) vaccines and there were no plans to resolve these before the rollout of the Covid-19 vaccines.

535. The VDPS hadn't been updated since 2007 and therefore the amount hasn't risen with inflation which would be £213,018. This was not considered in the pre roll-out assessment [CC/434 - INQ000292597).

536. The amount (if received) by a VDPS claimant (£120,000) is a drop in the ocean compared to overall financial and life losses. Such an amount, particularly for younger claimees, does not make up for loss of earnings, quality of life nor pension contributions. Other short-term means of financially supporting vaccine-injured while waiting for the VDPS to be reorganised were not part of pandemic planning.

537. Our members have found the process of application difficult, most are acutely or chronically ill and many suffer cognitive difficulties due to the adverse reaction. Suffering from multiple new health conditions, many that cause fatigue both cognitively and physically mean that applicants have a vast amount of *'health admin'* to complete. The Vaccine Damage Payment Scheme application and probable subsequent applications for mandatory reconsideration and appeal add to the stress that the applicant is placed under.

538. It is extremely traumatic for some UKCVFamily members to relay the story of how they became ill and what happened thereafter. Many UKCVFamily members are diagnosed with PTSD due to their adverse reaction experiences and are working gently through them with trained psychologists and mental health practitioners. Some UKCVFamily members don't yet have access to mental health support and are extremely vulnerable. One part of the application form [CC/435 - INQ000411777] asks specifically to "Tell us what happened to

you" with no sign posting for mental health support during this process. When an applicant is rejected it can feel like they are being disbelieved, that their experience is being silenced and compounds the feeling of being outcast by society. When an applicant is accepted, the validation can cause the claimant to feel annoyed with 'the system' for having been through such a lengthy drawn-out process and many more feelings can arise. Whether applicants' cases are rejected or accepted for the payment, UKCVFamily feel the process of applying itself needs more careful consideration in respect of the psychological well-being of its applicants.

539. There has been a lack of transparency in the Vaccine Damage Payment Scheme process. Claimants only had access to guidance that VDPS assessors use through a Freedom Of Information request. This should be a transparent system so claimants understand what they are being assessed on, and public trust is maintained. Guidelines for claimants are significantly lacking. It is unclear what applicants should include so the assessors can make a fair assessment. Many UKCVFamily members have had to pay for legal advice, just to help them understand and apply for the payment yet the website says legal advice shouldn't be necessary to make a claim.

540. It has been mentioned many times Parliamentary privilege that those adversely affected by Covid-19 vaccines (or indeed any vaccine) who are not eligible for the Vaccine Damage Payment Scheme can still claim state benefits such as

disability, Personal Independence Payment etc. This may be so, yet UKCVFamily feel that this is an entirely unfortunate response to people who have taken a government recommended and heavily publicised vaccination and have become disabled or chronically ill because of it.

541. Covid-19 vaccines were added to the list of vaccines that claimants could apply against in December 2020, suggesting that the government had considered supporting those who suffered adverse reactions in advance [CC/436 - INQ000361136).

542. However, the Vaccine Damage Payment Bill itself wasn't considered for reform prior to the roll out of the Covid-19 vaccines. **Parliamentary privilege**

Parliamentary privilege

Parliamentary privilege

543. Meanwhile, those patients have suffered financially, medically and emotionally as UKCVFamily members can attest. Some have been unable to work since they had an adverse reaction, losing their businesses and careers. Some have struggled to pay mortgages, to finance adaptations to their homes to accommodate their disability and others have spent vast amounts of money to seek private medical help.

544. Civil litigation can still be taken alongside claiming the Vaccine Damage Payment and it has been cited many times in the Parliament that this is the case. The Government response to a petition to remove indemnity from vaccine manufacturers clearly reiterates that the indemnity does not preclude the right of recipients to sue [CC/439 - INQ000377810] *"Although the legislation provides partial immunity from civil liability for vaccines supplied under emergency authorisation, it preserves individuals' right to sue the producers of the vaccine under Part 1 of the Consumer Protection Act 1987.*"

545. Given that the Vaccine Damages Payment Scheme was never intended to serve as compensation, to cover the loss of income, or to subsidise the long-term expenditure required by those managing life-long chronic conditions, many members are exploring or have explored civil litigation instead of or as well as putting in a claim to the VDPS to meet their likely long-term financial needs.

546. This possibility of civil litigation is initially an appealing one given that the typical sums awarded in cases resulting in serious harm and permanent disability are significant, and can match or outweigh that provided by the Vaccine Damages Payment Scheme. For example, the recent payment of £100,000 to victims and bereaved families of those involved in the infected blood scandal was explicitly referred to by Kit Malthouse MP as an interim payment, while he recognised the need for more significant ex gratia payments for the lifetime of those impacted [CC/440a - INQ000377812 and CC/440b - INQ000377813].

> *"Those affected by the infected blood scandal have suffered terribly over many years and that heart-breaking and unimaginable pain has been compounded by the financial uncertainty many have faced. These interim payments will start the process of securing that certainty. My priority is to get the money to those people as quickly as possible."*

Leaks to the press from Treasury staff at the time of the Inquiry in July 2023 estimated that the likely final payments will total between five and 20 billion pounds.

547. The case studies cited by solicitors our members have contacted suggest that some of our members could potentially expect payouts that would significantly alleviate their current financial stress and open the door to exploring more treatment options privately. For example, Blackwater Law represented a man whose misdiagnosed transient ischemic attack led to a significant stroke and a subsequent loss of mobility that will require life-long care. The man was awarded a payout of £1,000,000.

548. Law firms specialising in this field, point to the possibility of positive outcomes and significant financial compensation, with Blackwater Law stating NHS Resolution's statistics for 2022-23 show that 13,499 claims against the NHS were upheld (99% of the total) with 51% leading to the payment of damages. NHS Resolution itself states that *"80% of claims were resolved in 2022/23 without resorting to legal action"*.

549. As such, theoretically civil litigation would appear to be a viable option for many of our members who received the AstraZeneca vaccine which potentially fits the criteria to pursue a claim against the manufacturers under Part 1 of the Consumer Protection Act of 1987 [CC/441 - INQ000377814] on the grounds that the vaccines were defective. This is a course of action we know is being actively explored by some bereaved family members and seriously injured recipients of the AstraZeneca vaccine.

550. UKCVFamily members are also exploring potential civil liability action against employers who mandated full vaccination as a condition of employment even when the person had already suffered an adverse reaction to the first dose.

551. The final course of action members are exploring is the option to pursue a case of medical negligence against the NHS. This also appears a viable course of action, given the definition of a viable case by NHS Resolution: there was arguably a 'breach of duty" (delayed or inappropriate treatment that went against NICE guidelines, or a treatment given in the absence of informed consent), and "*medical causation*" (their current health issues are directly linked to this prior medical treatment).

552. This direct causation feels particularly clear in the case of some of our members who sought early medical attention for conditions such as myocarditis (now recognised to be a potential side effect of Covid vaccination). Despite presenting with known symptoms of the condition, their concerns were often dismissed as the condition was deemed very rare, or only seen in young men. In some cases, our members have finally been diagnosed up to two years on from when symptoms first presented and have suffered permanent damage due to this avoidable delay in treatment.

553. However, there are a number of barriers facing those wishing to pursue legal action. Many of these barriers are common to those that members face when

trying to make a Vaccine Damage Payment claim, for example the difficulty of making a claim, the time and financial investments required, the complexity of dealing with a complex legal process while managing an unstable health condition and also the concern about psychological stress caused by reliving a very stressful period in an adversarial process.

554. Among the vaccine injured members of UKCVFamily, awareness of the feasibility of pursuing a civil liabilities claim is low. Many believe that this is not a legal possibility due to the Government granting indemnity to vaccine manufacturers. The knowledge that it is legally possible to sue vaccine manufacturers is limited, and according to our members, some law firms have even incorrectly stated that manufacturers were granted full indemnity.

555. A poll conducted among our members showed only 4% are currently pursuing legal action, while another 15% are exploring their options. The vast majority of our members believed that pursuing a claim would be either impossible or not worth the stress. The key barrier cited by our members was the difficulty of proving causation when the vaccines (and indeed the vaccine technology) are so new that the side effects are not well known or studied, and there are few peer-reviewed articles that can be cited to help support the claim. As mentioned elsewhere even when our members have "*Adverse reaction to a Covid-19 vaccination*" documented on their permanent medical records, this has not proven liable for a VDPS payment, nor would it necessarily mean they could

prove causation in a court of law.

556. While many UKCVFamily members would be keen to pursue action against vaccine manufacturers, some are also reticent about pursuing the NHS for negligence given their continued reliance on the service for care. There is a need to reassure the vaccine injured that seeking redress for errors in their care will not impact their future treatment.

557. The current time-frame set for medical negligence claims is also a barrier for many of our members whose conditions are still evolving and who are still waiting to see the small number of specialists who may be able to provide a diagnosis or confirm causation. NHS Resolution states that "*claims for personal injury are subject to a 'limitation period' of three years. A claimant must issue their claim at court within three years of the alleged negligence taking place or within three years of becoming aware that something went wrong.*"

558. The three year time limitation to take legal action is insufficient, particularly for a group who have largely suffered significant disability, had to deal with loss of jobs, family, and friends, as well as health. Many of us were acutely ill for some time and legal action wasn't feasible then. Many members of UKCVFamily are reaching the 3 year mark now, still chronically ill and our reactions are only recently getting scientific recognition.

559. UKCVFamily would query this time limitation and request that the three year

deadline be extended given the novel vaccine technology combined with current NHS waiting lists and their ongoing illness means it is not realistic for many members to pursue litigation within the current timeframe.

560. UKCVFamily members have found that finding a solicitor willing to take on a liability claim against a pharmaceutical company are few and far between. Even members with letters from UK-based consultants that clearly state both a permanent diagnosis and causation, have been unable to find a solicitor to take on their case. Some have explicitly been told that the only claims worth pursuing are those related to vaccine-induced thrombocytopenia and thrombosis (VITT) caused by the AstraZeneca vaccine, while others have been told verbally that vaccine damages claims are “too political” for firms to want to attach their name to.

561. UKCVFamily are aware of only one solicitor currently pursuing vaccine injury cases in the UK and they are too busy to take on all our cases. Furthermore, with the VITT cases taking a prolonged period of time already, pursuing other cases isn't deemed feasible at this stage. UKCVFamily would like the Inquiry to investigate why solicitors are so reluctant to take on cases of vaccine damage.

562. One additional likely reason for the lack of interest shown by solicitors, even those working for firms who specialise in this field is that they are likely to be very time-intensive and the financial rewards for lawyers even in the event of a

successful case are likely to be low (UK law means successful lawyers do not get a share of the damages only extra fees).

563. Perhaps even more importantly, the chances of a successful claim for vaccine injuries is far lower than that for other medical treatments. To date, in the UK there have been no successful civil liabilities actions for any vaccine, despite successful claims for other drugs and medical procedures.

564. This is in sharp contrast to other nations with similar legal structures such as the US which has seen successful suits against manufacturers of both the Gardasil human papillomavirus and Pandemrix, the H1N1 pandemic vaccine. As noted by Richard Goldberg in an article published online by Cambridge University Press:

> *"There is compelling epidemiological evidence of an increased risk of narcolepsy following vaccination with the H1N1 pandemic vaccine Pandemrix, especially in children, and the Vaccine Damage Unit and the Secretary of State have previously accepted a causal link between the development of narcolepsy and Pandemrix…(despite the) absence of any epidemiological study supporting an increased risk of narcolepsy following vaccination with Fluenz Tetra"* [CC/442 - INQ000377815].

565. A further barrier for many of our members, and potentially for the solicitors they have contacted, is that the novelty and complexity of these cases, particularly

the determination of causation, will mean that the legal cases are likely to take years, even decades to reach a successful outcome.

566. The cost to the Government and the NHS in defending civil liability claims is hugely expensive and also comes at the loss of large amounts of senior NHS staff members time. As stated by the 2022/3 NHS Resolution report, *"The amount spent on claims in 2022/23 was £2.64 billion"*. Parliamentary privilege Parliamentary privilege

567. Logically, significant NHS time and money would be saved by avoiding these medical negligence suits by reforming the Vaccine Damages Payment Scheme so that the vaccine injured are able make a successful claim and receive a more generous payout to avoid feeling financially compelled to pursue a civil liabilities case. This reform would help NHS Resolution meet its top priority key performance indicators of reducing the volume of claims that reach legislation and reducing the time to resolution of claims. It would also help reduce the Treasury's expenditure on successful claims by significantly reducing the legal fees and time required to settle each case.

568. It is the contention of UKCVFamily that this reform would also be fairer to the vaccine injured and as a result could potentially help reduce vaccine hesitancy in future pandemics by reassuring members of the public that there is adequate, long-term compensation to cover life-time expenditure on care in the case that

they are unlucky enough to suffer an adverse reaction to any vaccine.

569. Vaccine Damage Payments was debated in 2015 some 36 years after the introduction of the VDPS [CC/444 - INQ000377817]. These conversations have been going on for far too long, UKCVFamily believe it is now time for change.

570. In a poll of our members 91% said that they feel the Vaccine Damage Payment Scheme is inadequate, the further 9% had never heard of the scheme.

571. UKCVFamily believe that the government should learn from historical failures and those who have spent years campaigning and provide adequate and timely; financial, medical and psychological care to individuals impacted by mass vaccination programmes, medical tragedies and adverse reactions. There is a need to consider not just the benefits of vaccination, but how to adequately respond to individuals directly damaged by it, in a more kind and compassionate way.

572. UKCVFamily are concerned that the Vaccine Damage Payment Scheme is failing those people it was set up to help and this concern is shared by a number of MPs and Peers. The scheme was originally meant to be an interim measure and although it has been updated since 1979, it has been left to patient advocacy groups throughout its history to highlight the need for these amendments. The Bill should now be reformed to reflect modern Britain and the values we all have come to trust. UKCVFamily urge the Inquiry to investigate

whether the Vaccine Damage Payment Scheme was adequately considered and updated in the context of the Covid 19 pandemic and vaccine roll out, and whether it is still fit for purpose and for future emergencies, taking all of the points made in this document into account.

ISSUES THE COVID-19 VACCINE BEREAVED FACE SPECIFICALLY

573. The Inquiry has heard from the Covid bereaved families throughout the modules so far and many of the issues the Covid-19 vaccine bereaved families face overlap with issues raised by other Core participants.

574. Losing a loved one suddenly is tragic under any circumstances, it is extremely important that the process that follows after such a death is investigated as swiftly and as gently as possible for all involved. However, UKCVFamily bereaved members have faced multiple challenges that we will outline below.

575. UKCVFamily bereaved members found that when their loved ones became ill, that they were being told to avoid hospitals, due to Covid-19 and this was a barrier to seeking prompt medical attention.

576. Some UKCVFamily bereaved members feel that their loved ones who died weren't told the potential risks prior to vaccination. They feel that if the risks had been stressed properly at the time of vaccination, or in the public messaging

during the rollout of the Covid-19 vaccines, that they may have seeked medical attention sooner.

577. UKCVFamily bereaved members found that deaths that happened during imposed lockdowns and restrictions were not being investigated. There are accounts of Coroners refusing to investigate deaths, despite the death occurring within hours of the deceased's' Covid-19 vaccination.

578. UKCVFamily bereaved members have found it is very difficult to challenge a Coroners' decision and that any such challenges have a time limit of three months from the date of death [CC/445 - INQ000377818]. Some of the bereaved were not made aware of this, ran out of time and were subsequently refused. UKCVFamily believes there needs to be clearer instruction on how to challenge a Coroners decision and that the time limits involved should be made apparent to loved ones, who are grieving, especially in the context of sudden death.

579. UKCVFamily bereaved members also feel that there is a lack of a complaints system to question Coroners' decisions. Currently the Judicial Conduct Investigation Office handles complaints regarding behaviour and personal misconduct by a coroner, but not regarding Coroners decisions specifically. Stated on the JCIO website –

"Misconduct means personal misbehaviour which is serious enough to require

the Lord Chancellor and the Lady Chief Justice to take formal disciplinary action."

580. UKCVFamily bereaved members have had to ask the coroners in their loved ones' cases to look into the Covid19 Vaccines as a possible factor - as in all of their cases the vaccine was administered prior to death.

581. UKCVFamily bereaved members have had to instruct solicitors to judicially review decisions made by Coroners, which is very stressful when grieving and also expensive. The system for complaints is confusing and adds further trauma to an already very difficult situation.

582. One UKCVFamily bereaved member was told by a coroner to "Get a solicitor and open an investigation" when she asked the vaccine to be looked into as a possible factor regarding her daughter's death. Her daughter was 17 years old.

583. UKCVFamily Bereaved members have felt that no one *wants* to investigate the deaths of their loved ones, they have felt there was no concerted effort to research Covid-19 vaccine adverse reactions and deaths possibly linked to them. When Coroners have been approached by family members of the deceased, they have been described as 'aggressive', 'hostile', 'cold' and 'dismissive'. These are families grieving a sudden and unexplained death and we feel this is highly inappropriate behaviour.

584. UKCVFamily vaccine bereaved members are concerned because deaths where a Covid-19 vaccine was implicated were not properly investigated in their experience. These concerns are around the vaccine adverse reaction death data potentially having been missed and as such, causal links may have been omitted. Bereaved UKCVFamily members are also concerned about the lack of a national database of coroners decisions/findings. Early detection of the deaths arising from a potential safety signal in 2021, may very well have saved other deaths and injuries from occurring. The lack of PFD reports is also concerning.

585. A member of UKCVFamily bereaved made a Freedom of Information request "Deaths following receipt of the Covid-19 vaccination between January 2021 through to September 2022" [CC/446 - INQ000377819]. The report concludes:

> "*Unfortunately, we do not hold an analysis where individuals have died within 48 hours of receiving a COVID-19 vaccination specifically. This information would need to be created, involving the linkage of the NIMs dataset to ONS mortality data, followed by subsequent manipulation of the data and statistical judgement to identify deaths that occurred within 48 hours. Under the Freedom of Information Act 2000 (FOIA), public authorities are not obliged to create new information to respond to FOI requests".*

UKCVFamily bereaved members would like the Inquiry to investigate why this data hasn't previously been generated and analysed given the unique situation in the context of mass vaccination of a novel vaccine still under temporary

authorisation.

586. Some UKCVFamily bereaved members were told by doctors verbally that their loved one's death could have been caused by vaccination, but this wasn't subsequently given in writing.

587. UKCVFamily bereaved members that didn't have a chance to prove, or disprove, a causal link to vaccination feel this is extremely unfair and that they have been left without closure. They feel that they have been left with more questions than answers.

588. Of the deaths that were deemed causally linked to Covid-19 vaccination via death certification, UKCVFamily bereaved members have waited up to a year to be awarded the Vaccine Damage Payment.

589. Those that have been declined the Vaccine Damage Payment have now had to apply for a 'mandatory reversal' which is distressing and has prolonged the trauma and loss they have felt.

590. Members of UKCVFamily bereaved have waited a year for an inquest which is not allowing them the space to grieve.

591. UKCVFamily bereaved feel that they have been silenced. They have felt that their loved one died and they haven't been allowed to speak about it because

the general consensus is that they were sacrificed “for the greater good”.

592. UKCVFamily bereaved members are concerned that deaths where the vaccine may have been implicated haven't been investigated thoroughly. UKCVFamily bereaved believe this should have happened to not only benefit them, so they had clear answers but also for the sake of society.

COVID VACCINE’S IMPACT ON IMMUNISATION IN THE UK

593. **Parliamentary privilege**

594. **Parliamentary privilege**

595. This follows a report by the Royal College of Paediatrics and Child Health that showed in England: for 2021–2022, there was a decline in uptake for 13 of the 14 routine vaccination measures for children, no vaccinations met the 95% target set by the WHO, and regional uptake of routine vaccinations (MMR, Polio) was at its lowest in London [CC/449 - INQ000377822].

596. An ONS survey about Covid vaccine hesitancy in young people (aged 16–29) found the reasons included distrust of the vaccine (safety and content), distrust of government and authorities encouraging take up, concern about side effects (including on fertility), and the belief that the vaccine was unnecessary for those at low risk of harm from the virus. These concerns have specifically been seen in sub-groups of the Scottish population. Data from the Scottish Government's YouGov polling reveal that, in April 2021, 47% of those who rated themselves as less likely to receive a vaccine reported "being concerned about the safety of vaccines" as one of the main deterrents to uptake [CC/450 - INQ000377824]. More recently, in January 2022, 29% of the hesitant indicated concerns about having had a reaction to or feeling unwell because of the vaccine as reasons for not wanting to get a booster, with 54% of parents of 5–11 year olds expressing worries about the safety of the vaccine in March 2022.

597. The decline in uptake in other vaccinations post the rollout of the Covid-19 vaccines is a trend seen not just in the UK. WHO and UNICEF data shows global vaccination coverage declined when the Covid vaccine rollout began in 2021, with 25 million infants who were scheduled to receive childhood vaccinations not being brought forward for them. This is the largest sustained decline in childhood vaccinations in approximately 30 years. The percentage of children who received three doses of the vaccine against diphtheria, tetanus, and pertussis (DTP3) — a marker for immunisation coverage within and across

countries — fell 5 percentage points post-Covid, to 81%. Unicef reported that, in most countries, people below the age of 35 were more likely to report less confidence about vaccines for children, after the start of the pandemic [CC/451 - INQ000377825].

598. The lack of adequate support for individuals who experience adverse effects from the Covid-19 vaccine has contributed significantly to vaccine hesitancy. When people perceive that their concerns about vaccine safety and potential side effects are dismissed or ignored, they may become more hesitant to vaccinate themselves or their children. This hesitancy arises from the fear of being left to cope with serious health issues or financial burdens without proper assistance. It's crucial for healthcare systems and public health authorities to establish comprehensive support networks for vaccine-injured individuals, offering medical care, compensation, and emotional support.

599. A Daily Mail article 'Probe into why NHS staff still aren't getting Covid jabs - as data shows only one in 10 got latest booster in parts of the country from August 2023 stated that *'just four in 10 frontline NHS workers in England got the latest Covid booster jab and the figure falls to just one per cent at some trusts in those parts of the country. Meanwhile, fewer than half had the flu vaccine.*' [CC/452 - INQ000377826]. There will be reasons why less frontline staff are taking the Covid-19 vaccine, it would be important for the Inquiry to contact the company who have initiated this study on behalf of the NHS, "Birkenhead-based

consultancy ICE Creates", to gather more information.

600. Annual flu vaccine uptake has also been affected. Frontline NHS workers and staff are prioritised for the flu and Covid vaccination drives yet ,according to UKHSA data from Seasonal influenza vaccine uptake in frontline healthcare workers in England: winter season 2022 to 2023', just *'49.4% of all frontline health care workers (HCWs) in NHS trusts with direct patient care received the influenza vaccine in England, a decrease of 11.1 percentage points compared with that seen in the 2021 to 2022 season (60.5%). This is the second consecutive season to show a decrease in vaccination of frontline HCWs, this is the lowest uptake since the 2012 to 2013 season.'* [CC/453 - INQ000377827]

601. According to the Strategic Advisory Group of Experts on Immunization (SAGE), reasons given for vaccine refusal or hesitancy include a lack of confidence, complacency, and inconvenience.

602. This encompasses four categories: religious reasons, personal or philosophical beliefs, safety concerns, and a desire for more information from the healthcare providers. Many surveys show these particularly apply to parents considering having vaccines for their children.

603. An ONS survey about Covid vaccine hesitancy in young people (aged 16–29) found the reasons included distrust of the vaccine (safety and content), distrust

of government and authorities encouraging take up, concern about side effects (including on fertility), and the belief that the vaccine was unnecessary for those at low risk of harm from the virus [CC/454 - INQ000377828].

604. These concerns have specifically been seen in sub-groups of the Scottish population. Data from the Scottish Government's YouGov polling reveal that, in April 2021, 47% of those who rated themselves as less likely to receive a vaccine reported "being concerned about the safety of vaccines" as one of the main deterrents to uptake. More recently, in January 2022, 29% of the hesitant indicated concerns about having had a reaction to or feeling unwell because of the vaccine as reasons for not wanting to get a booster, with 54% of parents of 5–11-year-olds expressing worries about the safety of the vaccine in March 2022 [CC/455 - INQ000377829].

605. A Vaccine Opinions Survey of 2,482 respondents conducted by the DHSC covering the period 7th - 16th September 2021 [CC/456 - INQ000377830], states that 'The main reasons for those who remained unvaccinated included "feeling that the risks of a COVID-19 vaccine were too high or the benefits were too low", "distrusting or feeling discontent towards vaccine stakeholders" such as the government and vaccine manufacturers, and "lacking sufficient, trustworthy or favourable evidence on vaccine side effects, safety or effectiveness"'. At this point many may have heard first hand from family or friends of vaccine adverse reactions, and the lack of support the vaccine injured

were receiving.This lack of support could well have led to further concerns around safety of the Covid vaccines among this cohort

606. A study of over 12,000 UK participants from May 2021 'Predictors of COVID-19 vaccine hesitancy in the UK household longitudinal study' stated that '"the main reason for vaccine hesitancy was concerns over future unknown effects of a vaccine, with 42.7% citing this as their main reason" [CC/457 - INQ000377831].

607. Safety concerns are prevalent within those who have had a small number of vaccines and those who remain unvaccinated against Covid-19. A BMC article 'Exploration of attitudes regarding uptake of COVID-19 vaccines among vaccine hesitant adults in the UK: a qualitative analysis.' The study describes how concerns about the safety of the Covid-19 vaccine were frequently mentioned by participants.' One such response was as follows: "I *know [my friend's] boyfriend, suffered from neurological problems and developed neurological issues where they've ended up in hospital, unable to walk. Just generally struggling with their mobility. Constant shakes. Not being able to look after themselves.*" [CC/458 - INQ000377832]

608. A further study by Healthwatch Reading Project reviewing Covid Vaccine refusal in the town of Reading showed that 76% of respondents to the survey were concerned about vaccine side effects. Responses included: "*I know personally people who had worrying side effects". "Look at all the side effects now being*

brought to light when we all got told the jabs are safe." "Side effects from the first two are making me feel physically low." [CC/459 - INQ000377833]. The lack of open and honest discussion regarding potential vaccine harms can significantly erode public confidence in vaccination programs. When individuals perceive that health authorities or medical professionals are not addressing their concerns or acknowledging the possibility of adverse effects, it can fuel scepticism and mistrust. Transparent communication about vaccine risks is essential to maintain public trust. Failing to address these concerns can inadvertently reinforce vaccine hesitancy, leading to reduced vaccination rates.

609. While vast amounts of resources have been spent on researching vaccine hesitancy, vaccine misinformation and the decline in routine vaccinations, none of the literature that we could find demonstrated that there had been any qualitative data collected on opinion regarding further vaccination from those who had suffered a Covid-19 vaccine adverse reaction or their families.

CONFLICTS OF INTEREST

610. Conflicts of interest have the potential to arise in the complex financial and other links between pharmaceutical companies and politicians, Coroner's, doctors, hospitals and other health organisations and private practice.

611. In March '21, The Guardian newspaper reported that during a meeting with the

1922 committee, *"Johnson hailed the fact that more than 28 million people have been given a first jab in the UK, saying: "The reason we have the vaccine success is because of capitalism, because of greed my friends."* [CC/460 - INQ000377835 and CC/461 - INQ000377836)

612. Pharmaceutical companies have made vast amounts of revenue during and from the pandemic. Indeed, Oxfam reported "*The UK alone has potentially paid £1.8 billion more than the cost of production for the Pfizer and Moderna vaccines —enough money to pay every worker in its National Health Service (NHS) a bonus of more than £1000."* [CC/462 - INQ000377837]. And with the current NHS crisis, every penny counts.

613. An article published in The Guardian in 2021 [CC/463 - INQ000377838], referred to a study that found "*Drug companies are giving groups of MPs and peers that campaign on health issues hundreds of thousands of pounds a year in "hidden" funding that could hand them "undue influence", research has found. The pharmaceutical industry has built up a "hidden web of policy influence" over dozens of all-party parliamentary groups (APPGs) at Westminster by making hundreds of "non-transparent" payments to them, as part of the industry's wider effort to lobby those in power"* [CC/464 - INQ000377839].

614. In 2013 Rishi Sunak PM, left his position as Co-partner at Theleme Partners

Ltd, a financial investment company, to pursue his political career. Theleme Partners Ltd has a parent company based off-shore in the Cayman Islands which is the address of almost 40,000 companies according to the Good Law Project and was described by President Barack Obama as "*That's either the biggest building in the world or the biggest tax scam in the world," he said.*" [CC/471 - INQ000377840 and CC/466 - INQ000377841]

615. Theleme has substantial investments in Covid vaccine manufacturing company, Moderna. According to *Business Today "As of November 7, 2022, Theleme's top holding was 6,004,406 shares of Moderna worth over $710 million and making up 34.6 per cent of the portfolio value. "* [CC/467 - INQ000377842]

616. It was revealed that Mr Sunak may still have financial investment with Theleme, in the form of a blind trust according to the Ministerial Register of interests [CC/468 - INQ000377843]. Mr Sunak has repeatedly said that he would release his full tax returns and eventually he did release a pared down return in March 2023 [CC/469 - INQ000377844]. The Guardian said at the time " *However, this tax statement offers no detail of the fund's contents, such as whether or not the prime minister holds an interest in the Covid 19 vaccine-maker Moderna, which supplied the UK government. Sunak's former employer, the hedge fund Theleme Partners, is known to have been a major investor in Moderna. He has previously declined to say whether he holds or held shares in Moderna.*"

617. Annual reports for Theleme published on Companies House show that the company made over £109 million in the year to 31/3/22. According to The Guardian "Sunak's office refused to disclose whether his investments included a stake in Theleme's fund or Moderna at the time his blind trust was created. A Treasury spokesman said: "*The Cabinet Office has set out what are judged to be the relevant interests in the regular list of ministerial interests.*" [CC/470 - INQ000377846] We believe it would be in the interest of the Inquiry to request sight of Rishi Sunak PMs full detailed tax return to allay any concerns that there may have been a possible financial conflict of interest.

618. Mr Sunak also hired his former partner at Theleme, according to the *Good Law Project* [CC/471 - INQ000377840], *"In 2020, Sunak hired John Sheridan, a partner at Theleme to advise the Treasury on Covid policies. The fund has invested 34% of its pot in Moderna – its single biggest investment – reported to be valued at $710m."* The UK government then went on to sign a 10-year deal with Moderna [CC/472 - INQ000377848]. Research Professional News said, "The UK government has refused to reveal how much it has spent on a 10-year deal with the US pharmaceutical company Moderna—despite growing public interest in the UK's vaccine manufacturing capability." [CC/473 - INQ000377849] We feel that for full transparency the Government should disclose the amount spent on the deal with Moderna.

619. Sir Patrick Vallance, the UK's Chief Scientific Advisor and part of the UKs

Vaccines Taskforce during the Covid-19 pandemic, was discovered to have over £600,000 worth of shares in pharmaceutical company, Glaxosmithkline. The Daily Mail reported at the time (September 2020, CC/474 - INQ000377850) "*A senior Conservative MP and ex-Cabinet minister told The Telegraph that Sir Patrick should have declared his stake in GSK. 'The policy of this Government is to try to suppress Covid at every opportunity until we get a vaccine,' the MP said. 'That makes it more likely that a vaccine will be prioritised by the Government and he happens to be holding shares in one of the leading companies that are developing it. It is a potential conflict of interest. If he is making decisions on vaccines and advising the Government on them, then he either needs to divest himself of the shares or make a declaration every time he touches on the subject. In the Commons, every time MPs raise an issue in which there is a registered interest, they have to declare it. Every time he is talking about vaccines, or in TV he should put it on the table" The Government said that Sir Patrick holds a deferred share bonus which will mature in April 2021 but declined to comment on the size of the holding or its value.*``Previously in July 2020, Sanofi and GlaxoSmithKlien had signed a deal with the Government to supply up to 60 million doses of Covid-19 vaccine [CC/475 - INQ000377851]. We believe that for full transparency Sir Patrick Vallence should disclose how much revenue he earned from his shares in GSK and the Inquiry should investigate whether this should have been declared during the pandemic when Sir Vallance was advising in his capacity as Chief Scientific Advisor and the Vaccines Taskforce. The Inquiry should also investigate any communications

between Sir Vallance and GSK and if there is any evidence that his involvement with GSK could have potentially influenced any decision making on his part.

620. The Daily Mail reported at the time that Sir John Bell, a government advisor on Covid-19 testing had, in fact, £700,000 in shares in Roche, a company providing such tests and was on the company's board as a non-executive director until March of 2020. The Mail said "*In early May, the Government agreed to buy £13.5 million of Roche's antibody tests, which the firm said were '100 percent accurate'. Sir John states he played no role in the decision.*" [CC/476 - INQ000377852). We believe that the Inquiry should investigate whether this financial conflict had any implications during the procurement and public expenditure on Roche Covid tests.

621. '*Conflicts of interest among the UK government's covid-19 advisers*' [CC/477 - INQ000377853], by Paul Thacker, investigative medical journalist stated "*The BMJ asked the Department for Business, Energy, and Industrial Strategy (BEIS), which announced the Vaccine Taskforce, to confirm that Bell had reported his "long list" of financial interests. We also asked to see any forms Bell had filled in as evidence. Contradicting its own press release which listed Bell as a taskforce member, a BEIS spokesperson told The BMJ, "Sir John Bell is a member of the expert advisory group to the Vaccine Taskforce, rather than a member of the taskforce itself. "The spokesperson added that the expert advisory group is not involved in commercial decision making, and that those*

involved must declare their conflicts of interest. The spokesperson did not respond to The BMJ's request for copies of Bell's declarations.The BMJ also approached Oxford University, Bell's employer, to ask for documents that confirm he had disclosed his "long list" of financial interests. Stephen Rouse, Oxford University's head of communications, responded, "Professor Sir John Bell has always declared his financial interests and board membership at Roche, in accordance with the university's conflict of interest policy for all staff." Oxford did not respond to The BMJ's repeated request to see evidence of this disclosure. The BMJ is now seeking the financial disclosure form of John Bell through a freedom of information request to Oxford." It may be useful to the Inquiry to request sight of this financial disclosure. We ask if in this instance it would have been more appropriate that expert advisors be subject to the full financial disclosure that members of the Vaccine Taskforce itself were.

622. The British Medical Journal flagged up more potential financial conflicts of interest during the Covid-19 pandemic saying "*Calls for greater transparency around such decisions have included those bodies focused on science and health, such as the Scientific Advisory Group for Emergencies (SAGE), as well as taskforces charged with advising on vaccines and testing. Although Downing Street has become more transparent in disclosing the advice of SAGE, it has kept members' financial conflicts of interest unpublished and shown little concern that advisers to the coronavirus Vaccine Taskforce have financial interests in pharmaceutical companies receiving government contracts. When*

The BMJ sought further information on these bodies, such as lists of members' interests, the information was denied or requests were unanswered." The Inquiry may find it helpful to seek the information that the British Medical Journal was denied access to.

623. Paul Thacker, investigative medical journalist who writes for the BMJ wrote an investigative piece *'Covid-19: How independent were the US and British vaccine advisory committees?',* [CC/478 - INQ000377854]. Thacker, "*looked at experts sitting on the covid-19 authorisation committees at the US Food and Drug Administration (FDA), as well as those on the UK's Joint Committee on Vaccination and Immunisation (JCVI), which advises the government on vaccines. It was not possible to repeat the exercise with the UK's Medicines and Healthcare Products Regulatory Agency (MHRA), which licences medicines and gave temporary authorisation for covid-19 vaccines, because the MHRA and its adviser, the Commission on Human Medicines, make almost none of their meetings or documents public."* and later on says "*Transparency problems increase with the UK's MHRA, which authorises vaccines after seeking advice from the Commission on Human Medicines, an independent expert scientific advisory body to government ministers. The commission does not make its advice public, publishes a scant record of meeting minutes, and has not disclosed its members' declarations of financial interest since 2018."* [CC/479 - INQ000377855]. Full records of minutes from the Commission on Human Medicines and its members' declarations of financial interest would be of

importance of the Inquiry to request for full disclosure and transparency regarding possible conflicts of interest that may have occurred. Meetings between the CHM and the MHRA would also help the Inquiry understand the processes discussed in the Covid-19 vaccine rollout and also any potential discussion regarding Covid-19 vaccine adverse reactions.

624. The report also found that while "*the JCVI's December meeting on 22 December 2020, the minutes report that 18 of 19 members had "no registered conflicts of interest,"* the report went on to say," *In some cases, an expert has made a disclosure but the committee has not deemed it a conflict.".* This is then evidenced by two such non-conflicts of interest, one existing with Professor Adam Finn, the report says" t*he JCVI reports him as having "no personal payments from manufacturers of vaccines" but adds that he is a local principal investigator for the Oxford-AstraZeneca covid vaccine."* Another example given was "*in the case of the UK's JCVI, the chair of the covid-19 meeting is Wei Shen Lim, a professor at the Nottingham Biomedical Research Centre, who JCVI says has "no registered conflicts of interest." The same document, however, further states that Lim's "institution has received unrestricted investigator-initiated research funding from Pfizer for a study in pneumonia in which Professor Lim is the chief investigator (non-vaccine related)." And in a preprint published only months before the JCVI's December meeting, Lim reported this Pfizer grant.*"

625. A spokesperson for Public Health England (now UKHSA) told the BMJ that

conflicts of interest must be reported "*only if they directly relate to the matter, rather than more widely*". We note that this is different to other areas of science, for example, the International Committee of Medical Journal Editors emphasises that conflicts can be financial or non-financial and should be declared if they could be perceived as conflicts [CC/480 - INQ000377857]. Similar sentiment is shared by other groups with regards to transparency.

626. In addition, JCVI only requires disclosure going back 12 months, which Thacker and others (cited in Thacker) argue is not an adequate timespan. Indeed, based on experience of the scientists in UKCVFamily journals often require between 3-5 years of declarations.

627. Whilst conflicts of interest do not necessarily mean a biassed evaluation, it is important for public trust that we understand where recommendations are coming from with full transparency. We therefore support Thacker's request for full reporting of conflicts of interest. Within this, we support Thacker and Roderick's calls for full transparency with regard to decision making, meetings, and evaluations of evidence, etc. This would help assess whether conflicts of interest interfered with decision making or seems to introduce bias.

628. It would be of interest to the Inquiry to find out what the JCVI deems a conflict and what they deem isn't, for full transparency, all potential conflicts of its members should be disclosed to the Inquiry.

629. In April 2021, the two Oxford scientists, Dame Sarah Gilbert and Prof Adrian Hill who worked on the AstraZeneca vaccines, floated shares in their spin-off company Vaccitech on the New York Stock exchange. A report by The Guardian newspaper said "*The UK government gave Vaccitech a grant of at least £155,000 to help fund the development of the coronavirus vaccine, which is based on a virus that causes common colds in chimpanzees. However, the Treasury is not listed on the firm's shareholder register and it did not immediately response to requests for comment."* It goes on to say that "*Gilbert who became a household name as a result of her work creating Oxford's Covid-19 vaccine, owns 5.2% of Vaccitech*" and that "*Hill also owns a 5.2% stake, according to filings at Companies House". "A spokesperson for Oxford University declined to comment and Gilbert and Hill did not respond to requests for comment."* [CC/482 - INQ000377858]. The company has since been rebranded as Barinthus Biotheraputics as of autumn 2023. Is this a potential conflict of interest?

630. In May 2023, Sir Johnathan Van Tam, former member of the Covid 19 Vaccines Taskforce and Chief Medical Advisor, took a role as a senior medical consultant at Moderna. As part of his role during the pandemic, Sir Johnathan would've contributed to decisions regarding vaccine supply contracts and investments in manufacturing of the Covid-19 vaccines. According to the *Financial Times,* 'Rose Whiffen, senior research officer at Transparency International UK, said

the government should prohibit ex-senior civil servants and ministers from taking up positions where they have had substantial responsibility for policy that is relevant to the hiring company. "*Currently, there are only threadbare safeguards against abuse of the revolving door between the public and private sector," she said, adding this created a "risk of privileged information being misused for commercial benefit*". While Sir Johnathan is prohibited from lobbying the department of Health and Social Care and is not allowed to have any involvement with bids relating to the health ministry until 2024, there are still concerns. *'Jordan Urban, a researcher at the Institute for Government think-tank, said people should not be "overly concerned" when specialists leave government to go into industry. However, he said the broader problem was that the government's rules "have no teeth" and "the individuals to which they apply can ignore them with no penalty".* UKCVFamily ask if, considering the gravity and weight of decisions made by Sir Johnathan, these sanctions are tough and robust enough to prevent potential conflicts of interest? Rose Whiffen or Jordan Urban may be useful for the Inquiry to engage with regarding this issue.

631. In relation to Covid-19 vaccine public messaging we also ask whether there were incentives involved that influenced such high spending on promoting specifically vaccination, for example, conflicts of interest (such as links to the pharmaceutical industry), or other things, resulting in a bias towards vaccination over other measures, such as air quality measures, research into therapeutics, or messaging about other preventative measures.

632. We now draw the Inquiries' attention to potential conflict of interest concerns found in the 'First Do No Harm' Report', (INQ000361115). "*A major concern raised by patient groups is the role of industry funding in organisations responsible for advice and regulation. The activities of the MHRA are currently funded primarily through the pharmaceutical industry on the medicines side, and 95% through the DHSC on devices. Additional funds for clinical trials and inspections of notified bodies come mostly from the DHSC. The MHRA told us that they ensured independence through stringent conflict of interest policies, and use of external experts without interests*".

633. **Parliamentary privilege**

634. **Parliamentary privilege**

635. The MHRA is funded (via two different mechanisms) by the pharmaceutical industry. This is unusual with most European countries having more independent and impartial bodies. Parliamentary privilege

Parliamentary privilege

Parliamentary privilege There was also considerable traffic between the application teams in pharma companies and the approval teams at the MHRA leading to potential accusations of a lack of impartiality. We ask the Inquiry to investigate if this, and the fact that the Covid-19 vaccine manufacturers had accepted a considerable amount of risk in developing vaccines that may or may not be used, played a role in pressurising the MHRA to approve a vaccine so rapidly.

636. The government spending on Covid-19 public communications particularly in the media was mainly through two organisations; OMD Group Ltd and MullenLowe UK. Figures from the cabinet office show that the government spent in excess of £184m on communications relating to Covid-19 in 2020 alone [CC/484a - INQ000377860]. We have explained previously how UKCVFamily question the amount spent on communication with the public regarding Covid 19 vaccine adverse reactions, or lack thereof. Considering this huge spend of public money on media communications and with such large amounts of funding going to these two main recipients, we ask the Inquiry to examine, were there any financial conflicts of interest?

637. Many members of UKCVFamily have experienced delayed medical care and rejected referrals to specialist clinicians. Prior to the Covid-19 vaccine roll out, no medical research facilities were set aside for those who may suffer a severe adverse reaction to a Covid vaccine, leaving UKCVFamily members in the hands of their local services. This has led members of UKCVFamily to seek care in the private medical sector wherein one appointment with a private consultant can cost up to £400. Private care can run into thousands of pounds with 20% of our members polled spending £10,000 or more. Many of our members have used all their life savings on private care and being too ill to work, this money has soon dwindled.

638. The Centre for Health and Public Interest report revealed that in 2020, NHS England signed a contract with the private hospital sector to cover all of their operating costs in return for the private companies making their facilities completely available to help the NHS cope with the Covid-19 pandemic. A few months later, it was revised so that the private sector would be responsible to the NHS for *'no less than 75%'* of its overall capacity and then in January '21 '*the remaining hospitals would be paid a sum based on a guaranteed minimum number of treatments'*. The report goes on to say that the total cost for this contract is still unknown but says that '*Government estimates put the total cost for the period March 2020 to March 2021 at £2bn'* [CC/484b - INQ000377861].

639. Within the report it is also mentioned that, '*In total, the 187 private hospitals*

accounted for 0.08% of the national total of 3.6m Covid bed-days.' The report goes on to call for a full public account of the 2020-2021 report to answer questions regarding how much the value for money this contract was, why the private hospitals carried on giving non elective procedures, why the amount of purchased capacity was reduced just before the predicted second wave of Covid hit and to what extent did the contract protect the interests of the private companies than those of the NHS.

640. In light of our members' experiences and the amount spent in the private hospital sector by our members, UKCVFamily ask if the government considered making private funding available for those who took the government indemnified Covid-19 vaccines, had a severe adverse reaction and were left with inadequate treatment. Could any of the private hospitals, that had been heavily funded by the NHS, have seen, treated, studied and researched those of us who suffered Covid-19 vaccine adverse reactions? Why wasn't money allocated to provide a swift, proactive and robust response for the vaccine injured in the private sector? Sid Ryan, David Rowland, David McCoy and Colin Leys are the authors of the report and may be able to provide the Inquiry with more information.

641. It appears that during the roll out of the Covid-19 vaccines, the government had spent a considerable amount of public money on everything BUT provision for those who would inevitably suffer an adverse reaction to a Covid-19 vaccine. Severe adverse reactions WERE expected yet do not appear to have been

considered hardly at all.

642. The Financial Times reported that "*During the last two financial years, the DHSC reported nearly £15bn of write down costs associated with PPE and other health items. The department estimated that the continuing cost of storage and disposal of excess and unusable equipment stands at £319mn".* The article goes on to say, "*The National Audit Office on Thursday said the department for health and social care did not complete an "effective programme of year-end stock counts" to assess the quality and quantity of coronavirus-related items, such as lateral flow tests."* [CC/485 - INQ000377862]

643. We ask the Inquiry to investigate why the unnecessary expenditure of public money on excess equipment and PPE took place during the Covid-19 pandemic and why stock counts seem to have been ineffective.

644. In contrast, as of 23rd October 2023, 148 claimants have been notified that they will receive (or have received) the Vaccine Damage Payment. This totals £17.76mn. The government are spending more on disposing unusable equipment and excess PPE than they are paying claims to those adversely affected by the Covid-19 vaccines. With the DSHC reporting £15bn of write down costs associated with PPE, this amount of money would fund 125,000 claims to the Vaccine Damage Payment Scheme. As of 23rd October, there are 7,544 claims to the Scheme [CC/486 - INQ000377863].

UKCVFAMILY FORMAL ENGAGEMENTS

645. Since early 2022, we have reached out to individual MPs, government departments, the devolved administrations, other public bodies such as mental health services and/or charities, vaccine manufacturers, the MHRA, the Yellow Card System, the NHS, and the media. Many of our members have reached out to these bodies on an individual basis. In this section, we will explain how we have reached out as an organisation, on behalf of our members [CC/487 - INQ000377864].

646. In March 2022 we launched an individualised MP campaign, providing support to any of our members who needed assistance in communicating with their MPs. As of October 2023, we have directly contacted around 220 MPs whose constituents are members of UKCVFamily and have experienced adverse reactions to a Covid vaccine. We sent the MPs personalised emails respectfully asking them to help their named constituent. We did not comment on the rollout itself. We have received encouraging responses from about 29% of the MPs, who provide support in these ways:

a. They directly support their constituents by ensuring they have access to medical and financial support. Some MPs get directly involved with their constituents' care, in some cases communicating directly with medical

professionals. Some MPs write letters of complaint on behalf of their constituent if they had not been treated with the standard of care required within the NHS. And in some cases, MPs directly communicate with DWP offices, to ensure that their constituent is financially supported — this direct communication from MPs often resulted in increased communication from DWP representatives. Some MPs meet directly with their constituent.

b. They make an effort to learn about the wider issues affecting the vaccine-injured on the whole. Some watch our documentaries. Some meet directly with UKCVFamily representatives to learn more about our group and what they can do to help us.

c. Some become our voices in parliament, supporting parliamentary discussions around the topic of adverse reactions, specifically asking questions, scheduling debates, and proposing private members' bills.

647. As an organisation, we have also reached out to or been contacted directly by some other MPs. Some have vaccine-injured constituents they are trying to support and want to learn more about our group; some have an interest in and would like to support the vaccine-injured in general. We send all interested MPs a copy of our information pack and Caroline Pover's book, *Covid Vaccine Adverse Reaction Survival Guide* [CC/488 - INQ000377865], and make

ourselves available for a meeting.

648. While we remain positive about the MPs who are willing to support their vaccine-injured constituents, or our group as whole, this has sadly not been the case for the majority of our members. According to a survey we conducted, just 9% of our members feel supported by their MPs. This has made dealing with this situation so much worse for them.

a. 33% of MPs that have been contacted about their vaccine-injured constituent has ignored both the constituent's and our attempts at contact; and

b. 38% of MPs that have been contacted responded in an unsupportive manner.

649. It may be useful to learn more about how MPs were instructed to respond to any vaccine-injured constituents asking for support. Was there any communication directed to MPs either encouraging them or discouraging them from being connected in any way with the vaccine-injured community? Are there any reasons why so many of our members have been unsupported by their political representatives?

650. 200Some of the supportive MPs wrote to the vaccine minister to raise concerns,

only to receive the same standard response, which always promoted the vaccine and completely failed to address the questions being asked. These responses from the vaccine minister failed to even acknowledge the multitude of issues — medical, emotional, and financial — that impact someone whose health has dramatically deteriorated post-vaccine [CC/489a - INQ000377866, CC/489b - INQ000377867, CC/489c - INQ000377868, CC/489d - INQ000377869 and CC/064 - INQ000377930]. This is an entirely inappropriate way to respond to concerns about someone who is vaccine-injured. It's like responding to someone who's been in a serious car accident by telling them about all the benefits of cars, and how many people haven't been in car accidents. Many of those letters were sent by Nadhim Zahawi. He would be best placed to provide information regarding the justification for what he considered to be an appropriate response to MPs seeking support for their vaccine-injured constituents.

651. One of our members managed to secure a meeting with their MP, during which the MP dismissed their health problems and did not provide any practical support or even kindness. As the constituent left the meeting, the MP and two of their staff members laughed at them on the way out, with the MP shouting at them to get another jab. This is the reason that UKCVFamily has a safeguarding policy where we do not encourage any member to attend a meeting alone with their MP. We should not have to be encouraging our members to take a chaperone to meetings with their MPs.

652. When representing our Scottish members and communicating with Members of the Scottish Parliament (MSPs), we have faced extra challenges in gathering support because health care and some benefits are devolved matters, while others are governed by UK wide policies, therefore require the intervention of an MP and an MSP. We are sure that ScottishVIG will be able to provide more details in the challenges specifically facing the vaccine-injured in Scotland.

653. Northern Ireland: We represent members from Northern Ireland and assist in communicating with Members of Parliament and Members of the Legislative Assembly (MLA). While UK wide policies will be applicable there are also local considerations with Health and Social Care in Northern Ireland (HSC) and also political considerations with both Nationalist and Unionist involvement. Perhaps Vaccine Injured and bereaved Support group Northern Ireland (VIBS-NI) would be best placed to provide more information about the specific challenges facing the vaccine-injured in Northern Ireland. info@vibs-ni.co.uk

654. UKCVFamily also represents members in Wales. One of our members, Mrs Alison Butler, has had an extensive investigation conducted by Aneurin Bevan University Health Board. Mrs Butler raised a complaint and query, the conclusion took over a year to reach her. The conclusion to this investigation was *"The investigating officer has liaised with a range of clinical teams to try to identify services that may be able to support you, specifically regarding*

diagnosis of the vaccine injury. I am very sorry that we do not have specialist services within the Health Board that are able to support you. The ABUHB Covid Vaccine Programme Board considered your case on 28 September 2023, and they have escalated your query to the Welsh national covid vaccination team. Public Health Wales responded advising that there is not a pathway in Wales for vaccine injury diagnosis. They have advised that you can apply to the UK Vaccine Damage Payment scheme, Vaccine Damage Payment: Overview - GOV.UK (www.gov.uk).

655. *Attached to this letter is a paper copy of the application form for your convenience. I am very sorry that Aneurin Bevan Health Board has not been able to support* you" [CC/491a - INQ000508095, and CC/491c - INQ000377873]. In a letter to another of our Welsh members, Mr Christopher Williams, Eluned Morgan suggests that Mr Williams, "*may benefit from directing any future correspondence to the JCVI and MHRA, as I am unable to provide any further information to the responses I have already provided.*" [CC/492a - INQ000377874 and CC/492b - INQ000377875].

656. This echoes the experiences of UKCVFamily members in England, Ireland and Scotland regarding the lack of treatment pathways and support for those who have suffered an adverse reaction to a Covid-19 vaccine.

657. UKCVFamily has reached out to and attempted to work with the All-Party

Parliamentary Group on Covid-19 Vaccine Damage on a number of occasions. However, we are not involved in the APPG beyond one of our representatives attending meetings in an observation capacity. We are always looking to work more closely with MPs committed to finding solutions to the challenges our group face; and we welcome contact from MPs who want us to be actively involved in implementing those solutions.

658. On 13 July 2023, myself, Caroline Pover, and four of our members organised a private meeting in Westminster kindly hosted by one of our MPs. We invited 216 MPs to a thirty-minute presentation explaining the activities of the support group and the challenges that our members face, followed by an extensive Q&A. Eight MPs attended [CC/493 - INQ000377876].

659. We have continued with our efforts to represent our members to their MPs, and to reach out to MPs in general on behalf of our group, and have had several meetings with interested MPs since July. As mentioned above, we consider approximately 70 MPs to be supportive to individual constituents; we now have ten MPs who are willing to actively support UKCVFamily as a whole. Supportive MPs should not underestimate the positive impact their willingness to listen and act with kindness and integrity has had. We are deeply grateful. But we do not understand why they are so few, and why those who do support us, are only willing to do so quietly. Does the taboo surrounding vaccine injury extend to MPs? It may be useful to learn more about MP's reluctance to support the

vaccine-injured.

660. Many of our members have reached out on an individual basis to government departments such as the MHRA, the DHSC, and the DWP, with no response.

661. Our members have considerable challenges accessing DWP benefits. For many of us, this is the first time for us to apply for the disability or ill-health benefits that the DWP administers, and the process itself is extremely challenging, especially if we have cognitive challenges. Some of our members have DWP ministers as their own MPs, and are fully aware of the challenges that some vaccine-injured have in accessing DWP support. As an organisation, we have been in direct contact with the following DWP ministers as part of our MP campaign:

a. Guy Opperman (Minister of State for Employment): We contacted him regarding a vaccine-injured constituent and do not appear to have had any response.

b. Laura Trott (Parliamentary Under-Secretary of State for Pensions): We have contacted her regarding a vaccine-injured constituent, and the MP has been supportive of the constituent. We are currently hoping to arrange a meeting to discuss our group's needs.

c. Mims Davies (Parliamentary Under-Secretary of State for Social Mobility,

Youth and Progression): We have contacted her regarding a vaccine-injured constituent, and the MP has been supportive of the constituent but is not engaging with our group.

Dr Therese Coffey, Secretary of State for the DWP, from 8 September 2019 to 6 September 2022, may be best placed to provide information regarding how well-prepared the DWP was for possible claims due to adverse reactions. We contacted Dr Coffey in March 2022, on behalf of one of our members who is a constituent of hers, so she is aware of the challenges of the vaccine-injured.

662. We have also attempted to contact the Department of Health and Social Care (DHSC), with very little response. Again, some of our members have DHSC ministers as their own MPs, and we have made them fully aware of the challenges that some vaccine-injured have in accessing health and social care. As an organisation, we have been in direct contact with the following DHSC ministers as part of our MP campaign:

a. Maria Caulfield (Parliamentary Under-Secretary of State for Mental Health and Women's Health Strategy). We contacted Maria Caulfield on 3 May 2022, introducing our group and requesting a conversation [CC/494 - INQ000377877]. We did not receive a response.

b. Neil O'Brien (Parliamentary Under-Secretary of State for Primary Care and Public Health). We have contacted Neil O'Brien on behalf of two of our members, who are his constituents. We are not aware of any support he has offered to the individuals, and he has not engaged with our group Matt Hancock, Secretary of State for Health and Social Care, from 9 July 2018 to 26 June 2021, may be best placed to provide information regarding how well-prepared the DHSC was to support those dealing with adverse reactions.

663. We have also attempted to contact specific bodies within the DHSC, specifically the MHRA (Medicines and Healthcare products Regulatory Agency), NHS England, and the NHS Business Services Authority.

664. MHRA: I have contacted Dame June Raine on a number of occasions on behalf of UKCVFamily, requesting information about what the government and the MHRA have put in place for those who suffer adverse reactions following vaccination. I specifically asked questions regarding the treatment of the vaccine-injured, NICE guidelines, NHS care pathways, and Yellow Card reporting. I received two responses from representatives of the MHRA Customer Experience Centre that did not address our issues nor indicated any interest in learning more about our community and the challenges we face.

665. Records of the MHRA meetings are available until 19 January 2021 and contain

the following references to how to manage adverse reactions to the Covid vaccine:

a. Work on overhauling the Yellow Card reporting platform has already begun. New technologies have been introduced for the reporting of adverse events for products used to treat Coronavirus as well as vaccines and our COVID-19 vaccine active surveillance system has been developed in addition to the implementation of new analytical methodologies and enhanced use of the Clinical Practice Research Datalink (CPRD).

b. Our four-pronged approach to surveillance involves enhanced passive surveillance (comparing Yellow Card reporting rates to background incidence rates – 'observed vs expected' analysis), targeted web-based active surveillance (to characterise safety in specific cohorts excluded from clinical trials), 'rapid cycle analysis' of electronic healthcare records (proactive surveillance of pre-defined adverse events of special interest in Clinical Practice Research Datalink (CPRD) data to rapidly detect/strengthen safety signals) and ad hoc epidemiological studies of significant safety concerns.

c. There are nine main recommendations made by the review (which can be

found in Annex 1). In particular, Recommendation 6 states - The MHRA needs substantial revision, particularly in relation to adverse event reporting and medical device regulation. It needs to ensure that it engages more with patients and their outcomes. It needs to raise awareness of its public protection roles and to ensure that patients have an integral role in its work. The IMMDS Review proposed high level changes to regulation to strengthen patient safety: • Establishing clear legal frameworks around safety decision-making which include the systematic involvement of patients and the public • Improving medical device regulation • Overhaul adverse event reporting to create a transparent, user-friendly system that recognises the contributions of those who make reports and engages with them throughout the analysis and decision-making process.There must be delineated obligations placed on manufacturers, healthcare professionals and the MHRA • Identifying risk profiles and teratogenicity for medicines used in pregnancy • Developing a protocol for a prompt system-wide co-ordinated response to safety decisions related to medicine or medical device.

666. It has been extremely difficult to find any information regarding how the MHRA planned to monitor and support the vaccine-injured as the rollout began and continues. The minutes of MHRA meetings that were held after 19 January 2021 may be able to provide some information regarding how adverse reactions were managed. And Dame June Raine would be able to provide more information

regarding the management of adverse reactions, and specifically why the MHRA has not been interested in engaging with UKCVFamily — the largest group in the UK representing those severely impacted by the Covid-19 vaccines. We feel that this is crucial to understanding how the MHRA was prepared and also how it responded as the rollout continued.

667. In March 2022, we emailed all the NHS Medical Board Executive Directors in the UK that we could find contact details. We again asked how we could collaborate or at least talk to someone regarding the NHS pathways for those suffering adverse reactions. We did not receive one response.

668. NHSBSA (NHS Business Services Authority). Our individual members have contacted the NHSBSA regarding their claims to the Vaccine Damage Payment Scheme (VDPS). As detailed in the section above about the VDPS, we have found the NHSBSA system for the VDPS unprepared, complicated, distressing, unnecessarily lengthy, and dismissive.

669. NIHR (National Institute for Health Research). We initially contacted Karin Batty, RGN, PGDipPH Research Associate from the Global Vaccine Data Network who replied and said that we needed to contact associates closer to home. We then emailed a researcher within the NIHR and we had this response initially from the HPRU in Immunisation "It must be very frustrating for those of you who are struggling to obtain a diagnosis and access treatment, or to take part in

research. I'm afraid that we're probably not the right team for your question, as our research team doesn't cover clinical research investigating genetics or immunology." The following email went on to signpost us to the NIHR site for Covid-19 research which we did contact and were invited to a public engagement zoom meeting to discuss barriers in the uptake of the flu vaccination campaign. However, since then we have not been invited to participate in any further research. [CC/495 - INQ000377878, CC/496a - INQ000377879 and CC/496b - INQ000508100.]

670. In March 2022, we also wrote to over 100 academics, researchers, scientists, and doctors within the UK. We introduced our group, and described our members' situations in detail including symptomatology, issues we face because of lack of research, and the stigma we are dealing with when attempting to get medical help. We included a survey that we had conducted from our membership, detailing age, gender, vaccine brand, symptoms, testing, and diagnoses. We specifically asked for collaboration and help in finding the mechanisms driving the adverse reactions we were experiencing, saying, *"... we desperately need doctors and scientists to study our reactions ..."* and *"... it is of great scientific interest to understand our reactions. Firstly, this will aid in better vaccine development. Secondly, tests can be developed to screen for those at high risk of severe and chronic adverse reactions."* We received some sympathetic replies but were unable to find anyone willing to formally help us. We were made aware of medical professionals who have been reprimanded for

highlighting vaccine injury within their organisations. Any support offered to our community was seen as controversial and potentially damaging to their professional reputations.

671. Doctors and scientists are starting to investigate Covid vaccine-injury around the world with many publications now peer reviewed (over 1000, CC/497 - INQ000377882) and also in scientific media such as Science Mag. UKCVFamily are concerned that academics, scientists, doctors, and medical staff feel that the silent culture of discrimination regarding adverse reactions within the medical community itself, prohibits them from fulfilling their duties and exploring the underlying mechanisms and nature of adverse reactions to a Covid vaccine. Perhaps Professor Fiona Watt, Chair of the Medical Research Council, may be able to provide more information regarding the topic of adverse reaction research in the UK.

672. Many of us assumed that the vaccine manufacturers themselves would be interested in researching us, even if they were not obliged to. However, when we have contacted the manufacturers we have discovered a "not our problem" kind of attitude, with AstraZeneca claiming that such reactions that we are experiencing do not exist, and that there is nobody at the company responsible for dealing with them. Yet the MHRA mistakenly emailed one of our members a copy of their Yellow Card report, with annotations made by the vaccine manufacturer. We are concerned that the indemnity that the manufacturers

were provided with has absolved the manufacturers from any responsibility for or interest in any unexpected adverse reactions that occurred after rollout. Representatives from the companies responsible for each of the vaccines made available in the UK (AstraZeneca, Pfizer, Moderna, Novovax, Johnson & Johnson, would be best placed to outline exactly their policies and procedures for dealing with members of the public who contact them regarding possible or diagnosed adverse reactions).

673. AstraZeneca were noted to say in a BMJ article, "*AstraZeneca and regulatory authorities carefully record and assess all reports of potential adverse events associated with use of Vaxzevria. From the body of evidence in clinical trials and real world data, Vaxzevria has continuously been shown to have an acceptable safety profile and regulators around the world state that the benefits of vaccination outweigh the risks of extremely rare potential side effects."* [CC/498 - INQ000377883] UKCVFamily would like to know what is considered an acceptable risk and also how AstraZeneca worked with the MHRA when assessing adverse reactions to the AstraZeneca vaccine.

674. We also attempted to contact other public organisations, specifically those in the field of mental health. Suicide prevention is a hot topic in the UK, with frequent public messaging encouraging anyone struggling to reach out for help — this message needs to extend to the vaccine-injured. A survey we conducted amongst our members indicated that 76% of our members had considered

suicide since experiencing their adverse reaction. Group admins regularly have to request welfare checks from the police. I put significant effort into reaching out to the most well-known mental health charities in this country, with very little positive response. The most notable are as follows:

a. Covid Aid contacted us, the email asked "*I am writing to enquire about the support that you offer to those who have had an adverse reaction to Covid-19 vaccines. I work for Covid Aid, a UK wide charity dedicated to supporting those affected by Covid19. We get a lot of enquiries from individuals who have been negatively affected by the vaccine, and I am struggling to find support for them. Therefore I was wondering what you offer*" I subsequently had a meeting with a representative and they concluded that they'd be happy to signpost those who'd suffered an adverse reaction to UKCVFamily.

b. Thrombosis UK responded and are very supportive. They gave us resources to pass on to our members that have been diagnosed with VITT to help guide them and keep them up to date with research regarding the condition.

c. British Red Cross responded supportively and provided an online mental health workshop for our group members called "Adapt and Recover from adversity".

d. The CEO of Papyrus UK sent an encouraging email back and was pleased we had introduced UKCVFamily to their organisation.

e. Mindsong.org have been very supportive of UKCVFamily and gave our members a free zoom workshop that included breathwork, singing and a relaxation to end.

f. The Central London branch of The Samaritans also responded sympathetically.

g. None of these charities replied to us; Mind UK, SHOUT, PTSD UK, Myocarditis UK, Together UK, Gain UK, Young Minds, five branches of smaller groups of The Samaritans local to some of our members, No Panic UK, Mental Health.org, Anxiety UK, Self help UK, Mens Health Forum UK, Calm UK.

h. A letter we sent to the CEO of Rethink, a large UK mental health charity had this response "Thank you for your letter and I am pleased that your members have found Rethink's services to be of help during times when their mental health is challenged. We acknowledge the impact of physical health conditions, including or especially, those difficult to diagnose, on a person's mental well-being. As you say this can in some cases lead to an

individual seeing suicide as their only way to escape their suffering. Rethink Mental Illness is not neutral on the issue of the Covid vaccine, having successfully campaigned to ensure people with severe mental illness were prioritised for the vaccine. We employ around 1000 people, and we also made it mandatory for all of our front-line staff to be vaccinated. Clearly all medication including psychiatric drugs have risks, but we felt the benefits outweighed these during the pandemic."

675. The Ministers of State (Ministers for Care and Mental Health) would be best placed to elaborate on the consideration of the vaccine-injured in their policies during the planning for and aftermath of the rollout:

a. Maria Caulfield, 2022–present

b. Gillian Keegan, 2021 to 2022

c. Helen Whately, 2020 to 2021

d. Caroline Dinenage, 2018 to 2020

676. In addition, Parliamentary Under Secretaries of State, would be best placed to assist the Inquiry regarding the vaccine rollout specifically and how the government planned to address and aid those who suffered an adverse reaction to a Covid-19 vaccination

a. Maggie Throup MP,2021-2022

b. Jo Churchill MP, 2019-2021

677. In March 2022, we also reached out to over a hundred reporters from outlets including the BBC, ITV, Daily Mail, The Telegraph, and The Observer. We had two replies, in which we were told that writing about us wasn't in the public interest. Two mainstream media journalists told us that they were not allowed to feature anything about vaccine reactions. We would like to know what information or instructions media outlets were given regarding the coverage of adverse reactions to the Covid vaccine. The following may be able to provide more information:

a. Tony Hall, Baron Hall of Birkenhead, Director-General of the BBC, 2013–2020

b. Tim Davie, Director-General of the BBC, 2020–present

c. Maggie Carver, Interim Chairman of Ofcom between January 2021 and April 2022

678. Caroline Pover and I spoke directly to one mainstream media journalist who asked to speak to us in confidence. He was employed by a major media company, and spoke to us on condition of anonymity. He sat in his parked car, outside his office throughout our conversation, with the windows up, and was clearly concerned that his colleagues would find out about our conversation. He

described a toxic workplace culture around the topic of vaccination, and said that he was afraid of losing his job if he was found out to merely be talking to us.

679. We were contacted by a number of independent media representatives, most of which we turned down because we were concerned about how we would be represented. we do not want our experiences to be used for any agendas other than getting help for our community. Stories about vaccine injuries could be found in numerous alternative media, many of which increased in popularity during the rollout. However, information shared on some of these platforms was and still is terrifying for the injured, especially those in the early stages of their illness.

680. We featured in two documentaries: former British MEP James Wells' "*UKCVFamily: A Letter to my MP*," released in May 2022 and former ITV and BSKYB News Executive Mark Sharman's "*Safe and Effective: A Second Opinion,"* released in September of the same year. Having had a significant career as director of Sky Sports and subsequently Channel 4, Mark Sharman specifically produced his documentary in a style that was suitable for a television channel. However, Channel 4 rejected the documentary by email. UKCVFamily agreed to participate in both films with the strict agreement that we would have control over the final edit so if our experiences were misconstrued, we could withdraw. In the production of " *UKCVFamily: A letter to my MP*", we asked for

psychological support for all those taking part which was provided before, during and after filming.

681. The mainstream media silence around vaccine-injured remained until March 2023, when The Daily Express launched a "*Justice for Jab Victims*" campaign featuring our members, starting with two double-page spreads on consecutive days, including a mention on the front cover. We worked closely with the journalist to introduce her to the people she needed for her story. We have been impressed with how The Daily Express has led the way in fair, balanced reporting in the mainstream media about adverse reactions [CC/499 - INQ000377884, CC/500 - INQ000377887, and CC/501 - INQ000377888]. The Telegraph have also now started reporting on our group's issues as of autumn 2023.

682. Reaching out to all of the aforementioned organisations — political representatives, government bodies, medical professionals, the media, and charitable organisations — has been an extremely challenging and arduous task, all the while conducted by our own representatives who are themselves still trying to manage their own health conditions. There has been a distinct lack of interest in working with, supporting, or discussing patient experts in vaccine injury. In many cases, as indicated, there has been active avoidance of the topic. While the mainstream media can go a long way to improve the stigma surrounding vaccine injury, the government needs to take steps to eradicate the

discrimination that exists.

683. More urgently, the NHS needs to assemble a team of medical professionals who can contribute to research, inform clinical guidelines, and help provide specialist care to post-vaccine patients. The NHS also needs to work closely with UKCVFamily representatives who are themselves highly knowledgeable regarding possible tests and treatments that other vaccine-injury support groups are accessing in other countries and sharing via the React19 International Coalition.

Reports we have published or contributed to, and/or evidence we have given (for example to Parliamentary Select Committees)

684. As indicated above, we have reached out to numerous public bodies, including MPs who are government ministers and/or in parliamentary committees. We have attempted to make ourselves available to the NHS, the MHRA, and the vaccine manufacturers, for any research that may be conducted regarding adverse reactions to the Covid-19 vaccines. None of our attempts to communicate with those bodies have resulted in our experiences being published in any materials.

685. A few of our members' cases have been mentioned in parliament, as their MPs have attempted to ask questions about services that have been made available

to us, for example, on 2 March 2022, Alicia Kearns MP said: "*I have a wonderful 38-year-old female constituent, a mother of three, who after her first shot of AstraZeneca has had horrendous, life-limiting conditions. The NHS seems to have closed its doors to her: for 10 months she has been asking for help, but no one will give it. She has had to go to Germany to get the specialist blood analysis she needs. So can the Minister kindly say what medical ongoing support and pathways the NHS has created within its support specifically to ensure that people like my constituent get the help they so desperately need to live healthier, happier lives?*" Maria Caulfield MP replied, "*If my honourable friend contacts me after the debate I will be happy to find out what specific help is available for her constituent in the local area.*" The UKCVFamily vaccine-injured member, Ms Charlotte Voce, can attest that Alicia Kearns did make contact with Maria Caulfield and the advice given was to apply for the Vaccine Damage Payment. No medical pathways were opened for Ms Voce so Alicia Kearns made contact with Ms Voces' GP who referred her to a vaccine allergy clinic; the clinic subsequently rejected the referral. Ms Voces' GP then tried to refer her to a Long Covid Clinic but that referral was also rejected. Ms Voce ended up paying to be seen at a private Long Covid clinic who helped her manage symptoms with various treatments but Ms Voce said it was very expensive, too expensive to continue. Ms Voce also said that the doctor at the private clinic told her that they had seen lots of other people suffering Covid-19 vaccine adverse reactions.

686. I have attended by invitation the Oxford Covid Vaccine No Fault Compensation Schemes Project Advisory Board Meeting in a patient representative capacity [CC/502 - INQ000377889].

687. Ms Pover and I on behalf of UKCVFamily, contributed to a section of The Perseus Report called 'Listening to Patients" [CC/503 - INQ000397186, pg14].

688. The Covid Inquiry is the first time that we have been given the opportunity to present any formal evidence.

Any lessons we consider can be learned or recommendations UK CV would wish the Inquiry to consider

689. In an unprecedented rollout and mass vaccination campaign, the number of people in the UK affected by adverse reactions to a Covid vaccine has highlighted the dire need for change. The experiences of our members are evidence that those impacted by adverse reactions to vaccines were given minimal consideration, if any consideration at all, as this country responded to the recent health crisis.

690. We believe our experiences also provide evidence that those experiencing adverse reactions to vaccines in general have never been given due consideration, and this urgently needs to change. We hope that there are many lessons that can be learned from the experiences of our group — not just

lessons that should be implemented for future health crises, but also for the benefit of those that have suffered from vaccine harm (any vaccine — not just Covid) both in the past and the present. UKCVFamily recommendations incorporate a wide range of areas: medical, financial, emotional, and cultural, and we have outlined our suggestions below.

691. The first and foremost task is to urgently establish exactly how many people in the UK are dealing with or have dealt with an adverse reaction to any of the Covid-19 vaccines. As an indication, a survey could be issued to the three million who had the first vaccine but not the second; but ideally with the intention to issue a survey to every person who received a Covid-19 vaccine. Text messaging was used extensively to call people for their vaccinations, a similar method could be used in this scenario.

692. Secondly, as the Covid deaths were counted by Public Health England (see report referenced in section above on Vaccine Safety) as being deaths within 60 days of a positive Covid-19 test, we need to urgently conduct a survey to determine the number of deaths that occurred within 60 days of a Covid-19 vaccination.

693. Whilst we understand that the Inquiry is about the government's handling of a specific health crisis, and the Covid-19 vaccine, we would ask the Inquiry to considerthat the experiences of TIME FOR ACTION and the UK Association of

HPV Vaccine Injured Daughters may be beneficial to incorporate in future policies relating to vaccines.

TRAINING & GUIDELINES

694. The Green Book to discuss less well-recognised adverse reactions and provide guidance on further information sources.

695. The establishment of detailed NICE guidelines for adverse reactions to vaccines.

696. Clear mention in all training and guidelines that adverse reactions as yet unknown may occur; such material should not give the impression that all adverse events are known. Emphasis must be given on the limits of our knowledge, especially in reference to a new pharmaceutical product or procedure.

697. Widespread mandatory training across all healthcare workers regarding known adverse vaccine reactions, with updates immediately upon new reactions being recognised.

698. Training for those in contact with potential patients with adverse reactions, specifically paramedics, A&E staff, 111 helpline staff, nurses, and GPs — not just the vaccinators.

699. Instructions regarding the management of post-vaccine syndromes, including the importance of finding the pathology so treatment can be initiated, particularly considering that underestimating adverse events is more serious than overestimating them.

700. A transparent and open procedure for those bereaved who wish to challenge a Coroner's decision. Information should be given to the bereaved, as standard, at the outset of the decision making process so at any time a query or complaint about that decision can be made.

701. It should be made a legal requirement that all deaths are properly investigated with an inquest, and if the family wishes a post-mortem, where the family suspects a causal link to an adverse reaction to a vaccine especially where the vaccination is under temporary authorisation.

702. Prevention of Future Death reports should be filed by Coroners as a legal requirement when a death is confirmed as being caused by a vaccination explicably when that vaccine is under temporary authorisation.

TESTING

703. We suggest the following tests as standard to help identify relatively common pathologies in post-vaccine patients:

a. Full blood count including mean platelet volume and kidney and liver function;

b. Clotting: D-dimer, platelet factor 4, protein C and S, tests for antiphospholipid syndrome, venous oxygen saturation (SvO2);

c. Inflammation: ESR, CRP, IL6;

d. Mast cell activation: N-methylhistamine, 11B -Prostaglandin F2α, Leukotriene E4, serum tryptase, 24-hour urine sodium;

e. Autoimmunity: ANA, rheumatoid factor;

f. Cardiovascular and endocrine: cortisol, TSH, free T4, troponin, VEGF, pro-BNP;

g. Neurocardiology: 14 day Holter monitor, ECG, Cardiac MRI, echocardiogram, tilt table test (or NASA Lean Test or a 10-minute standing test, considering wait times for tilt table testing), Romberg's test, skin biopsy (for small fibre neuropathy), nerve conduction tests;

704. Pulmonary: gaseous exchange, V/Q scan. The following tests may be useful to

identify pathophysiological dysfunction which may exacerbate damage, even if such problems are not the primary pathology:

a. Nutrition (and related): vitamin B12, B12 cofactors (MMA and homocysteine), intrinsic factor, vitamin D, vitamin E, folate, copper, zinc, magnesium, iron, transferrin, gut microbiome;

b. Metabolic health: total and LDL cholesterol, HbA1c and/or fasting glucose, triglycerides.

705. International research in Long Covid and similar conditions which are occurring post Covid19-vaccination are discovering a variety of possible explanations, one of which is microclotting. Microvascular damage is extremely difficult to detect with the standard testing procedures available in the UK, particularly in the early stages of disease progression, and microclot damage has not been seen before. More sensitive tests are often needed to show damage, particularly if the patient has been symptomatic for several months.

MEDICAL MANAGEMENT

706. The NHS needs to urgently assemble a team of medical professionals who can contribute to research, inform clinical guidelines, and help provide specialist care to post-vaccine patients.

707. The NHS needs to work closely with UKCVFamily representatives who are themselves highly knowledgeable regarding possible tests and treatments that other vaccine-injury support groups are accessing in other countries and sharing via the React19 International Coalition.

708. An independently-funded dedicated research team needs to be established to discover the nature of adverse reactions to vaccines in general but specifically Covid-19 vaccines, with additional funding made available as part of the country's response to any future health crises that involve vaccination.

709. Specialists in the field of vaccine-damage need to be encouraged and supported - financially and professionally — in coming forward to treat those impacted not only by the Covid-19 vaccines but by all vaccines, past and future.

710. A dedicated, independent clinic should be established for treating those affected by adverse reactions. This clinic should be managed by staff who are very experienced in adverse reactions to vaccines, and be led by the vaccine-injured themselves. The clinic should offer access to healing modalities that are not purely pharmaceutically-based but also incorporate traditional medicine and a holistic approach as well as "out-of-the-box" thinking and a willingness to experiment with possible healing tools. It is important to stress that the experience of the vaccine-injured often (and understandably) results in a

reluctance to be treated by pharmaceutically-based medicine, and an interest in exploring a wide range of healing modalities, not necessarily provided by the NHS, is essential.

711. Those suffering adverse reactions to a vaccine need a clear clinical pathway that doctors can use to refer them to.

712. Doctors instructed to discuss prior vaccination when patients present with complex symptoms; just as it is standard to ask about any new medications, life stressors, and smoking history.

713. There are multiple treatments available through the NHS that can at least alleviate symptoms and improve quality of life for vaccine-injured patients. Considering the safety profile of some of those treatments and the length of time the vaccine-injured have now been suffering, we need to urgently start at least trying some treatments, even if we do not have the test results to warrant them.

714. The option of access to treatments (such as antivirals) that have been provided to others who are immunocompromised or not receiving any vaccines needs to be made available to the vaccine-injured who would like access to them.

715. Long Covid clinics need to be consistent in whether they are willing to see vaccine-injured patients or not.

716. When Patient Information Leaflets change, all patients who were vaccinated before those changes were made, should be notified. Anyone who has been experiencing any of the symptoms listed in the updated leaflets should have:

a. vaccination considered as a possible cause,

b. thorough testing for the conditions that have come to light as being related to vaccination,

c. immediate treatment for their symptoms, and

d. assistance from a medical professional in filing a Yellow Card report.

GENERAL HEALTH MANAGEMENT

717. More widely publicised information about other ways of managing Covid-related illness and/or ill-health in general, for example the other therapeutics mentioned above.

718. In the event of other health crises, public messaging should prominently include steps the public can take in order to manage their own health, specifically steps

to develop a strong immune system.

719. Consideration that in the event of other health crises, investment should be made to ensure that all UK residents have access to fresh fruit and vegetables, high quality vitamins, appropriate exercise, fresh air, and stress management support.

FINANCIAL

720. Urgent reform of the VDPS or a new redress scheme entirely.

721. A reduction in the eligibility criteria for the VDPS or a new redress scheme entirely.

722. Financial support for temporary disability caused by vaccination as well as permanent.

723. Compensation for loss of earnings.

724. The removal of limited eligibility criteria if there is a clear medical diagnosis or bereavement caused by vaccination.

725. In cases where there is a medical diagnosis or bereavement clearly determined

as caused by vaccination (such as a coroner's report), payment of damages to be issued within 28 days of the diagnosis or report.

726. Payment of funeral expenses.

727. Compensation to dependents.

728. A financial contribution made toward any healthcare expenses incurred as a result of the NHS not being able to meet the medical needs of the vaccine-injured.

729. Emergency funding made available for experimental testing/treatment/research of the vaccine-injured.

730. Where vaccination was a condition of employment, and the employee suffered an adverse reaction, the employer recognises the reaction as a workplace injury.

731. Two million pounds (the average amount of investment Long Covid services each received, as mentioned earlier in this document) to be immediately invested in services provided toward the development of a vaccine adverse reaction support service, in consultation with UKCVFamily.

732. All vaccine manufacturers to be subject to an "adverse reaction contribution," for every vaccine administered to the public. This would fund the ongoing medical, financial, and emotional support of those experiencing adverse reactions. This fund could be distributed by an independent group of vaccine-injured individuals, who would allocate the funds to research, treatment, and marketing, as well as individual support to those impacted.

733. DWP to train staff in understanding the complex nature of vaccine injuries and develop a policy of how they are handled during assessment of benefits claims.

734. Production of condition insight reports by the DWP.

735. Financial recompense to be made to members of the vaccine-injured community who spend their time providing information or evidence, or working alongside healthcare or government bodies to improve the services available to and understanding of the vaccine-injured community.

EMOTIONAL

736. Research amongst NHS mental health services to establish any possible changes in a demand for services, and whether vaccination has formed part of discussions. The research would need to be anonymous and steps need to be taken to ensure that staff felt they could speak openly about their observations

with fear of repercussions.

737. Funding for a helpline dedicated to the emotional support of the vaccine-injured and bereaved.

738. Mental health organisations (such as the BACP) to be encouraged to include support for the vaccine-injured as part of its areas of expertise.

739. Institutions providing courses for mental health practitioners to be encouraged to feature medical trauma including vaccine injury as part of its syllabus.

740. All suicide prevention public messaging to include the mention of someone suffering with a vaccine injury and/or someone with a medical injury.

741. All Vaccine Damage Payment Scheme (or alternative scheme that may arise) claimants to be provided with specific mental health support throughout the process, from form completion through to any potential appeal.

CULTURAL

742. An immediate cessation of all censorship around the topic of vaccine injury in mainstream and social media.

743. MPs to be actively encouraged to support the needs of their vaccine-injured and bereaved constituents without fear of repercussions.

744. Research to establish the medical profession's attitudes into reporting symptoms that they or the patient considers may be due to adverse reaction to vaccination.

745. A national awareness campaign highlighting possible symptoms of adverse reactions to vaccines, and encouraging those suffering to seek help and where that help is.

746. A national awareness campaign for the Yellow Card System following a full, transparent safety review of how it operates.

747. A review of advertising regulations surrounding pharmaceuticals in general and specifically relating to vaccination, regardless of whether such advertising is being conducted during a health crisis.

748. An investigation into whether the Covid vaccine campaign broke the law in its adherence to advertising regulations.

749. A policy whereby campaigns promoting vaccination must always prominently

include:

a. the fact that adverse reactions may and do occur,

b. what immediate, short-term, mid-term, and long-term symptoms of an adverse reaction may look like, and

c. reporting procedures in the event of an adverse reaction.

750. A national campaign to combat the stigma and discrimination surrounding vaccine injury; and to encourage kindness, sympathy, and understanding of those who have suffered adverse reactions.

751. Measures to make hate speech toward the vaccine-injured a criminal offence in the same way that hate speech toward other disabled people is a crime.

752. A complete ban on free food being offered in exchange for vaccines. Also to extend to discounts or free services, to ensure that it is entirely an individual's choice in getting vaccinated, and that choice is related to their health and not their financial circumstances. Lower-income individuals should not feel pressured in any way.

753. In future health crises, vaccinations should be given in a proper location. Festivals and concerts should not have vaccination tents within them.

754. The use of behavioural science should be scrutinised, from an ethical standpoint, before use of it again in future public health crises.

755. The establishment of a bioethics committee to deal with health crises (there is currently no replacement to the Emerging Science and Bioethics Advisory Committee that closed in 2014).

VACCINE MANUFACTURING & MONITORING

756. The consideration of whether the practice of using another, well-established, vaccine as a placebo during vaccine trials should be replaced by the practice of using a saline placebo.

757. The consideration of implementing a "risk assessment" before administering a vaccine to any member of the public, such as the one used in Japan during the early phase of the rollout there, where vulnerable individuals, those with underlying conditions, or those who'd previously had an adverse reaction to a vaccine, were not permitted to take the Covid vaccine.

758. Individual patient level safety monitoring in the form of an app or such like, when a novel vaccine is rolled out 'en mass'. Patients could log symptoms post

vaccination and alert any new symptoms/issues immediately, directly to the app. Doctors and hospitals could also log adverse reactions via the app.

759. The active encouragement of any members of the public who participated in the Covid-19 vaccine trials to come forward to provide information about the process.

760. Vaccine manufacturers to provide evidence of how trial participants who withdrew from Covid-19 vaccine trials were recorded, what reasons they had for withdrawing, how many of those were due to ill-health, and what symptoms they had. Some UKCVFamily members have AZD1222 recorded in their medical records, were these people in a trial without being informed?

761. We ask whether the MHRA, HCM, the Expert Working Group's and JCVI properly scrutinised data, particularly with regards to those who did not complete the trial.

762. Vaccine manufacturers to provide evidence of how myocarditis was managed during the trials.

763. Evidence of when AstraZeneca became aware that their product had problems with clotting. Was this before February 2021 as mentioned in the New England Journal of Medicine article *Thrombotic Thrombocytopenia after ChAdOx1 nCov-*

19 Vaccination? Or was it during the trials? Why was it not released or questioned immediately?

764. Evidence regarding the adverse events that occurred during the AstraZeneca trials that induced the temporary stop to the trial, including what the events were, and how causality was inferred.

765. Use wider methods for causal inference when determining adverse events in trials (which are, by definition, not powered to detect adverse events). This includes, but is not limited to, trials to taking and storing blood samples pre- and post-vaccination (longitudinally) to help determine whether there are measurable clues regarding adverse events, thus improving causal inference.

766. Vaccine manufacturers to explain why biodistribution and pharmacokinetics were not explored in such detail until after the rollout, for the Inquiry to investigate whether this should be a requirement in the future, and urge researchers to understand the implications for this long-term in healthy people, as well as whether it is contributing to illness in those suffering adverse events.

767. Investigations into why the risk of thrombocytopenia as a result of viral vectors wasn't considered relevant to the Covid vaccine development, as it has been known about since at least 2007.

768. Future vaccine trials to offer full transparency, including the reaction, the investigations being undertaken, and how a causal link to the vaccine has been ruled *out* (rather than ruled in).

769. Ensure those who dropped out of the study for any reason (which might include adverse reactions) are not excluded from vaccine efficacy estimates (thereby improving validity).

770. To ensure all trials that will be used as evidence for approval for use in the UK are conducted in a fashion that is clearly identifiable as a Phase 3 trial (i.e. not different protocols in different cohorts), with the full trial protocol published *a priori*.

771. To ensure all trials that will be used as evidence for approval for use in the UK do uphold their no detriment clause to participants, e.g. if a suspected reaction occurs, the participant gets fully investigated and treated at no cost to themselves.

772. All raw trial data gathered by pharmaceutical companies to be released before roll out implementation of any vaccination. All raw trial data to be released immediately by pharmaceutical companies involved in producing the Covid-19 vaccines. Currently regulators do not hold participant level data sets and

industry is not legally obliged to release these to researchers nor the public. Data must be released when trial results are announced, published, or used to justify regulatory decisions in the future for full transparency.

773. All contracts between the government and the pharmaceutical companies who developed the Covid-19 vaccines, to be published to the Inquiry, in full and unredacted. Given the huge amounts of public money spent, it would be in the interests of transparency to do so.

774. Vaccine developers to publish their clinical trial protocols on a publicly accessible registry.

775. Clinical trials to be compelled to proactively collect long term safety data.

776. The government to adopt and enforce legislation requiring the pre-registration of all clinical trials and the publication of summary results within 12 months of their completion.

777. Vaccine developers to provide evidence of Covid-19 vaccines Phase 4 testing.

778. Mandatory reporting by healthcare professionals on any suspected adverse reactions within 60 days of vaccination, without fear of professional repercussions.

779. Research into what underlying conditions, if any, may make an individual more prone to experiencing an adverse reaction to vaccination.

780. The establishment of a more robust follow up process to the Yellow Card System. Currently, none of the reports are followed up or investigated to an adequate standard. There should be an extension of the scheme to include thorough investigation and support of cases that have not been resolved.

781. A batch analysis to determine whether certain batches were associated with higher rates of adverse events.

782. Reinstatement of the NHS internal reporting system concerning adverse reactions that was retired.

783. Vaccine manufacturers to be given responsibility for investigating adverse reactions to their products. This would include a dedicated department within every company, responsible for working closely with vaccine injury groups.

784. Consideration of the ethics of allowing pharmaceutical companies indemnity for any injury experienced as a result of their product.

785. Consideration of 'regulatory flexibilities', 'rapid reviews' and 'rolling reviews' made specifically for the Covid-19 pandemic such as remote inspection of manufacturing facilities, compliance with good manufacturing practices etc. and

what lessons can be learnt from this.

786. Immediate research into UKCVFamily members symptoms.

787. Establishment of a study into the approximately 20% of the UK population that has not received any Covid vaccines, to compare any health issues they are facing with the health issues seen in the vaccinated population, including those who have not experienced symptoms of an adverse reaction.

SUMMARY

788. The treatment of the vaccine-injured and those bereaved by vaccination, in this country has historically been a source of shame. Neglect and discrimination has been brought to light through the Covid-19 vaccination rollout and is now resulting in serious mistrust of British institutions — especially government and healthcare. In order to rebuild trust from the general public — vital in the event of future health crises — this country urgently needs to have an effective and compassionate means of medically, practically, financially, and emotionally supporting the vaccine-injured and bereaved.

789. The United Kingdom needs to create a vaccine injury program of which it can be proud. It is time for change.

CASE STUDIES

500 words from people who have personal experience of as many of the eight topics as possible. UKCVFamily exhibits 105 case studies [CC/504 - INQ000508042].

STATEMENT OF TRUTH

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: Personal Data

Dated: 17/10/2024