Witness Name: Scottish Covid Bereaved

Statement No.: 1

Exhibits:

Dated: 18/04/2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF MELANIE NEWDICK OF SCOTTISH COVID BEREAVED

I, Melanie Newdick, make this statement on behalf of Scottish Covid Bereaved (SCB). The information and examples contained within this statement have come from my discussions with members of the SCB, statements that members have provided to the legal team and I have also included some information and examples from my own personal knowledge and experiences.

History, Purpose and Aims of Scottish Covid Bereaved

1. The Scottish members of our group originally started out as part of the group Covid Bereaved Families For Justice UK (CBFFJ) which was formed on Facebook in June 2020. Following our meeting with The First Minister, Nicola Sturgeon, in March 2021 it became clear we needed to be an autonomous group/branch within CBFFJ organisation, especially after it became a Limited Company with directors without informing the membership. At that stage we became a sub group of CBFFJ but arranged all of our lobbying and press activity ourselves. Following a clear difference between our group approach on several major topics and that of the main CBFFJ group we formally severed our connection with them in September 2022 and became a completely separate group, namely Scottish Covid Bereaved (SCB).

2. Given the very nature of our Group and that we have come about as a consequence of bereavement as a result of the various responses made by both the UK Government and

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- the Scottish Government we have highlighted issues after the fact rather than prior to the decision making.
- 3. Since our first press article in July 2020 with the BBC (on Care Homes) we have had a consistent and positive press presence via TV, Radio, Newspapers and Social Media mainly in, but not limited to, Scotland.
- 4. Our political campaign, ultimately leading to the formation of the Scottish Public Inquiry, began in September 2020 with the then Scottish Labour Leader asking a question on our behalf at FMQs. Since then, various questions have been asked on behalf of members by politicians from all political parties.
- 5. Whilst our activities have been mainly in Scotland, in the absence of anyone else doing it, we have participated in actions with the original CBFFJ Group in its efforts to secure a UK Inquiry. We are very conscious of the overlap in both Pandemic Planning and the actual handling of the pandemic between the UK Government and the devolved Nations. We feel it is especially important to be knowledgeable about the whole process to assist the Inquiry in identifying areas where the original Pandemic Planning fell short not only in Scotland but in the UK as a whole and we believe we cannot do one without the other.

Membership of the Scottish Covid Bereaved

- 6. We are a group of bereaved individuals united in a common goal. We do not want our loved ones' deaths to have been in vain. We want lessons to be learnt to stop others having to go through what we have been through. We also believe that by sharing our experiences, both good and bad, we will assist both Inquiries in their establishing what really happened, and therefore further assist both Inquiries in arriving at their conclusions, recommendations and lessons to be learned for future pandemic planning.
- 7. Although our group came about due to bereavement, there are members of our group dealing with other consequences of the pandemic. Our membership includes a number of healthcare and other frontline and key workers, many of whom may be suffering from post-traumatic stress disorder and other impacts of the trauma that they experienced, and they are finding that there is little, or no support afforded to them.

- **8.** We have members of the group who are either from an ethnic minority group or have a loved one who died who was from an ethnic minority group. They are able to describe first hand the healthcare inequalities experienced within those groups.
 - Scottish Government vaccine data from November 2022 and 2023 shows that the highest vaccine rates were for white people of 57.9% and 51% respectively. The lowest were for African people with 22.8% and 12.9% respectively.
- 9. We also have members suffering from Long Covid who can demonstrate that there is a lack of medical knowledge and treatment in dealing with this condition. We understand that there is a significantly developing field of medical research in relation to Long Covid, however, we understand that there are limited specialist services treating Long Covid in Scotland. Furthermore, any treatments our members receive is based on where they reside, i.e a 'postcode lottery'.
- 10. Additionally, our membership includes relatives of an individual who contracted covid whilst in custody and died in custody. The individual had asthma and after becoming unwell with Covid and displaying significant Covid symptoms he was denied fundamental health care.
- 11. Given the diversity and geographical spread of our group, we are able to provide information in relation to a number of areas of interest in this module. Some issues include, vaccine distribution to various groups, the geographical barriers to accessing vaccines, vaccine hesitancy in relation to a number of groups and concerns regarding vaccine misinformation.

An overview of concerns which SCB has identified in relation to the matters set out in the Provisional Outline of Scope

The preparedness of the UK for the rapid development of a 'Disease X' vaccine in early 2020

- 12. From the evidence heard in Module 1, it appeared that the UK had been preparing for an influenza pandemic and therefore an influenza vaccine. Again, it appeared that scientists had been working on the development of a 'Disease X' vaccine, based around a coronavirus, and that the usual barriers to development at pace including funding, access to regulatory approval were expedited.
- 13. Professor Dame Sarah Gilbert in her Richard Dimble by Lecture in December 2021 set out the development of the Oxford Astra Zeneca vaccine, and talked about how the usual barriers to development including funding and regulatory approval were expedited, allowing the development of the vaccine at pace. Overall, the vaccine development was one of the 'successful' elements of the pandemic management.
- **14.** It might be helpful in terms of 'lessons learned' to have the experts clarify what 'barriers' were removed and by whom in order to enable the rapid development and production of the vaccines to take place and what changes to systems and processes have been put in place since that time.

The process for the Covid19 vaccine development wasn't clearly explained. As a result, many people may have assumed that the process was cut short in some way. Perhaps if people had understood that testing was run simultaneously rather than concurrently as it had done in the past, and that regulators reviewed information throughout the vaccine trials rather than receiving it all at the end as had happened previously.

A clearer and easier to understand explanation of the process would have been helpful in giving confidence around the Covid19 vaccine development, as this would have reassured people that steps weren't removed, the process was reorganised to save time.

It would also be helpful to know if this process is now the one that will be used for vaccine development going forward in the UK.

The pace of vaccine development, procurement, manufacture and approval.

- **15.** The UK Government appeared to be very decisive about their vaccine procurement. The SCB would like to know what, if any, issues did Scotland and it's Government experience regarding vaccination procurement.
- 16. The SCB are concerned that the procurement and distribution of vaccines in Scotland appeared to be behind that of other parts of the UK. Valneva, a company based in Lothian, started working on producing a Covid19 vaccine in Scotland. It was given an order to produce 100 million Covid19 vaccines and then later had it's contract terminated by the UK Government. This resulted in a court case where the UK Government has had to pay Valneva damages.

The SCB understands that Valneva had previously received Scottish Government funding to help develop it's work in Lothian. The SCB would like to know if this had an impact on the overall vaccine program in the UK, or in Scotland.

Vaccine delivery programmes and prioritisation decisions in Scotland.

- 17. The SCB understand that the first vaccine was received on the 8th December 2020 with great fanfare. However, the subsequent roll out of the vaccine to some of the vulnerable members of our society was slower. The first vaccine was given to a care home resident in Scotland on the 14th of December 2020, 6 days later with one health board only starting to vaccinate care home residents on the 17th of December 2020 10 days later. The SCB also understands that there were missed opportunities to administer vaccines to vulnerable people who were in hospital, so potentially with increased exposure to Covid 19.
- **18.** On the 4th of December 2020 Helen Whately, the UK Minister for Social Care wrote to local authorities about Covid19 vaccine deployment. In that letter she confirmed that older care home residents were top priority for receiving the vaccine, but that details of getting

the vaccines into care homes couldn't be shared yet due to the difficulties getting the vaccine into care homes. It asked for care home managers to make arrangements for staff to receive the vaccine in the meantime.

- 19. Within our group we have members who had relatives who were vulnerable in-patients in hospital and delays with vaccine distribution resulted in their untimely death. The SCB would like NHS hospital management asked whether there were issues with vaccine distribution to those patients and if this resulted in those in NHS care and vulnerable to infection not receiving vaccines timeously.
- 20. The classification of vulnerable groups qualifying for early vaccine administration did not include those in the younger age group. As a result of this unvaccinated younger, vulnerable individuals contracted covid and died. Had they been included in the vulnerable category, they would have received their vaccine before they contracted covid and this may have prevented their death.
- 21. The SCB believe that there were missed opportunities to vaccinate those in custodial settings at the earliest opportunity, given the risks associated with this type of setting. In particular those with pre-existing health conditions which made them more vulnerable to serious illness from Covid 19.
- 22. A common issue that has been raised by the SCB is that their relative had received a letter with an appointment date for their vaccine. However, as a result of being an inpatient in hospital they were unable to attend their appointment. Given that people in hospital are amongst the most vulnerable in our society, there were missed opportunities to vaccinate them.
- 23. We understand that healthcare workers were prioritised and vaccinated early in the vaccine roll out program, and that some of their vaccinations were being administered within the hospitals. The SCB would like to know why vulnerable inpatients were not similarly vaccinated.

- **24.** One of our SCB members has said, "My Father was not offered a vaccine although the health care professionals caring for him were. I have not received a satisfactory reason for why this 82 year old long term in-patient was not vaccinated in December 2020 as part of the Wave 1, Week 1 rollout priority groups."
- 25. The SCB are concerned that there was disorganisation and lack of consistency in the delivery of vaccines and that Scotland lagged behind England in protecting it's population. They are concerned that if their relatives had been vaccinated on the same timescale as other parts of the UK their relatives would have had more chance of surviving the virus. Furthermore, the SCB have concerns that the vaccine rollout was not consistent throughout Scotland.
- 26. Different health boards in Scotland had different vaccine delivery programs and we understand that this led to some confusion between families and friends who lived in different health board areas. For example, NHS Highland used a GP model for initial Covid19 vaccine delivery, whilst other health boards such as Greater Glasgow used vaccine hubs.
- 27. The SCB have asked why certain key workers were prioritised over others, for example, why were teachers, school staff, police, supermarket staff and other key workers not offered the vaccine at the same time as other keyworkers were being vaccinated. It would be helpful to understand more about the decision not to prioritise all key workers with the initial Covid19 vaccination.
- 28. One of our members has said, "Now I ask myself why all frontline workers weren't given access to early vaccination. Why was it only NHS & carers. I appreciate that was very important to do but I feel my husband who was also a frontline worker delivering to customers on a daily basis should have been included in the early roll out. I feel if this had happened my husband might still be with us today."
- 29. We understand that due to issues with storage of vaccine, there were times when unused vaccine was being disposed of, as once it had been taken out of the fridge it had to be used. Our members find it hard to hear of vaccine being wasted when their vulnerable relatives were unvaccinated, many with pre-existing medical conditions making them more vulnerable to the effects of Covid-19.

30. One member of the SCB has said, "When the first vaccine was rolled out at centres and after everyone had been immunised any Pfizer vaccines left over were offered to friends or relatives of the staff as long as they could attend quickly eg. 10 mins. The staff couldn't make up more vaccines, they could only offer the ones that were made up already. All staff were then told that this practice was to stop and all left over vaccines were to be disposed. These could have immunised so many more people but went in the bin instead. Money was wasted along with less people being vaccinated."

Vaccine safety

- **31.** Whilst members of the SCB were anxious to learn of medication and vaccines which would protect themselves and their families against the effects of Covid -19. Understandably, there was also some concern about the safety of any vaccines.
- **32.** We have members who have pre-existing health conditions who felt that there was a lack of information available to them in order to assess risk with taking a vaccine as against the risk to them of not having the vaccine, given their health issues.
- 33. One member of the SCB has said, "There appeared to be high level of concern about the speed with which the vaccines had been developed and therefore concerns regarding their safety and efficacy. It may be important for lessons learned to consider how vaccine safety is contained within public health messaging and how the media impacted upon concerns regarding vaccine safety by reporting adverse incidents out of context. Most people developed their vaccine understanding by accessing the media. Personally, on the Facebook social media platform, I saw significant numbers of 'posts' which were not verified, appeared unfiltered and not checked and which were factually incorrect and promoting misinformation."
- **34.** It would be helpful to understand more about any plans to deal with/mitigate social media algorithms and the spreading of false/harmful information in relation to public health messaging in the future.

35. The overwhelming feeling of the SCB is that the benefits of the vaccines in preventing Covid-19 and serious complications, far outweigh any currently known side effects. However, it is important that the safety of Covid-19 vaccines is constantly monitored.

Public messaging about the Covid-19 vaccines in Scotland and steps taken to address vaccine hesitancy

- 36. In general, the SCB consider that the messaging was straightforward, simple and effective. However, as we have previously highlighted, issues have been raised by vulnerable groups who didn't feel they had sufficient information in order to make decisions on getting the vaccine. In particular, there are members of the SCB who have pre-existing health conditions, who were anxious about how any vaccine would interact with their medication, but also the risks to them by not being vaccinated.
- **37.** One of our members has said the following, "I do not think enough specific information was given (or was available) to young women of childbearing age to allow them to feel happy to go ahead. I do think that the governments and media did a good job in the main to debunk conspiracy theories etc about the drugs."
- 38. There are members of the SCB who were concerned at the time of the initial vaccine roll out to hear reports in the media regarding vaccine hesitancy on the part of social care workers. This was particularly concerning for those members who had relatives residing in care homes. The SCB question why there were lower rates of vaccine uptake amongst social care workers in comparison with healthcare workers. This is an issue the SCB would like to see addressed when vaccines are being rolled out in future.
- **39.** The SCB also considers that in future, with regards to public messaging and addressing vaccine hesitancy, it should be taken into account that the World Health Organisation warned of what it described as an 'infodemic' in relation to vaccine public messaging. This

was an overabundance of information about vaccines and the importance of vaccination that actually had the result of increasing mistrust in the vaccine.

40. In terms of public messaging around vaccination, improvement is not necessarily just about the message or repetition of the messages. It's about building confidence and trust. As the Scottish Government research showed using community leaders can be particularly effective when communicating with ethnic minorities, and those with the most challenges such as people living in the most deprived areas.

Barriers to uptake of the vaccine and disparities in vaccine coverage between identifiable groups within Scotland.

- 41. We understand from the members of the SCB that in relation to the elderly or those in vulnerable shielding categories, they experienced a number of barriers. For example, there was anxiety about going into a busy setting, mixing with significant numbers after they had spent a long period during the pandemic in their own homes shielding. This issue discouraged many from attending their vaccination appointment. Furthermore, the way in which things were organised at the vaccination centre meant having to stand in a queue, for long periods of time, often in inclement weather. This was problematic, in particular, for those with medical conditions causing them problems with their mobility. Some were simply unable to stand in a long queue and had to take the decision to not attend their appointment.
- **42.** Additionally, the public transport infrastructure in Scotland often made if very difficult for those requiring to use this to attend their appointments. Again, leading to people not then being able to attend at their vaccine appointment.
- **43.** We understand that there were also issues for those with complex and profound learning disabilities, who lived in residential accommodation. One of our members has explained,

"My late cousin who lived in an ENABLE care home with 3 other residents and had been shielding as she was extremely vulnerable, was expected to attend an appointment in a mass vaccination centre. The 3 other residents who were all several years younger than my cousin but equally vulnerable, were all offered their vaccinations on different dates and again, expected to attend a mass vaccination centre.

At that time, ENABLE, the care home provider, had not allowed the residents to leave the care home, not even allowing them to go into their fully enclosed garden.

The Care Home Manager and my late Aunt complained about the residents being expected to attend a mass vaccination centre in terms of risk and also setting out the logistical issues involved given that each resident would have needed 2 carers each to accompany them. Finally, it was agreed that Community Nursing staff would come to the care home and vaccinate the 4 residents on the same day."

Geographical Barriers to Vaccine uptake

- **44.** The Covid19 vaccine was initially distributed through GP practices and vaccine hubs. This meant that those at the highest risk of death from Covid19 were not vaccinated first due to the complications of getting the vaccine to them in their care homes.
- **45.** In April 2022 the Scottish Government changed the vaccine policy to allow health boards to deliver the vaccine as they saw fit within their local area. In some rural parts of Scotland, such as NHS Highland, the health board continued to use GP practices as this was the most effective method of vaccinating, with the most convenience for patients, particularly in rural areas.

In April 2023 the Scottish Government stopped allowing NHS Boards to use GP practices to deliver vaccines. Whilst the SCB understands that Vaccines in NHS England continue to be delivered through GP practices. This led to a report produced for NHS Highland which showed the decline in uptake of all vaccines. Many of the issues were due to the problems of low population numbers and long travel distances.

46. A Scottish Government study into vaccine delivery in 2019 ahead of these changes worked with focus groups. They chose not to work with anyone who was vaccine hesitant

as they felt they would have nothing to add to the learning. This seems like a missed opportunity to learn more about the barriers to vaccine uptake. Instead of learning from people about the barriers and trying to mitigate these in the new approach to vaccination delivery, the study simply chose to ignore them.

Health Literacy

- 47. The World Health Organisation defines health literacy as the ability to; "gain access to, understand and use information in ways which promote and maintain good health". Currently, those with the highest health literacy are able to make use of more health resources than those with the lowest health literacy.
- **48.** The SCB understand that there is inequality in healthcare provision with those in the most deprived areas not being able to access the same healthcare as those in the least deprived areas. During the pandemic this was evident through vaccine uptake rates and also higher numbers of Covid19 deaths in more deprived areas.

The pace of research exploring new therapeutics and the effectiveness of existing medications in treating Covid-19.

- **49.** In terms of the use of new therapeutics and medications we understand that there wasn't sufficient communication between our members and their relatives who had been offered medication.
- **50.** For example one client has said, "My late mother was offered a 'trial drug' when she was admitted to hospital with Covid 19 in June 2020. She refused this option as she was told that it would mean repeat hospital visits once she got home. Nobody discussed this me and if I had understood that had been an option when it was first raised with my Mum I would have taken a different view. I don't know what this drug was.

My Mum was given Dexamethasone (orally) as a 'last roll of the dice' but it was too little too late. Mum was given Dexamethasone on the same day that it had a great deal of press coverage as a new drug in the treatment of Covid 19 so I didn't perceive any delay in it being offered to her.

My husband was also given Dexamethasone in December 2020/January 2021 as part of his treatment.

The researchers certainly had ample potential for research given the numbers of people in hospital with Covid 10. Sadly, neither the research re treatment nor the vaccination were of use to my Mum. My husband was 6 weeks away from having his first vaccination when he died."

Access to vaccines and therapeutics in Scotland.

- 51. The SCB had relatives who, while seriously ill with Covid-19, were not given, or timeously given, oxygen therapy or ventilation and subsequently died. There are SCB members whose relatives were not given anti-viral medication and medication to assist with covid-19 symptoms, for example Dexamethasone, when this would have relieved their symptoms.
- **52.** We understand that there was a particular issue with those with covid in care homes being unable to access treatment options. Indeed, we understand that due to many care home residents not being admitted to hospital, this resulted in them being denied access to therapeutics.
- **53.** There were also issues with prescribing certain medication, for example opiates, in care homes, due to the unavailability of medical practitioners.
- **54.** We have a member of the SCB whose husband was from an ethnic minority background who additionally suffered from pre-existing health vulnerabilities. He was admitted to hospital but was not given access to therapeutics and subsequently died. This member has asked, "Why when it was known that ethnic minority groups were disproportionately affected by Covid was nothing done to address this."

Any Lessons SCB considers can be learned or recommendations SCB would wish the Inquiry to consider

- **55.** One of the main issues for the Scottish Covid Bereaved was the distribution of the vaccine to those in vulnerable categories. The SCB would wish the Inquiry to consider how the vaccine was administered to those in vulnerable categories and what can be done to improve this in future pandemics.
- **56.** Mass vaccination centres for those in shielding categories was problematic.
- **57.** There were also issues with access to the vaccine for children and younger adults with severe clinical conditions.
- **58.** The SCB consider that in future those organising vaccine distribution should be mindful of the challenges faced by those living in rural communities regarding access to vaccination centres due to issues with public transport.
- **59.** In terms of vaccine distribution it may be helpful to consider allowing individual health boards to implement their own system for vaccine distribution, suited to their particular population.
- **60.** The SCB consider that there requires to be better communication in future with relatives in situations where therapeutics are being discussed/ offered. Patients who are unwell and vulnerable may not be in a position to make these decisions alone.
- 61. The SCB is made up of a diverse range individuals from different age groups and with different vulnerabilities. While the majority of the SCB are supportive of vaccines, what we understand is that people need to be given information about vaccines, including associated risks, to allow them to make an informed decision regarding whether or not they decide to have the vaccine. This can only be done if there is sufficient research and openness with the public about this to allow them to have confidence in vaccines.
- **62.** Finally, as mentioned previously, people need to have access to accurate information so that they can make informed decisions on whether the vaccine is safe for them. Therefore,

there also needs to be stricter controls over vaccine misinformation appearing in the media and on social media. It would also be helpful if there is more targeted provision of information on vaccines being provided to those in particular groups who may have certain medical vulnerabilities or groups with high rates of vaccine hesitancy.

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.

Dated: 19 4 24