

IN THE UK COVID-19 PUBLIC INQUIRY

MODULE 4

**WRITTEN CLOSING SUBMISSIONS FOR THE SCOTTISH
COVID BEREAVED**

1. The Scottish Covid Bereaved appreciate that all of us in the United Kingdom are lucky to have this module: had a vaccine not been found, developed and rolled out, the nation's experience of the pandemic would be far different than what it ultimately was. The Bereaved endorse what was said by Counsel to the Inquiry in his opening submissions: the evidence suggests overwhelmingly that the UK Covid-19 vaccines successfully protected the people of the United Kingdom against a virus that was killing and was liable to kill hundreds of thousands of people¹
2. While the development and deployment of vaccines was one of the more successful parts of the United Kingdom's response to the pandemic, it does not mean that that success was unqualified. The country could have been better prepared. Plans and systems could have been in place which would have allowed for a quicker and more efficient response. While it cannot be said with certainty, more lives could have been saved.
3. Neither Scottish Covid Bereaved nor the rest of the population know what the next pandemic will be, nor when it will strike. It is hoped that when the time comes, a successful vaccine can be developed. The country should not, however, be left with simply hope that processes and procedures will be in place to ensure that when the time comes vaccines are developed

¹ [1/23/8-12]

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and deployed at pace, and delivered firstly to the most vulnerable and to the rest of society as soon as possible thereafter.

4. The ultimate recommendations will be for the Chair to make. In order to assist the Chair, Scottish Covid Bereaved highlight the following issues and proposed recommendations.

Vaccine hesitancy/vaccine confidence

5. At the outset of this Module, there was discussion around the use of the term vaccine hesitancy, and whether the term vaccine scepticism should be used. The Scottish Covid Bereaved consider that the preferred term should be vaccine confidence, with people having confidence in vaccines to a greater or lesser extent.
6. It is the experience of the Bereaved that many were not confident that there was sufficient information to allow them to make properly informed decisions about the vaccine. This was particularly the case for pregnant women and those suffering from pre-existing health conditions. Many of the Bereaved are also parents, and had concern about the use of the vaccine on children and young people.
7. Scottish Covid Bereaved submit that confidence is not a constant. It can easily be won or lost. Confidence can be won or lost. The best inoculation against a loss of confidence is education. Education about the history of vaccines. Education about the process of producing vaccines. Education about the content of the vaccines themselves. Education about the success of vaccines.
8. The Covid-19 pandemic took place in the social media age. It is unknown in what age the next pandemic will take place. It seems clear to the

Bereaved, however, that there is no longer a trusted authoritative source of information. While in previous crises families may have gathered together in front of a radio or television to hear the same news that was being broadcast into every home, in this pandemic each one of us was able to get a news feed selected by algorithm. This news was not subject to official oversight or censure. Misinformation and disinformation, from apparently trustworthy sources, can be spread with a couple of taps on a screen. Scottish Covid Bereaved consider that it imperative that prior to the next pandemic as much as possible is done in relation to public health messaging to ensure that the public has confidence in all vaccines. If the population has trust in vaccines that are routinely used, it is likely that they will have trust in the new ones that come to fight the next pandemic.

9. The Scottish Covid Bereaved accordingly make the following recommendations:

ONE: DISCOURAGE POLITICIANS/ JOURNALISTS FROM MAKING FALSE CLAIMS

10. Scottish Covid Bereaved accept that this recommendation will not ultimately be in the gift of the Chair. It is a responsibility which individual politicians and journalists will need to take upon themselves. Society can, of course, help by fostering a culture where such false claims are not tolerated and ensuring that politicians who make them find themselves at the mercy of the electorate. In this regard, Scottish Covid Bereaved highlight the evidence of Professor Nicholas White, Professor of Tropical Medicine at Oxford University and Mahidol University, Bangkok:

“So clearly a clinical trial involves recruitment of people, and it's really important that people have a fair chance to understand why – to give fully informed consent, as we say. So of course, we can't protect people from

learning all sorts of things, but what we should do is try to discourage politicians, journalists, from making claims which are not true, and which might influence people adversely. I mean, it's of great contemporary interest across society at the moment.”²

TWO: USE THE NHS AS A TRUSTED BRAND TO TACKLE VACCINE HESITANCY

11. While the experience of the Scottish Covid Bereaved primarily relates to Scotland, they are confident in stating that the NHS is one of the most trusted ‘brands’ throughout the UK. Scottish Covid Bereaved submit that politicians and civil servants should use the power of the NHS ‘brand’ to assist in the roll out of the next vaccine. The Bereaved highlight the evidence of Dame Emily Lawson of NHS England:

“...The NHS is an incredibly powerful, highly recognised brand, and for some groups, as we learned during the pandemic, it's not -- no organisation is really trustworthy, because of previous experiences. So yes, it is incredibly powerful, and we had to reach outside the NHS and its heavy brand in order to make sure we were reaching everybody.”³

THREE: PROVIDE SUFFICIENT INFORMATION TO THOSE IN PRISON ABOUT VACCINES

12. Scottish Covid Bereaved appreciate that there are a great many groups containing vulnerable individuals. Prisoners represent one such group but with an additional factor that a great many prisoners may have underlying or deep-seated mistrust or distrust of those in authority. They will have limited access to sources of information out with the prison environment.

² [8/30/17-8/31/1]

³ [35/139/8-14]

Additional steps should be taken to ensure that those in prison are provided with sufficient information to allow them to make decisions of the vaccines. Prisoners, many of whom remain in overcrowded aging prisons, should not receive a death sentence due to a lack of information.

Data systems

13. Scottish Covid Bereaved consider that a recurring issue throughout the course of this Module was the need to improve data systems. It is perhaps obvious that in order to provide vaccines and therapeutics to the most vulnerable, authorities need to know who the most vulnerable are. There may be many factors which will make an individual vulnerable to the next pandemic: age; gender; ethnicity; physical or learning disability. There may be factors which cannot currently be predicted. Having comprehensive and accessible data is essential to allow an efficient response to the next pandemic.

FOUR: LEARNING DISABILITY REGISTER

14. Scottish Covid Bereaved appreciate that for many with a learning disability, and their loved ones, it can feel like their needs are often overlooked. It is essential that those in authority have access to data to allow them to identify those with a learning disability in order to allow for them to be sufficiently prioritised in the pandemic response. Scottish Covid Bereaved note that such a Register was proposed by the JCVI but, according to Derek Grieve, former Deputy Director to the Health Protection Division in the Scottish Government, had not been put in place:

Q. And finally, in relation to disabled people, you've already referred to the fact that initially, I think, there wasn't a Learning Disability Register in place in

Scotland; is that right?

A. That's correct.

Q. Did you put one into place?

A. I don't believe there is one. I think the JCVI advised that we should be - we should use it, and Scotland didn't have one. I don't -- I'm not sure if it still does, but we don't have such a thing.”⁴

FIVE: REQUIREMENT FOR DATA REPRESENTING VULNERABLE/ DISABLED PEOPLE

15. Similarly, Scottish Covid Bereaved consider that there requires to be accurate and accessible data to allow for identification of those who will be most vulnerable as a result of the pandemic. While this will of course be of use in the vaccine rollout, it is of importance in the research and development of any vaccine. Without being able to identify those with vulnerabilities, scientists will be unable to measure whether the vaccine works. A better method than that currently in place is required. Scottish Covid Bereaved commend the evidence of Professor White:

“Yes. So let me say that in the -- overall, if we look at medical research in Covid, the UK was very strong in clinical research. And perhaps the weakest part of that impressive portfolio was phase II. So, phase II is that transition, when you've got a drug, a new drug or even an old drug at a different dose, your first attempt to try to see does it work in people or not? And for that, you need a way of measuring that. And unfortunately, we didn't have a good way of measuring it and what people did was a large number of small, and unfortunately inconsequential trials, which

⁴ [14/54/23-14/55/7]

could never have answered: did the drug work or not? We needed a better method and that was not developed.”⁵

SIX: A UK-WIDE NATIONAL HEALTH DATA SYSTEM

16. Scottish Covid Bereaved consider that in order to allow for decisions to be made, particularly in relation to the roll-out of vaccines and the identification of the most vulnerable, there requires to be a data system across the United Kingdom that allows for relevant information to be quickly and easily identified. Scottish Covid Bereaved note the following evidence from the Rt Hon Nadim Zahawi, the former Under-Secretary of State for Covid-19 Vaccine Deployment:

“Q. As it happened, the government commissioned a report into health data, it's called the health data review, and it was led by Professor Cathie Sudlow.

A. Mm.

Q. It reported in November of last year, 2024. I wanted to ask you, and I appreciate it's not something that you've been required to look at, but I wanted your impression.

A. Mm.

Q. Amongst the five recommendations that Professor Sudlow made were these two recommendations: that there should be a national health data service in England for health data; and secondly, that there should be a UK-wide approach to streamline data and, therefore, to better -- well, to improve understanding by all the governments within the four nations of the impact of the data and what can be learned from it. Are those two recommendations something that you would endorse? Was it your view that something did need to be done about setting up a national data

⁵ [3/10/7-19]

service and having a consistent aggregated approach across the United Kingdom?

A. Yes, with caveats. So yes, I do think some streamlining and rationalisation of data sources is necessary, and also making sure that we're using the very best labels, the very best categorisation, because it is confusing. You know, you talked about the use of the term "BAME" -- there was so -- there's a plethora of labels that was being used. We never knew whether we were all talking about the same thing or not. So yes, in principle, I do think that that is something that should be done. I don't know the genesis of Professor Sudlow's work, but I have come to this conclusion via separate avenues. However, there is a challenge now with how well government itself is placed to deliver this sort of system. And I remember, it's over 20 years ago now, when I was working on a project for the NHS Spine, when we were supposed to have a National Health Service, you know, IT system, and it failed. Government is not necessarily great at delivering these systems. They tend to be big boondoggles for the private sector, but there are private sector companies that can deliver this. There need to be caveats around that. There is a big debate going on about how we use health data. Should we let AI into the system? Because the more data you have, the harder it is to process, and you start to require machine learning and so on. And there are many ethical concerns about allowing this data to be used by pharmaceutical for profit sectors and so on. I personally have no issues with that, but those things need to be considered in tandem if we are going to do this. There are a lot of risks as well, which I've seen from being in government, having security briefings about how external actors outside our country try to destabilise information systems. There would be a big risk in creating something like this. It's important that we are aware of those and have things to mitigate,

but in principle, I think that this could work. How we deliver it would be the question, and make sure it could be quick and successful.”⁶

SEVEN: ALIGNEMENT OF DATA ACROSS THE FOUR NATIONS

17. In order for any such UK-wide data system to be workable, there requires to be an alignment of data across the four nations of the United Kingdom. Scottish Covid Bereaved consider that any data system would be pointless if the data populating it was not consistent. It is understood that this was a challenge during the pandemic and it is hoped that there can be a common system put in place to prevent this from happening again. Scottish Covid Bereaved refer to the evidence of Dr Ben Kasstan-Dabush, Assistant Professor in Public Health & Policy at the London School of Hygiene and Tropical Medicine and Lecturer in Global Health Policy at the University of Edinburgh:

“Well, you know, the limitation I think that we came up against was that UK-wide picture, you know, the alignment of data across the four nations, to be able to look at coverage in particular cohorts, age demographics, et cetera, and it's that alignment, I think, of how data is collected and stored that there could be significant room for improvement across the four nations.”⁷

18. Having such data available would allow for patterns to be identified across the United Kingdom as a whole, and would be the best way of identifying risks at the earliest possible opportunity⁸. The data sets require to be linked and analysed by experts on a regular basis.⁹

⁶ [13/51/11-14/53/21]

⁷ [49/19412-19]

⁸ [32/126/7-12]

⁹ [20/80/18-23]

EIGHT: USE OF DATA TO IDENTIFY THOSE AT RISK AND PROVISION OF ANTIVIRALS

19. If data is available to identify those most at risk from a pandemic, steps can be taken to provide them with protection before symptoms of the disease emerge. Scottish Covid Bereaved understand that a common method of this is through the use of antivirals. Rather than relying on people becoming ill and presenting themselves to GPs or hospitals, it would be of benefit if pre-emptive treatment could be provided to them. This would be of benefit both to the individuals but also the healthcare systems, as it would reduce the number of admissions during the pandemic. Scottish Covid Bereaved note the evidence of Sarah Moore:

“Yes, I think in terms of delivery mechanisms, I’m really thinking about the NHS. Antivirals are a very commonly used medicine, they are regularly very difficult to get to people at the right moment, so this is a longstanding complexity within our treatment system. Our treatment system relies on people falling ill, having a symptomatic, and then going to the GP. That is a very reactive way of doing medicine, and I’m making the observation that there are ways of trying to use data and home diagnostics to spot people much earlier on, and therefore get the kinds of medicines that catch disease at a very early stage to knock it out before the symptoms emerge. That is the way that medicine is going across the board, and in order for our health system to be up to date and ready for the next epidemic, it is worth us thinking today about how we put in place those kinds of mechanisms.”¹⁰

¹⁰ [11/51/1-18]

Barriers to uptake

20. Scottish Covid Bereaved consider that it would be futile to have a population willing to take the vaccine if there were not in place systems that allow for the efficient delivery of the vaccine. Scotland, with its larger rural and island-based communities, faces additional challenges in the delivery of vaccines. Scottish Covid Bereaved welcome the restoration of vaccine delivery to GPs in the Highlands and Islands, following an intervention from the Health Secretary.

NINE: BETTER ACCESS/ENGAGE LOCALLY

21. Whether in the Highlands and Islands, or our major cities, Scottish Covid Bereaved consider that any effective rollout programme requires there to be easy access to vaccines and therapeutics. This should be done at as local a level as possible. This is the only way to eliminate barriers to vaccination. All establishments delivering vaccines require to be fully accessible. Scottish Covid Bereaved are supportive of the evidence of Professor Heidi Larsson, that the more we can bring vaccines closer to people is only an asset¹¹

Vaccines and monitoring

22. Scottish Covid Bereaved accept that it is often individual relationships rather than formal structures which influence decisions. The Chair is clearly unable to ensure that all those in positions of power are competent and capable. This Inquiry can, however, help to foster a culture where experts are listened to and relied upon by those making key decisions.

¹¹ [46/182/15-17]

TEN: NATIONAL VACCINES AGENCY

23. Scottish Covid Bereaved consider that come the next pandemic, an invaluable source of expertise would be a National Vaccines Agency. While it is appreciated that there may be considerations of independence and cost, the Bereaved note that the pandemic brought forth a great many changes and governments found themselves able to put in place systems and processes that would previously have been unthinkable. It is not beyond the capabilities of our politicians and civil servants to put in place a National Vaccines Agency. It is far preferable to have this body up and running and making sure the UK's capability is being monitored rather than trying to play catch up when the pandemic is already here¹². Unless the expertise is already in place, the country will find itself where it was in early 2020 rather than being properly prepared. An investment in a National Vaccines Agency should be seen as an investment in our health and our future.¹³

ELEVEN: INTERNATIONAL SURVEILLANCE

24. Covid-19 was a truly global pandemic. From the early scenes in China, through Italy, to our own homes, we watched the pandemic spread and people die. Pandemics are a global threat and require global monitoring. Similarly, science is an international discipline and any Vaccines Agency should be monitoring threats worldwide and also adopting international best practice.

¹² [9/33/21-9/34/1]

¹³ [18/59/3-17]

Conclusion

25. Scottish Covid Bereaved note the evidence of Lord Bethell, that we are in a worse shape now than we were five years ago. The NHS faces difficulties including recruitment. International surveillance is not what it should be and the UKHSA has been denuded of heft and resources. In many areas, the country has not moved forward¹⁴. This is a matter of deep regret. It is hoped that the recommendations proposed by Scottish Covid Bereaved, and others, can assist the Chair in putting the United Kingdom on a better footing than it currently is.

26. Scottish Covid Bereaved have been grateful for the opportunity to contribute to the Inquiry's work in Module 4. As the Bereaved set out in their opening submissions to this Module, their approach has been to help the Inquiry come to a view about the best recommendations possible to ensure that all lessons that can be learned, are learned. It is only through this work that when the next pandemic comes, all nations of the United Kingdom will be able to research, develop, and roll out vaccines to the population. It is hoped that this will be done in an efficient and fair manner that will allow the greatest protection against the next pandemic.

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¹⁴ [18/59/3-17]