Witness Name: Kamran Mallick
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF KAMRAN MALLICK ON BEHALF OF THE DISABLED PEOPLE'S ORGANISATIONS

I, Kamran Mallick, will say as follows: -

1. I am the Chief Executive Officer of Disability Rights UK ('DR UK') and make this statement on behalf of four Disabled People's Organisations ('DPO'). This statement is made in response to the Rule 9 Request for Evidence dated 30 August 2023, for Module 4 of the Covid-19 Public Inquiry. I make this statement on the basis of my own knowledge or belief. Where something is outside my own knowledge, I refer to the source. I would be happy to give oral evidence to the Inquiry in Module 4 to expand upon the matters set out in this statement or address any other issues arising.

2. This statement has been prepared in cooperation with four DPO: DR UK, Inclusion Scotland, Disability Action Northern Ireland ('DANI') and Disability Wales/Anabledd Cymru ('Disability Wales'). Each of these organisations meet the United Nations definition of a DPO as set out at General Comment No.7 (2018) paragraph 11, as they are majority led, directed, governed and staffed by Disabled people.[1] The DPO are distinct from disability charities that represent Disabled people, however well, rather than enabling us to represent ourselves.

3. Through all four DPO, we have substantial reach across all four nations of the United Kingdom. For example, DR UK has a substantial following on social media with over 72,000 X (formerly Twitter) followers and had over one million visitors to its website

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[1] The DPO use the term 'Disabled people' to mean people facing disabling social barriers due to their impairments or conditions regardless of their age. This includes physical impairments, mental health conditions, hearing difficulties, d/Deafness (including those that use BSL as their first language), visual impairments, learning difficulties and neurodiversity.

during the pandemic. Inclusion Scotland represents Disabled people across Scotland with a network of over 50 DPO members and partner organisations, alongside individual members. Disability Wales has over 100 member organisations, 29 of which are full member DPO, and had around 200,000 and 216,000 views of their website in 2020-21 and 2021-22 respectively. DANI is the largest Northern Ireland wide Disabled person's led organisation and membership organisation.

4. Each DPO provides a variety of different support services which can include: advocacy, employment support services, digital connectivity, transport, community integration, information and advice, and mental health and wellbeing services. In addition to these services, the DPO also raise awareness, campaign and work with government departments on key issues impacting Disabled people in society with the goal of improving legislation, policies and practices. Our vision is a society which is inclusive and adapts to meet the needs of Disabled people rather than one that expects them to fit in and we aim to achieve that by ensuring Disabled people are actively consulted and involved as decision makers on the decisions that affect us.

5. According to the DWP family resource survey for the financial year 2020-2021 (KM/1 INQ000489460), there are around 14 million Disabled people in the UK; we make up 22% of the population. Around 42% of older people are Disabled people, 21% of working-age adults and 9% of children. These figures are higher in specific nations, for example 35% of Scottish adults are disabled (KM/2 INQ000182780). Disabled people have a wide range of impairments and/or long-term health conditions. We include autistic people, people with learning disabilities, those with sensory, cognitive, mobility and energy-limiting impairments, and people with mental distress. Some of us face multiple discrimination on the basis of disability, race, age, being LGBTQIA or other protected characteristics.

6. In this statement I have used the terminology 'people with learning disabilities' to ensure consistency with the terminology used by both the vaccine prioritisation lists and many of the articles exhibited. However, the DPO note that this term is incompatible with the social model of disability given that the word 'disabilities' is used in place of 'impairments' rather than as it should be, namely to denote disabling barriers.

7. The following are views and experiences gathered by all four DPO through our contact with Disabled people, other DPO and government departments across the UK. I have also referred to reports that have been drawn to the DPO's attention through our work

in this sector which we think are relevant to the scope for Module 4 and will be of assistance to the Inquiry. In preparing this statement, each DPO has conducted a search of our records, however, this has brought up a large number of documents and communications and we have not yet been able to identify if all relevant communications have been exhibited to this statement. It is also the case that some DPO have seen a transition of personnel since the relevant period. I hope to have exhibited the key documents, however, if other relevant documents come to my attention at a later date, I will provide them to the Inquiry.

Consideration of Disabled people during testing, development and approval of vaccines and therapeutics

8. Disabled people accounted for six out of every ten deaths related to Covid-19 across the UK according to the Office for National Statistics (KM/3 INQ000089756), National Records Scotland (KM/4 INQ000184679) and Northern Ireland Statistics and Research Agency (KM/5 INQ000438343). This shocking figure summarises the disproportionate impact that the Covid-19 pandemic had on Disabled people but it by no means tells the full story. Not only were Disabled people more likely to die, we also suffered physical and mental harm due to the lockdowns and associated measures in ways that others did not. People with well-established care systems lost them overnight and they no longer had access to food, medicine, hygiene, sources of information or basic human contact.

9. This disproportionate impact of both Covid-19 and the non-pharmaceutical interventions ('NPIs') on Disabled people was well known to the UK Government and the Devolved Administrations. It therefore ought to have been central to any consideration of vaccine and therapeutic prioritisation and the development of delivery programmes. Indeed, the need to conduct Equality Impact Assessments was a statutory requirement under the Equality Act 2010, and Section 75 of the Northern Ireland (1998) Act, however, it is the DPO's concern that such considerations and assessments were inadequate.

10. At the outset, the DPO would draw the Inquiry's attention to the principles of the United Nations Convention on the Rights of Persons with Disabilities ('UNCRPD') (KM/6 INQ000279959) and the right of Disabled people to enjoy *"full and effective participation and inclusion in society"*.[2] The UK is a signatory to the UNCRPD and therefore has a

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[2] UNCRPD Article 3

duty under Article 4(3) to "*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations*" when developing "*decision making processes concerning issues relating to persons with disabilities.*" With the obvious potential that vaccines and therapeutics had to address the disproportionate impact of the pandemic on Disabled people, clearly the UK vaccination programme and assessments around therapeutic provision were 'decision making processes' concerning Disabled people that required the four nation governments to adopt the UNCRPD approach.

11. Disabled people and the DPO ought to have been engaged from the outset, through the testing, development and approval of the various Covid-19 vaccines and therapeutics, however, unfortunately that was not our experience. None of the four above mentioned DPO were asked to participate in testing, or feedback groups during the development of vaccines and therapeutics before their approvals and it is unclear to us what level of testing was done to assess their safety and effectiveness for Disabled people particularly those who were most susceptible to adverse health outcomes from Covid-19.

12. The effective consultation with Disabled people in these development programmes was not simply a requirement of international law but also a necessary step to encourage confidence in the safety of vaccines and therapeutics and ensure there was sufficient uptake to enable them to be an effective tool in reducing mortality rates and combating the disproportionate impacts of the pandemic. The importance of both considering Disabled people in vaccine development and communicating that consideration, was highlighted in a survey published by Disability Equality Scotland in the early days of the vaccine programme on 30 November 2020 (KM/7 INQ000417433).

13. The survey found that respondents' concerns related to the speed that the vaccines were approved and whether all possible side-effects had been identified and considered before the vaccines were to be distributed to the most vulnerable in society. Crucially the survey stated that, "*safety concerns can be alleviated by providing the public with clear and transparent information about the vaccine, which is distributed using a variety of accessible communication channels and formats.*" The DPO, with our expertise and networks, were well placed to assist in providing those accessible and reassuring communications, however, we were not always appropriately consulted to do so, as discussed below.

Vaccine and therapeutics delivery programmes and prioritisation decisions

14. That duty to closely consult, did not stop once the vaccines and therapeutics were developed and approved, it continued throughout their delivery. An example of the potential value of consultation can be seen in the prescience of the concerns raised when the Scottish Independent Living Coalition ('SILC') met with the official responsible for public communications for the vaccination programme, Jamie MacDougall, on 6 January 2021 (KM/8 INQ000417444). At that meeting concerns were raised regarding the accessibility of information, the provision of home visits, the prioritisation of individuals with learning disabilities given available data on their adverse Covid-19 health outcomes, and the need for supported decision making models to avoid any defaulting to Adults with Incapacity law. All of these concerns, identified by the DPO at such an early stage, developed into issues that needed addressing by the vaccination and therapeutics programmes and are discussed in detail below.

15. Starting with issues around prioritisation for vaccines, in the UK the decisions on who should be prioritised to receive the vaccines were made by the Joint Committee on Vaccination and Immunisation ('JCVI'). The JCVI is made up of medical experts and it is a concern of the DPO that there was inadequate representation of the interests and health vulnerabilities of Disabled people in this group as not one sub-group related to the risks Covid-19 specifically posed to Disabled people (KM/9 INQ000489463). This perhaps resulted in the priority list needing several revisions, discussed below, after campaigning by the DPO and others highlighted specific health vulnerabilities. The most notable omissions include the initial placement in September 2020 of all high-risk adults under 65 in category 6.

16. The first piece of interim prioritisation advice was published by the JCVI on 25 September 2020 (KM/10 INQ000417454). In that advice, "*high-risk adults under 65 years of age*" were only placed in category 6, meaning that category included all those on the CEV list who were under 65. This included a large number of Disabled people who were disproportionately impacted by both the virus itself and NPIs. As DPO, representing the interests of so many individuals on the CEV list who we knew had been so greatly impacted by the pandemic, we were disappointed with this low categorisation and on 17 November 2020, DR UK wrote to the Secretary of State for Health, Matt Hancock, to express deep concern that clinically extremely vulnerable people were so low down on the priority list (KM/11 INQ000238521). DR UK noted that this was all the more of a problem given that, in the second wave, shielding provisions were less supportive and less protective.

17. Similar concerns were also reflected in Scotland, in the survey published by Disability Equality Scotland on 30 November 2020 (KM/7 INQ000417433). Respondents were worried about the low prioritisation of Disabled people generally, with one stating "*I am extremely worried about disabled people with other underlying problems, not getting the vaccine quicker than they are saying. We are just as much risk as some people of dying from the virus. To be placed so far down the list is shocking.*"

18. The JCVI confirmed its priority list on 30 December 2020 (KM/12 INQ000408135) and although those on the CEV list had been re-prioritised, this was only a rise to Category 4 and those with underlying health conditions which put them at higher risk of serious disease and mortality were only placed in Category 6. The JCVI's advice published at the same time as the priority list confirmed that "*prioritisation is primarily based on age*" and concerningly did not specifically consider Disabled people.

19. It is notable that the prioritisation list did include residents in a care home for older adults and their carers as a distinct category to be prioritised regardless of any underlying health conditions. This was understandable and necessary considering the tragic and ongoing impact that the pandemic was having on care home residents. However, the statistics on mortality show the tragic impact that the pandemic also had on Disabled people generally, 60% of all mortalities, and yet no specific provision was made for Disabled people, including those under 65 who were not living in care homes, on the priority list. Instead, we were left to try and fit into one of the other categories that were primarily focussed on age or occupation. This worrying failure to protect Disabled people led to certain DPO and allies issuing a public statement on 17 February 2021 to ask that at least those with a learning disability, cognitive impairment or who are autistic should be included in Category 6 as well as Disabled people of a working age living in residential accommodation or hospitals (KM/13 INQ000417380).

20. The DPO were not only disappointed in the order of prioritisation but also in the confusion its ambiguity caused. For example, people with asthma may have been put in group four or group six or not prioritised at all (KM/14 INQ000417381) and the same lack of clarity also went for those with Muscular Dystrophy and spinal injuries. By 3 March 2021, many DPO, including DR UK, were encouraging people with an underlying health condition who had not been invited to receive the vaccination to contact their GPs as a matter of urgency, to outline their conditions, and request that they were put into cohort 6 (KM/15 INQ000417382). Even after the prioritisation lists had been confirmed,

confusion remained with reports of the misapplication of the list by NHS Trusts, for example, the Belfast NHS Trust in Northern Ireland (KM/16 INQ000474230).

21. In Scotland where the terminology of Clinically Extremely Vulnerable had not been used, instead it was the Shielding List and then the Highest Risk List, the prioritisation list was not only disappointing but also confusing due to its use of English terminology. At a Disability Roundtable on 7 December 2020, the official lead for the vaccination programme reported that people classed as 'clinically vulnerable' would be vaccinated in Category 4, but 'clinically vulnerable' was not defined and it was not confirmed whether the category was equivalent to those on the shielding list. When the list was published by the Scottish Government in January 2021, it only used the English terminology of 'clinically extremely vulnerable'. I would be grateful if the Inquiry could please request the formal minutes of the 7 December 2020 Disability Roundtable from the Scottish Government.

Prioritisation of individuals with learning disabilities

22. The delay in inviting all individuals with a learning disability, and not just those defined as 'severe or profound', was a particular concern to the DPO. This did not take place until 24 February 2021 (KM/17 INQ000417383) despite studies showing that individuals with learning disabilities were 3.6 times more likely to die from Covid-19 after adjustment for under-reporting (KM/18 INQ000417384). Studies in the USA even found that intellectual disability was the second greatest risk factor for Covid-19 mortality behind age (KM/19 INQ000417385). Young people with learning disabilities were particularly vulnerable being 30 times more likely to die (KM/20 INQ000279971).

23. In earlier modules, we have raised concerns about the slow recognition of the significant risks Covid-19 posed to individuals with learning disabilities, including in particular those with Down's syndrome, and it is sadly our concern that similar mistakes were made regarding vaccine prioritisation. To start with, it is unclear why the JCVI imposed such an arbitrary distinction between 'mild and moderate' and 'severe and profound'. Across the UK, this would have involved Doctors having to carry out time-consuming assessments of 1.5 million individuals to determine the degree of learning disability. It was not only time consuming but also left individuals to bring individual legal challenges calling for their prioritisation (KM/21 INQ000417387). At a meeting of the Covid-19 Moral and Ethical Advisory Group Wales ('CMEAG'), (KM/22 INQ000417388) concerns were raised that the 'severe and profound' definition equated to just 5% of the population.

24. The 3.6x increase in mortality rates quoted above was published on 12 November 2020 over a month before the JCVI confirmed its priority list, however, the health risks were known even earlier during the pandemic. As early as 16 March 2020 individuals with a learning disability were identified as being at an increased risk by the UK CMO (KM/23 INQ000417390).

25. Then throughout the summer and early autumn of 2020 the increasing data which highlighted the risks for those with learning disabilities led to the slow process of the UK Clinical Review Panel recommending on 30 September 2020 that individuals with Down's Syndrome were added to the definition of CEV, before they were then eventually added on 2 November 2020. Although this did ensure that individuals with Down's syndrome were prioritised once the JCVI included CEV to Category 4, it is disappointing that the lessons on the importance of protecting and prioritising those that the data showed to be at an increased risk were not learned. Instead, in the case of adequately prioritising individuals with learning disabilities, it was again left to the DPO and others to draw the four nation governments' and JCVI's attention to a risk that had been known long before the priority list was published.

26. The anomaly of the prioritisation of people with learning disabilities was epitomised by the fact that some carers were invited to receive their vaccination before those with learning disabilities who they were caring for. Despite early and persistent campaigning by the DPO, it appeared to take the publicity around the BBC Radio Presenter Jo Whiley's story and contact with Edel Harris for the UK Government to reprioritise those with learning disabilities (KM/24 INQ000417391, KM/25 INQ000417392 and KM/26 INQ000176785/37).

27. To add to the confusion, different areas took different approaches to calling individuals with learning disabilities. For example, the NHS Kent and Medway Clinical Commissioning Group took the decision on 9 February 2021, two weeks prior to the advice of the JCVI, to "*include all adults with learning disabilities who are on the GP learning disability registers in the first phase of the vaccination delivery*". This decision was taken expressly to "*mitigate health inequalities*" and ensured all 9,500 individuals on Learning Disability Registers in Kent and Medway were prioritised (KM/27 INQ000417394).

28. In England the situation was eventually resolved by calling all those on the Learning Disability Register for vaccination on 24 February 2021 (KM/17 INQ000417383). In Scotland, however, the situation was even more concerning as there was no Learning Disability Register to identify individuals for vaccination and instead it was often left to individual GPs. As Edel Harris, CEO of Mencap, noted:

"*I did keep saying how is anyone going to know to send my son a letter, because there's no learning disability register in Scotland, and if the JCVI definition is people with a severe or profound learning disability, who is actually deciding who those people are, to send them a letter? If it's not the GP, then it's just obviously not happening.*" (KM/28 INQ000417395)

29. Even after those with learning disabilities were prioritised, there were concerns over potential delays in them being able to receive the vaccine. In February 2021, People First Scotland, a DPO of those with learning disabilities, raised the issue of clinicians defaulting to Adults With Incapacity ('AWI') legislation, which purportedly relates to mental ill-health situations, however, in practice is often applied by statutory services, including clinicians, to decisions relating to people with learning disabilities (KM/29 INQ000417396). People First Scotland not only noted the inappropriateness of this legislation but also the delays it would cause in individuals receiving the vaccine due to the need to meet the various requirements of the section 47 form. Instead, People First Scotland called for a suspension of the AWI Act and current guidance, and for them to be replaced with a supported decision-making framework where independent advocates and close family members were asked to take on the role of supporter to help make quicker decisions regarding the acceptance of a vaccine (KM/30 INQ000366038).

30. In Wales, similar concerns were raised at a meeting of the CMEAG on 15 January 2021, where there was a worry that, due to the speed at which the vaccine programme was being rolled out, individuals would be discriminated against where a best interest decision could not be made quickly. There were also concerns around the definition of restraint when administering the vaccine to individuals under the Mental Capacity Act and it was noted that more work needed to be done on reasonable adjustments to prepare people for a less restrictive approach (KM/31 INQ000417398) and (KM/32 INQ000353343).

31. At a later meeting of the CMEAG on 12 February 2021 (KM/22 INQ000417388), Rhian Davies of Disability Wales, noted that some young care workers were receiving the

vaccine ahead of the people they were supporting and that Disabled people were being isolated and excluded while they waited for the vaccination. At the same meeting, concerns were also raised on the lack of diversity amongst advisors and decision makers when drawing up plans on prioritisation. The response received from the Chair, Dr Heather Payen from the Welsh Government, was that the JCVI had a number of sociologists, however, the DPO would point out that the inclusion of sociologists is not the same as drawing on a diverse pool of people with a range of life experience. Disabled people were disproportionately impacted by the pandemic and consequently vaccine and therapeutic prioritisation decisions, they should therefore have been involved at the centre of those decisions.

Prioritisation of carers

32. There was also confusion regarding the prioritisation of carers, including unpaid carers and personal assistants. Many Disabled people rely on carers to receive necessary support which is often provided at close proximity, the need for such carers to be prioritised should therefore have been self-evident and yet a universal approach was not taken. In England, Wales and Scotland, where the JCVI prioritisation list was followed, those working in care homes for older adults were placed in Category 1; those who were frontline health and social care workers were in Category 2 and yet unpaid carers were only placed in Category 6. In Northern Ireland, however, all carers were called to be vaccinated at the same time (KM/33 INQ000417401).

33. This lack of clarity led to the Chief Executive of Carers UK, Helen Walker, calling for unpaid carers to be distinctly prioritised because, *"just like key workers, unpaid carers are playing a crucial role in keeping older, disabled and seriously ill people safe from this virus"* (KM/34 INQ000417402). Even paid carers faced confusion over whether they fell into Category 2 when they were employed by Disabled people as Personal Assistants using the direct payment scheme or if they provided care through non-traditional care providers (KM/35 INQ000417403/26). At the CMEAG meeting on 12 February 2021, an argument was put forward that it would be better to keep all Personal Assistants in line with care home staff to keep those they were caring for safe (KM/22 INQ000417388).

34. Even when carers and personal assistants were eligible under the priority list, not all local authorities were aware that they were expected to take a leading role in identifying social care staff who should receive the vaccine, as highlighted by Baroness Campbell.

This led to personal assistants being "*bounced between GP, clinical commissioning group, and council, with no organisation taking responsibility for getting this done… resulting in disabled people and their PAs being left behind, extending the length of time they are at preventable risk of infection.*" (KM/36 INQ000417404)

Access to vaccines and therapeutics for Disabled people

35. Considering the high mortality rates for Disabled people during the pandemic noted above, it should have been clear from the outset of the vaccination programme that Disabled people's prioritisation for vaccines and therapeutics – as well as for their carers - needed to be carefully considered and clinical risk factors properly taken into account. That prioritisation should not simply apply to when Disabled people are called to receive the vaccine and when therapeutics should be provided, but also to the decisions around how the vaccine programme is delivered including the physical environment of centres used and the use of targeted and accessible communications. As one article stated, "*Regardless of where vaccination takes place, accessibility must be applied from start to finish – from deciding to get vaccinated, to booking systems, to the location and vaccination process itself*" (KM/37 INQ000417410/1). This accessibility can be broken down into four segments, communications, booking, physical accessibility and environmental accessibility.

Accessible communications

36. Starting with the communications around the vaccination programme, the DPO and their members experienced receiving letters regarding the vaccination programme in non-accessible formats. This could result in an individual having to wait for a carer or family member to assist them and this process could be delayed by lockdown measures. The minimum standard for communications should have been the NHS Accessible Information Standard which was revised in August 2017 and sets out a framework for the NHS and adult social care systems to meet the information and communications support needs of Disabled people (KM/38 INQ000417405).

37. Inaccessible communications were an issue throughout the pandemic with the Women and Equalities Committee reporting in December 2020 that by the time the vaccination programme was rolled out in the UK on 8 December 2020 (KM/39 INQ000237370), the latest letters on shielding were still being sent in inaccessible formats and the UK Government's coronavirus briefings continued to have no BSL interpretation regardless

of the importance of the content and despite being aware of the issue for many months (KM/40 INQ000176311/36). Even by 17 February 2021, the DPO were still alerting the UK Government to the need for Covid advice letters to be sent in plain English and accessible formats and for sources of information and support to be provided both digitally and non-digitally (KM/13 INQ000417380).

38. Disabled people were more likely to be 'very worried' or 'somewhat worried' about the effect the Covid-19 pandemic was having on their life compared with non-Disabled people (KM/41 INQ000417407). Respondents to the Women and Equality Committee felt that the way the Government communicated with Disabled people had the potential to unintentionally increase this worry and this could also be applied to communications around the vaccine programme. Disabled people were disproportionately impacted by Covid-19, they were more anxious and that anxiety was only exacerbated by not being able to access communications regarding the vaccine programme, the Government's main tool to combat Covid-19.

39. The need for accessible communications had been raised from the outset of the vaccine programme at a meeting of the Disability Equality Forum on 21 October 2020 before any vaccine had been approved, it was asked whether communications would be accessible and it was confirmed by the Senior Professional Adviser to the CMO of Wales that "*officials realise the importance of ensuring information on vaccines is accessible*" (KM/42 INQ000353422/§4.4). However, when the vaccination invitation letter was sent out in Wales, it was described as a 'standard letter' with constraints around formatting. A QR code to enable audio reading of the letter and large font and easily accessible versions were not provided until later (KM/43 INQ000282063).

40. This lack of accessible communications provided by central governments often left DPO to provide these communications ourselves. Despite not being consulted in the creation of the guidance or communication strategies, we felt it necessary to step in and ensure it was understood by Disabled people across the UK. An example of this was the work of Disability Positive who were able to proactively support the drafting of accessible communication for three local authorities/CCGs.

Accessible booking systems

41. As well as the need for accessible communications, it was also well known to the UK Government and devolved administrations that Disabled people were less likely to have

digital literacy skills (KM/44 INQ000489462)[3] and yet many vaccination booking systems were done online and often not in accessible formats. Booking websites ought to have been high contrast, with easy-to-read translations and telephone options for those unable to book online (KM/37 INQ000417410). At a meeting of the Disability Equality Forum in Wales on 27 January 2021, concerns were raised that d/Deaf or hearing impaired individuals were receiving phone calls inviting them to attend a vaccination appointment rather than receiving this information through their preferred form of communication and it was unclear whether Health Boards responsible for delivering the vaccine programme had access to a patient's communication preferences (KM/43 INQ000282063).

Physical and environmental accessibility

42. The physical accessibility of buildings should also have been central to selecting vaccination centres. This includes the accessibility of the location, as well as the physical environment of the building itself. Often it was left to the DPO to provide transport services where possible to Disabled people to ensure they could attend their vaccine appointments. For example, DANI's Disability Action Transport Scheme assisted Disabled people across 29 urban areas reach their Covid vaccine appointments (KM/45 INQ000417412).

43. DPO and our members also heard numerous reports of the physical environments of vaccine centres not being accessible. Many were 'pop-up' sites in neighbourhoods with no formal booking processes, long lines in sensory heavy environments, limited communications support and a lack of seating and heating. These sites were often put in areas of high infection rates where Disabled people would face the same increased risk and yet would need to attend unsuitable locations to receive protection.

44. One such experience of the inaccessibility of vaccine centres was that of DR UK's Covid Inquiry Manager, Dr Rupy Kaur Roberts, who has Cerebral Palsy and uses a powered wheelchair as well as requiring full time care support. She was living in Manchester at the time of the pandemic and experienced numerous difficulties in accessing the vaccine. Dr Roberts was not on the original priority list, however, was classed as a healthcare worker due to working in an NHS commissioned Tier 3 Adult Weight Management Service. The local vaccination centre for such service providers was the

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[3] A report in 2019 found Disabled people are 35% less likely to have essential digital skills for life.

Etihad stadium in Manchester. When Dr Roberts was unable to find accessibility information for the stadium online, her personal assistants who were also eligible as social care workers, offered to assess the accessibility of the process on her behalf. Sadly, when they arrived at the stadium, they found that there was no access available for wheelchair users and patients had to walk down several steps to access the area where vaccines were being administered. When they asked stewards about this issue, the response was either that there was no accessibility or that the stewards were not sure. Dr Roberts therefore returned to the Etihad vaccination website and was able to find a poorly advertised notice that the venue did not offer wheelchair access and such patients should call 111. However, when Dr Roberts rang 111, they simply advised her to call her GP which then resulted in the GP practice manager accusing her of trying to 'queue jump'. The entirety of this experience not only highlights the physical and attitudinal barriers Disabled people faced but also shows the worrying assumption experienced by many Disabled people that they do not lead multi-faceted lives such as being a healthcare worker.

45. Even in more conventional centres, temporary displays were often used to provide information without alternative formats, one-way systems were in operation without tactile guidance and staff members wore opaque face covers limiting their ability to communicate with those reliant on lip-reading. A positive example of the approach that could have been taken is the work of the James Paget University Hospital NHS Trust in setting up a low-sensory vaccination clinic for those with learning disabilities and/or autism (KM/46 INQ000417413). The specialist Learning Disabilities and Autism Nurse at the hospital considered the first 100 steps of the Covid-19 vaccine journey and how to improve the experience at the outset of the vaccination programme in December 2020. Sadly, however, such pre-emptive planning and the resulting low-sensory clinic was not repeated consistently throughout the UK. Considering the issues with the physical environments of many vaccine centres, the DPO would invite the Inquiry to obtain evidence on what equality impact assessments were carried out in selecting locations.

46. The DPO are also concerned as to the lack of home and/or third sector space vaccination centres. In general, the UK Government was slow to shift from the top down, centralised vaccination model to a more tailored delivery strategy which drew on local knowledge (KM/47 INQ000417414). The early focus had been on mass vaccination centres which appeared to be planned on the assumption that everyone would be able

to travel by car as they were often located outside of towns without connections to public transport.

47. In Wales, the Disability Forum had been promised in late October 2020 a "*blended model*" with "*occupational health delivery, mass vaccination centres, mobile units, care homes and for domiciliary based staff and in-home*" (KM/42 INQ000353422/§4.9). However, on 27 January 2021, Disability Wales notified the Disability Equality Forum, that they were receiving calls from people who had been informed they would have to wait weeks for a vaccination at home (KM/43 INQ000282063). The DPO in general heard of inconsistencies in GP practices with some willing to conduct home visits for vaccine appointments while others were not.

48. Some individuals with learning disabilities also required additional support due to extreme needle-phobia, a potential issue that was raised with government officials at the outset of the vaccination programme (KM/42 INQ000353422 /§4.8), this support was often not available at pop-up vaccination centres in high-infection areas.

49. Many of these issues with vaccine accessibility have also been recorded in the Northern Ireland Equality Commission report '*Progress Towards the Implementation of the UNCRPD in Northern* Ireland' which built on research conducted by DANI and noted that the combination of prioritisation and inaccessibility made many Disabled people feel as though they were at the 'end of the list' with respect to vaccine access (KM/48 INQ000142173). A further difficulty in Northern Ireland was that the Republic of Ireland operated a separate system leading to confusion as two closely linked populations were given differential access to type of vaccine, timing of access and type of setting.

Access to Therapeutics and Anti-Viral Medication

50. The DPO are also concerned about the development and access to Covid-19 therapeutics during the pandemic. The priority of all the UK governments appeared to be the vaccination programme, often at the expense of procuring and developing anti-viral medication. A report in December 2023 found that there were 1.2 million immunocompromised people in the UK who were still considered high risk because their conditions and medications made the vaccines ineffective (KM/49 INQ000417415). Many are still shielding or living restricted lives and a recent survey found that nearly one in four reported poor mental health. The failure to protect those who were unable to

receive or benefit from the vaccine has led to seven in ten immunocompromised people to say the Government had handled the pandemic very badly, an opinion only shared with three in ten of the general public (KM/50 INQ000417416).

51. Even before trying to access anti-virals, Disabled people suffered disproportionate difficulties in accessing routine medical treatments when compared with non-Disabled people (KM/51 INQ000417417). Considering this and the impact on immunocompromise individuals, the DPO are particularly disappointed by Government decisions not to procure a greater volume of therapeutics including Evusheld, which was an anti-body treatment manufactured by AstraZeneca and was available in 32 countries including the USA, Canada and France. Some data showed Evusheld had an 92% protection against hospitalisation and death and it was designed for patients who are unlikely to mount an immune response to Covid Vaccines or for whom vaccines are unsuitable. Despite this the DPO understand that the Department of Health decided not to buy doses of this therapeutic and they wish to know whether this decision was supported by evidence that it was ineffective or based on cost. (KM/52 INQ000417418).

52. Other treatments that were not made generally available through the NHS until later in the pandemic were the neutralising monoclonal antibody Sotrovimab and the antiviral Molnupiravir. These medications were designed to reduce the risk of a patient becoming seriously ill or hospitalised after they had contracted Covid-19, however, it was not until late December 2021 that the NHS announced that some Disabled people and those with certain medical conditions would automatically be offered them as soon as they tested positive for Covid-19 (KM/53 INQ000417419). The DPO invite the Inquiry to consider whether these specific medications, and synthetic antibodies and antivirals generally, could have been developed and approved earlier had the same degree of funding and resources gone into their development as had gone into vaccines. As it was, these therapeutics that could significantly reduce the risks of Covid-19 for Disabled people generally and specifically for those who could not receive the vaccine, were not provided until over a year after the vaccines.

Covid-status Certification systems

53. The Covid-status Certification systems also presented barriers to Disabled people as they excluded those without the technology or who needed digital support as well as individuals who could not receive the vaccination. The systems were different in each of the four nations. In England, a vaccine certificate was required for travel from 17 May

2021 and a Covid Pass was briefly mandatory for specific venues between 15 December 2020 and 27 January 2021, after which they were only encouraged to be used in high-risk venues and large events. In Scotland and Wales large venues and outdoor events were required to use Covid Passports from October 2021 and Northern Ireland required passes to be used for large events as well as pubs and restaurants form November 2021. Legal requirements for venues to require Covid Passports were eventually dropped in all four nations in February 2022 (KM/54 INQ000417420).

54. DR UK provided a response to the Government's consultation on Covid-Status certification on 29 March 2021 (KM/55 INQ000238529). In that response, we noted:

> *"A COVID-Status certification scheme has the inherent danger of compounding inequality within our society. It could create a situation where the most deprived, disadvantaged and discriminated against populations find themselves barred and excluded from everyday activities."*

55. Our response also noted that any certification scheme should be limited to environments or situations where there is a high level of risk to individuals, that communication methods need to be made both online and offline and in accessible formats, and that the certificate must be capable of being demonstrated in both digital and non-digital formats. It was also noted that such certification schemes would not only rely on vaccination status but also testing, which some Disabled people were unable to use for physical and psychological reasons. Our response ended with a warning that policing of face coverings had already shown the possibility for hostility from service staff and the public to exempt individuals and that should a certification scheme be rolled out, there would need to be mass training on the regulations and how to handle situations where an individual may be unable to test or receive a vaccine.

56. Inclusion Scotland were attendees at the Equality and Human Rights Roundtable on the Domestic Covid Status Certification on 2 June 2021, which was attended by the then Cabinet Secretary for Health and Social Care, Humza Yousaf, and Minister for Equalities and Older People, Ms McKelvie (KM/56 INQ000366039) and discussed the paper exhibited at KM/57 INQ000417424. Prior to that meeting Inclusion Scotland had created a list of potential issues with the certification scheme which I exhibit at KM/58 INQ000366040, those concerns included the digital accessibility of certificates, exemptions, support with access to vaccinations and testing, and the management of

data. I also exhibit at KM/59 INQ000417426 a survey from Inclusion Scotland in relation to this meeting that also raised these concerns around the certification scheme.

57. In England, Covid certification and general vaccine uptake amongst social care workers also raised issues for Disabled people who receive Direct Payments from local authorities to employ their own personal assistants. Skills for Care estimated that in February 2021, there were 140,000 personal assistants employed by 70,000 individual employers (KM/60 INQ000417427). Yet despite these large numbers no clear guidance was issued on how such employers could remain safe and if they could insist on staff being vaccinated. In Scotland the PA Employer Handbook did produce some limited guidance (KM/61 INQ000417428). Even when personal assistants were willing to be vaccinated, issues with prioritisation, discussed at paragraphs 32-34 above, often meant they were not.

Public messaging about the Covid-19 vaccines, monitoring and steps taken to address vaccine hesitancy

Targeted messaging

58. As set out above, effective public messaging has the ability to both influence a group of people's behaviour but also their wellbeing by improving confidence and reducing anxiety. This positive effect of public messaging was not what Disabled people experienced during the pandemic. Of those who said they would be unlikely to have a Covid-19 vaccine, Disabled people were more likely not to do so due to a concern that the vaccine was not safe and wanted to wait to see how well the vaccine worked (KM/41 INQ000417407/14). Even before the vaccine programme, governments ought to have been aware that targeted messaging to Disabled people and the wider public was required to overcome the negative experiences of health and social care for many Disabled people, which has been shown to discourage them from attending health and social care settings (KM/62 INQ000417429).

59. There was not enough accessible and targeted communication to allay these fears and in particular, DPOs were not adequately enlisted by the four nation governments to help provide accurate and relevant information. We could have been and should have been a great asset to government in targeting low intake groups with reassuring and accessible communication.

60. Clear and targeted communication was all the more important for individuals with learning difficulties as there were reports that they were being prevented from accessing vaccines by family members and carers who did not trust vaccinations (KM/63 INQ000417430) on top of the general vaccination scams that the DPO worked hard to alert their members to (KM/64 INQ000417431). Government communication strategies should also have been alert to the fact that Disabled people are more likely to be living on a low income (KM/65 INQ000417432), which proved to be an indicator of lower vaccine uptake (KM/66 INQ000417434).

Monitoring of low-uptake groups

61. There was also inadequate monitoring of the vaccine uptake amongst clinically vulnerable groups that included many Disabled people. The availability and efficiency of data relating to Disabled people was an issue throughout the pandemic and not just in relation to the vaccination programme. For example, the Disability Unit's ('DU') proposal to set up a Data Commission to understand factors driving increased mortality risk and improving on data collected by the ONS was never acted upon (KM/67 INQ000083918 /1 §3.1) and by 30 March 2021, three months into the vaccine programme, the DU was still expressing concerns about data deficiency, including the fact that data was highly dependent on the 2011 Census which was outdated and contained no disaggregation of disability by impairment type (KM/68 INQ000083885/15 and 32-6). Even by 7 June 2022, the ONS recognised that improvements still needed to be made in processing data relating to Disabled people (KM/69 INQ000089787).

62. With regard to the specific monitoring of vaccine uptake amongst different groups of Disabled people, the DPO are concerned that the general issues on data collection and the failure to make prompt early improvements affected the ability of the governments of the four nations to efficiently monitor vaccine uptake and left some individuals to fall behind. For example by 14 February 2021, one fifth of those who were on the CEV list in England still had not received a first dose of the vaccine (KM/15 INQ000417382).

63. On 5 July 2021, DR UK wrote to the UK Government expressing our concerns that despite being 7 months into the vaccine programme only two thirds of individuals on the CEV list had been double jabbed. Given that a major loosening of restrictions was planned for the 19 July 2021, we described ourselves as "*dismayed that almost one third of these high-risk groups remain without full protection*" and asked what plans the UK Government had to address this situation (KM/70 INQ000238533).

64. One area where there was a concerningly low vaccination rate was in people with severe mental illness and/or learning disabilities (KM/71 INQ000417440/2 and 15) with one study reporting that this may reflect challenges around access to the vaccine and suggesting a wider availability of the AstraZeneca-Oxford vaccine which did not have the logistical difficulties of having to be transported at extremely low temperatures.

65. Throughout the vaccine programme the DPO were concerned that vaccines failed to address some key inequalities that had continued throughout the pandemic. People with Down's Syndrome had a roughly 13-fold increased risk of dying from Covid-19 compared with the general population even after vaccination while those with dementia and Parkinson's disease had a twofold increase (KM/72 INQ000231460). Even after being fully vaccinated, ONS data released on 13 September 2021 noted that Disabled people were almost twice as likely to die of Covid-19 compared with non-Disabled people. This type of death after vaccination was termed a 'breakthrough death' (KM/73 INQ000417442). The ONS report noted: "*the characteristics of breakthrough deaths can reflect the characteristics of the population that is more likely to be double vaccinated as well as having an increased risk of a breakthrough death, and numbers are relatively low and should therefore be interpreted with caution*". DPO wish for data on this issue to be examined further to identify whether the vaccine was less effective for certain Disabled people, if so who and why. Also, if this was the case, why more social protections were not put in place for those Disabled people who remained (and remain) more vulnerable to adverse Covid outcomes even after vaccination.

Reduction of social distancing and pandemic related social support measures prior to full vaccination

66. Despite the incidents of low vaccine uptake identified above, the governments of the four nations continued to reduce restrictions and consequently social support measures. This meant that those who continued to shield based on their expert understanding of their own health condition and the information that was available were often left without the necessary support. At the time shielding was paused by the UK Government, 30 million people had received their first dose but only 4 million had received their second dose (KM/74 INQ000417443). Scope found that 75% of Disabled people planned to continue shielding until after they had received their second vaccine dose (KM/75 INQ000417445), leading to the Executive Director of Strategy at Scope summarising the position as: "*After a year of feeling abandoned and forgotten, now what little support*

remains for shielders could be removed completely." The DPO wish to examine whether government took sufficient account of vaccination rates amongst Disabled people before reducing support for those seeking to socially distance or isolate.

67. By 13 December 2021, despite the surge in cases caused by the Omicron wave and the country moving from Alert level 3 to Alert level 4, shielding support measures for the Clinically Extremely Vulnerable, including arrangements to facilitate the delivery of food and medicines, had yet to be reintroduced (KM/76 INQ000237425).

Engagement with Four Nation Governments

68. Although the opportunities for engagement varied across the four nations, a common theme was that the vaccination programme was the best tool governments had for combating the virus and therefore any suggestions that could be seen to be restricting the rapid roll out of that tool were discouraged. This stance was perhaps epitomised in a note of caution that was issued at a meeting of CMEAG on 12 February 2021, which stated that complicating the vaccination programme would slow down the delivery (KM/22 INQ000417388).

England

69. In England, DR UK found that there were no consultation arrangements which allowed for the views of Disabled people or DPO to be properly heard before decisions were made. There were virtual briefing sessions to advise civil society groups of what was planned but no proper engagement in the lead-up to key decisions being taken. Instead, DR UK was often left to advocate for the rights of Disabled people from the outside, for example writing public letters to raise key concerns, such as the one to Matt Hancock on 17 November 2020 or the open statement of 17 February 2021, both of which are discussed above.

70. Even if the level of engagement envisaged under the UNCRPD had taken place, DPO in England are not generally funded to participate in such consultation. Since Local Authority core grants were cut in the early 2000s, DPO in England have had a reduced capacity to participate in advocacy. In Scotland the DPO funded at local level are few and far between, meaning large portions of the population have not had the opportunity to collectivise.

71. There was a further issue for engagement with the UK Government, in that the Disability Minister sat within the Department for Work and Pensions ('DWP') and had a low profile in government. The DWP's agenda is to reduce the amount the Government spends on benefits and to get people, including Disabled people, into work. This means that the Minister who was primarily responsible for engaging with Disabled people and raising their concerns, including in relation to the vaccine programme, perhaps had other more pressing issues to deal with and was unable to ensure they were adequately considered. When the DU was set up, it was the hope of DR UK and other DPO that having the DU in the Cabinet Office would mean it had a strong voice across government, but regrettably that was not our experience.

Scotland

72. In Scotland, Inclusion Scotland participated in several roundtable meetings with the Scottish Government, including in November and December 2020, before the roundtable on 2 June 2021 that was focussed on the Domestic Covid Status Certification. Those roundtables are discussed above along with the Scottish Independent Living Coalition's meeting with Jamie MacDougal on 6 January 2021. Inclusion Scotland welcomed the broad membership of these groups, however, it was often their experience that they were increasingly presented with near final draft policies and plans at meetings, including on vaccination, and there was minimal scope to influence key decisions. An example of this are the requests for clarification of 'clinically vulnerable' discussed at paragraph 21 above that went unanswered in the final priority list.

73. There was also the National Vaccination Inclusive Steering Group which initially met weekly, then fortnightly, then monthly, to discuss the delivery of the vaccination programme and how best to make it accessible to people with protected characteristics, including Disabled people. Inclusion Scotland found these meetings helpful as they provided the opportunity to raise the concerns of Disabled people regarding accessible communications, prioritisation and eligibility, booking systems, and the environments of vaccination centres. The members were able to highlight both good and bad practices, for example, Inclusion Scotland commended GP surgeries and vaccination centres that were delivering vaccinations in a 'Drive-through' format that allowed Disabled people to remain in their car throughout. However, it was not clear that such feedback ever resulted in official policy.

Wales

74. In Wales, Disability Wales contributed to discussions and raised concerns regarding the vaccines in stakeholder groups including the Welsh Government's Disability Equality Forum and CMEAG, as well as Public Health Wales' Covid-19 Vaccination Equity Committee. As discussed above, the vaccination programme was discussed at meetings of the Disability Equality Forum on 21 October 2020 and 27 January 2020.

75. The Vaccine Equity Committee was established by Public Health Wales and met between April 2021 to October 2022. Its terms of reference stated that *"in the first instance, this group will focus on addressing inequalities in Covid-19 vaccination uptake,"* and this would include ensuring "*equitable access in different, given some may require greater input or additional tailored support."* (KM/77 INQ000417447) Due to ongoing work on coproducing the Locked-Out Report, Disability Wales was unable to take an active part on the Vaccine Equity Committee, however, there was representation from several other disability organisations, including members of the Disability Equality Forum.

76. Disability Wales was also a member of the CMEAG which first met in April 2020 and several of its meetings are discussed above. Providing advice on moral, ethical, cultural and faith considerations relating to health and social care delivery, the group contributed to vaccination policy papers including: Vaccination and Mental Capacity (discussed at meeting on 15 January 2021)(KM/31 INQ000417398); Vaccination and Reasonable Adjustment (discussed at meeting on 29 January 2021)(KM/78 INQ000417449); Covid-19 Vaccination Prioritisation for Disabled Groups in Wales 24 February 2021 (KM/79 INQ000417450); Covid-19 Vaccination Passports (16.04.2021)(KM/80 INQ000417451) and Consideration of Covid-19 Vaccinations: Children and Young People (18.06.2021)(see paper discussed at KM/81 INQ000313912).

Northern Ireland

77. In Northern Ireland there was no engagement or consultation between the Northern Ireland Executive and DPO regarding vaccination or therapeutic programmes. This meant that there was no opportunity for DPO to contribute their expertise and networks to decision making and no efficient process to raise concerns. Such forums clearly need to be established not simply to afford Disabled people the rights they should enjoy under

the UNCRPD, but also to assist decision makers in identifying key issues and ultimately mitigating the disproportionate impact of the pandemic.

Recommendations for future vaccination and therapeutic programmes

78. Throughout this statement I have set out issues identified by the DPO during the vaccination programme and specific steps that could have been taken quicker to address them. Many of the recommendations I have made to address these issues were encapsulated in the WHO and UNICEF Policy Brief 'Disability considerations for COVID-19 vaccination' which was published on 19 April 2021 (KM/82 INQ000417453) and the DPO would encourage any government to use this as a starting point to ensure Disabled people are actively engaged and considered in any future vaccination programme.

79. In summary, the DPO would suggest that the overarching recommendations that arise from those issues and experiences are:

- There should be co-production and co-design, with DPO and Disabled people, of disability inclusive vaccination and therapeutic roll out strategies as envisaged under the UNCRPD. Put simply in the motto of the DPO, there should be 'nothing about us, without us'.
- All communications and information, including booking systems and certification passes, must be provided in accessible formats which requires providing it in multiple different medias such as British Sign Language, Braille and Easy Read.
- DPOs should be properly resourced to become partners in the roll out of information campaigns that reach the most marginalised populations and ensure that messages are clear, inclusive and accessible.
- Patient records used to identify individuals to be vaccinated must record their preferred communication to ensure that all communications inviting them to be vaccinated are in an accessible format.
- Roll out strategies should give priority to Disabled people and their support networks based on clinical vulnerability for them and their carers.
- Vaccination centres must be accessible for people with a range of disabilities and audits should be undertaken to ensure that all vaccination centres have ramps or step free access and are fully accessible.
- Outreach, including home visits transportation services, should be undertaken to enable Disabled people, and particularly those with sensory or learning disabilities to access vaccination and therapeutics.

- Vaccination and therapeutic uptake must be specifically monitored in clinically vulnerable groups and these should be considered before the easing of any NPIs or reduction in support programmes for those who are shielding.
- Governments should take care to consider the potential benefits of therapeutics and resource the development of such medications to ensure they are used to work with any vaccination programme and address any potential shortcomings that such a programme may have.

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

Kamran Mallick
Dated: 18th July 2024