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UK COVID-19 INQUIRY

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

I, Kamran Mallick, will say as follows: -

1. I make this supplementary statement to clarify a point made in my first statement for Module 4 of the Covid Inquiry [INQ000474256] and to provide some more information about access to therapeutics. As with my first statement, this statement is made on behalf of four Disabled People's Organisations ('DPO'): Disability Rights UK, Disability Wales, Inclusion Scotland and Disability Action Northern Ireland.

2. With regard to the prioritisation of carers as described at paragraph 32 of my first statement, the DPO's understanding of this issue is based on publicly available guidance, government press releases and our experience of how the vaccination deployment operated in practice. It may be that there are additional reports we are not aware of or policy decisions made within government or local authorities that were not published. The main issue identified in my first statement at paragraph 32 was the confusion caused around the prioritisation of both paid and unpaid carers and that issue remains a concern for the DPO. However, I can see that it was inaccurate to say all carers in Northern Ireland were called to be vaccinated at the same time from the outset.

3. This statement aims to explain why there was confusion around the prioritisation of carers by highlighting the following issues:

    (a) For all carers, including paid and unpaid carers, there was confusion as to which prioritisation cohort applied to them.

(b) For unpaid carers, there was a delay in the Joint Committee on Vaccination and Immunisation explicitly prioritising unpaid carers.

(c) For unpaid carers, there were issues around the definition of eligible unpaid carers.

(d) For unpaid carers, there were issues around how they could be identified for the purposes of prioritisation on vaccination.

What compounded the confusion around these issues is that each devolved nation took a different approach in addressing them.

(a) Confusion around the prioritisation of all carers

4. The DPO's understanding is that each of the four nations broadly followed the JCVI advice published on 30 December 2020 [KM/12 INQ000408135]. The JCVI advice itself was confusing for all carers, as depending on their working relationship, they could fall under cohort 1 as carers working in care homes for older adults; cohort 2 as carers who were frontline health and social care workers; or cohort 6 as unpaid carers if they fell within the limited definition at footnote 3 as discussed below. In particular, personal assistants faced confusion as to which cohort they fell into, as they were not expressly referred to in the JCVI advice and it was therefore left to the personal assistants themselves to determine their eligibility based on the type of care they provided. As described at paragraph 34 of my first statement, even when personal assistants were eligible because they fell within an existing cohort description, local authorities and GPs failed to take responsibility for identifying and calling them for vaccination [KM/36 INQ000417404].

(b) Delay in JCVI advice explicitly prioritising unpaid carers

5. The earlier interim JCVI advice published on 25 September 2020 [KM/10 INQ000417454] made no reference to unpaid carers. That advice was updated on 2 December 2020 **[KM/83 INQ000234638]** but again it made no explicit reference to unpaid carers. The advice, when describing underlying conditions relevant to cohort 6, did contain the line that "*Further advice on risk groups, including clear definitions, are set out in the Green Book – Immunisation Against Infectious Disease*" **[KM/83 INQ000234638/6].** If someone took the time to find Chapter 14A of that Green Book published on 27 November 2020 **[KM/84 INQ000059136] [KM/85 INQ000474585]** they would see that cohort 6 included the conditions set out in Table 3. Table 3 itself then included "*Adult carers = Those who are in receipt of a carer's allowance, or those who*

are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill" **[KM/84 INQ000059136/10].** This by no means constituted clear and accessible communication that unpaid carers were included and crucially they were not explicitly included in the JCVI advice document. This caused deep and unnecessary concern amongst Disabled people and their carers, as by that stage it was well known that Disabled people had a greater risk of dying from Covid-19 and, therefore, those who were in a caring role should have been prioritised for vaccination. In response to the 2 December 2020 JCVI advice, Carers UK called for unpaid carers to be explicitly prioritised, as previously exhibited to my first statement [KM/34 INQ000417402].

6. On 30 December 2020 new JCVI advice was published [KM/12 INQ000408135]. This defined cohort 6 as "*all individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease and mortality*". On its face, this did not refer to unpaid carers. It was only if one went to footnote 3 at the end of the document that one could see reference to unpaid carers in that it intended to include: "*...those who are in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill*". Therefore, even when a group of unpaid carers was explicitly included in the finalised JCVI advice on 30 December 2020 [KM/12 INQ000408135], this was only as a footnote to the prioritisation list, which was difficult to find at the bottom of the document and meant that they were not expressly included in many press releases. In the absence of the footnote, there was no indication to the reader that the cohort was intended to include certain unpaid carers. The footnote itself adopted the same definition as the Green Book set out above [KM/12 INQ000408135/17].

(c) Issues with the definition of 'unpaid carer'

7. Although the initial definition set out above was reasonably broad, before cohort 6 was publicly called in any of the four nations, the Green Book had been updated on 12 February 2021, to restrict the definition of adult carer to "*those who are eligible for a carer's allowance, or those who are the sole or primary carer of an elderly or disabled person who is at increased risk of COVID-19 mortality and therefore clinically vulnerable"* **[KM/86 INQ000474586/11].** This added the requirement, to the second part of the definition, that the person being cared for must be clinically vulnerable and it was no longer sufficient that "*their welfare may be at risk if the carer falls ill"*. By both definitions referring to the "main", "sole" or "primary" carer of a Disabled person, these descriptions also failed to recognise the reality for many Disabled people, which is that, firstly, we rely

on more than one carer in order to live independently and to enjoy full and effective participation and inclusion in society; and secondly, that even if we are not clinically vulnerable to Covid-19, we can face risks to our welfare if our carer becomes ill with Covid-19 impeding their ability to care for us.

8. What added to the confusion around the definition was that each devolved nation took a different approach. It is a matter we would ask the Inquiry to investigate further, but the DPO's understanding is that in England the JCVI advice, including the description of unpaid carers in cohort 6, was followed with those falling in that category starting to be called from 15 February 2021 **[KM/87 INQ000474587]**. We are not aware of further guidance on the definition being issued in England.

9. In Northern Ireland, when cohort 6 was called on 17 February 2021, the definition of eligible carers was those who "*were born between 01/04/56 and 31/03/61 and are in receipt of Carer's Allowance or Carer's Credit; are a registered care home Care Partner; are the main carer of an elderly or disabled person whose welfare may be at risk if you as carer fall ill.*" This appears to be a version of the original JCVI definition with an additional age criterion so that only carers aged 60 to 64 were able to book their vaccine **[KM/88 INQ000474571]**. That age requirement was then dispensed with two days later on 19 February 2021 [KM/33 INQ000417401]. It was this decision that I referred to in my first statement at paragraph 32. It is difficult to understand why the initial age-related criteria was applied in the first place and the DPO would invite the Inquiry to explore this.

10. The Welsh Government faced similar difficulties in defining 'unpaid carers' and published its own clarifying guidance on which unpaid carers would fall within cohort 6 on 24 February 2021 **[KM/89 INQ000492866]**. This limited the definition to carers who were the sole or primary (see factor III) provider of specific care (see factor II) to a specific group of individuals at greater risk to the virus (see factor I).

11. The Scottish Government appeared to use a broader definition of 'unpaid carer' stating that it was "*using the definition for an unpaid carer as set out in the Carers (Scotland) Act 2016*" **[KM/90 INQ000474573]**. That Act does not actually define 'unpaid carer' but it may have been analogous to 'carer' as defined in s.1 of the Act. Literature from Carers Centres supported by the Scottish Government explained that the definition was broader than the JCVI advice because it also "*includes carers whom people rely on for day-to-day in-person support and access to the COVID-19 vaccination is not limited to only one carer in a caring relationship*" **[KM/91 INQ000474574]**. The initial calls for vaccination,

however, did not extend to everyone in this group as a press release on 22 February 2021 **[KM/92 INQ000474575]** described the eligible carers within cohort 6 as: "*unpaid carers who receive carers' benefits or who have been identified by GPs.*" It was said that carers who did not fall within this category would "*be asked to come forward to register for their vaccine at a later date.*"

(d) *Issues with identification of unpaid carers*

12. The final issue relates to the challenges each devolved nation faced in identifying eligible unpaid carers even after they had confirmed a definition. There was, and remains, no centrally held database of unpaid carers and although the Department for Work and Pensions presumably had a record of those in receipt of Carer's Allowance, this would not have included those who did not receive that benefit but were nonetheless the sole or primary carer of an elderly or Disabled person who was clinically vulnerable. This would no doubt have been a large cohort, as an estimated 4.5 million people became unpaid carers as a result of the pandemic and it is unlikely that, even if they realised they would be eligible to receive Carer's Allowance, they would have registered to receive that benefit by early 2021 **[KM/93 INQ000509857]**.

13. The challenge was therefore identifying the eligible unpaid carers not in receipt of Carer's Allowance. The most obvious solution to this would have been to allow such unpaid carers to 'self-identify', however, again the devolved nations took different approaches and there were delays in setting up such systems. In England, it appears that it was not until 17 March 2021 that a route was established for unpaid carers not already known to health and care services to check whether they were eligible and to apply for a vaccination appointment **[KM/94 INQ000474577]**.

14. The DPO understand that in Northern Ireland unpaid carers were, at least initially, able to self-identify from 17 February 2021, as the initial announcement invited individuals to book themselves rather than wait to be contacted and they were simply asked to "*respect* [the] *criteria when booking.*" In Wales, a self-referral form was put online on 8 March 2021 allowing unpaid carers to identify themselves for a vaccine from that date onwards **[KM/95 INQ000474578]**. In Scotland, that self-registration process for carers did not appear to take place until 15 March 2021 **[KM/96 INQ000474579]**.

15. What is evident from the above is that each nation faced difficulties in defining and identifying unpaid carers. These difficulties and the different approaches taken caused

considerable confusion amongst Disabled people and their carers, exposing both to the risks of the virus for unnecessary periods of time while they tried to understand the eligibility criteria and then faced further delays before they could access self-identifying registration processes. It is all the more disappointing that this issue impacted a group of individuals who provided such value not only to Disabled people during the pandemic but to society as a whole. Studies have shown that unpaid care in England and Wales alone is worth around £162 billion per year or £445 million per day [KM/97 **INQ000474580/9].** . The governments of the UK ought to have realised the importance of this service at a time when the social care sector was failing under the increased pressures of the pandemic and developed efficient vaccination processes for unpaid carers. The DPO would invite the Inquiry to explore whether there were alternative means of providing vaccine protection to Disabled people and their carers which meant they could be protected much earlier than they were and whether communications could have been clearer. This includes considering whether carers and personal assistants could have been vaccinated at the same time as those they cared for or assisted.

Access to Therapeutics

16. At paragraphs 50 to 52 of my first statement, I identified a series of concerns held by the DPO in relation to access to therapeutics. This included the position of over 1.2 million immunocompromised people in the UK for whom vaccines are ineffective and as of December 2023 were still shielding or living restricted lives, with poor mental health. This figure of over 1.2 million immunocompromised people for whom the Covid-19 vaccines are ineffective was taken from the *Forsaken But Engaged* report exhibited to my first statement [KM/49 INQ000417415].

17. Through our contacts, I have been made aware of the experiences of a Disabled person, Y, who has agreed that I share her story with the Inquiry. Her experience highlights the importance of ongoing access to Covid-19 therapeutics, and the continuing need for clear communication to both GPs and patients about the availability of Covid-19 therapeutics and prophylactics. We note that all currently available treatments on the NHS are therapeutics (administered after a Covid-19 infection), and there do not appear to be any prophylactics (preventative treatments administered before infection) [KM/98 **INQ000474581]** .

18. At the age of 28, over 30 years ago, when she was a litigation solicitor and head of litigation at a well-known law school, Y was diagnosed with progressive multiple

sclerosis ('MS'). As treatment for that condition, and as a result of the rapidly developing paralytic symptoms, Y received extremely high doses of oral and intravenous steroids. Unfortunately, these treatments resulted in dangerously raised intracranial pressure and when diuretic drugs failed to reduce the pressure in her cranium, Y had to undergo repeated lumbar punctures to save her life. Widespread endocrine dysfunction then developed manifesting in a hormone-havoc inducing pituitary tumour, osteoporosis and the fat disorder, lipedema. After a tetanus vaccine booster, Y's paralysis rapidly worsened and she was also diagnosed with chronic inflammatory demyelinating polyneuropathy. It took the help of an in-patient rehabilitation stay at the neurology hospital for her to re-learn how to sit, stand, climb stairs and walk short distances again. Sadly, Y never recovered normal mobility, balance, sensation or stamina after that booster vaccination.

19. The doctors at the neurology hospital informed Y that they suspected it was an immune system overreaction to the vaccine and Y should not have further vaccines. Within a year, Y had gone from an active and full life, doing things like backpacking solo in the Himalayas, to relying on a stairlift, walking aids and carers. For nearly 30 years, Y avoided further vaccines to avoid the risk of paralysis and her immune system overreacting.

20. During the pandemic, NHS letters and emails repeatedly warned Y that she was at serious risk from Covid. Y understood that risk to be heightened by the fact that she had previously had an adverse reaction to intravenous and oral Methylprednisone, a steroid. As steroids were, and continue to be, used by the NHS to reduce mortality in cases of a dysregulated immune response to a Covid infection, Y was concerned that she would not be able to receive such treatment if she contracted Covid. Considering this risk and understanding that there was no prophylactic treatment, that would afford protection equivalent to a vaccine available on the NHS, Y sought the advice of her neurologist, an eminent Professor of Neurology, and an Immunology Professor colleague of his, before deciding to try the Covid vaccine.

21. Y received a first dose of the AstraZeneca vaccine in March 2021, but was unfortunately unable to complete the necessary course of two doses, because her now long-stable CIDP flared up badly and took months to settle down. After further advice from her neurologist and the Immunology Professor, Y decided to try the Covid-19 vaccine again but this time the mRNA Pfizer vaccine which she received the first dose of in December 2021. Unfortunately, this led to Y swiftly developing myocarditis-type symptoms

accompanied by hypertension which persisted. Following those symptoms the Immunology Professor advised Y that it would be unwise for her to receive further vaccinations.

22. This inability to complete a course of the vaccine left Y living an anxious life as she continued to be advised by the NHS that she was at highest risk and should be vaccinated, apparently unaware of the fact that Y could not receive the vaccine on medical grounds. In August 2022, Y's fears were realised when she caught Covid-19. Shortly after registering her positive test online, a Covid Medicines Delivery Unit ('CMDU') doctor called Y to assess her for anti-virals and neutralising monoclonal antibodies ('nMABs'). As Y was already, on day one, experiencing meningitis-type symptoms, the doctor was extremely concerned considering her history of immune over-reaction. The doctor told Y that if she was experiencing such symptoms on day one, then she was likely to be in intensive care by day three or four. The doctor therefore arranged for Y to have an infusion of Sotrovimab at her local hospital having assessed that as the only anti-viral or nMAB suitable for Y. Paxlovid and other anti-virals were considered contraindicated in Y's case. Y received the infusion of Sotrovimab on day 2 of her Covid infection and recovered very quickly without noticeable sequelae. In fact, Y recovered faster than her fully-vaccinated husband. Y felt that the swift and efficient administering of Sotrovimab in August 2022 may have saved her from hospitalisation or worse.

23. The frequent and continuing warnings given to Y to get vaccinated have had a negative effect on her usually resilient mental health considering that she cannot be vaccinated safely. As the country opened up and life went back to 'normal' for most people, Y was acutely aware that the vaccine protection enjoyed by most people was not a safe option for her as she had been unable to receive the two-dose course of any vaccine let alone the repeated boosters recommended by the NHS for someone as clinically vulnerable as Y. There also remains no prophylactic drug affording equivalent protection to a vaccine available on the NHS meaning Y is entirely reliant on access to therapeutics which would be administered after she has already contracted Covid. This in itself results in Y being more fearful of catching Covid at all, compared to those who can be vaccinated. This fear is compounded by the fact that although the advice remains for people with Covid to 'try' to stay at home, there is no requirement to do so, or to wear masks in public spaces, and members of the public are unlikely to realise that Y is clinically vulnerable, and therefore particular caution should be taken to protect her from infection.

24. I provide the above story of Y as it is a personal account of one of the over 1.2 million immunocompromised people in the UK, referred to at paragraph 50 of my first statement, who by December 2023 were still considered high risk because their conditions and medications made the Covid vaccines ineffective [KM/49 INQ000417415]. The *Forsaken But Engaged* report sadly highlighted that Y's experiences were not unique, with immunocompromised people more likely to experience higher levels of worry, poorer mental health, lower perceptions of representation and lower trust in government [KM/49 INQ000417415/4].

25. Considering this impact, we invite the Inquiry to explore whether the development of both therapeutics and prophylactics were adequately prioritised so that they could be developed in a timely manner and whether there were clear communications around who would receive such treatments once they were developed. From our own engagement with DPO and Disabled people throughout the UK, we have been particularly concerned by the lack of knowledge across society and amongst Disabled people of therapeutics including nMABs and anti-virals both during the height of the pandemic and today. The DPO's understanding, based on publicly available documents, is that it was not until late 2021 that an advisory group was constituted to identify a set of patient conditions (or cohorts) that were deemed to be at the very highest risk upon community infection of an adverse Covid outcome and therefore should be considered for nMABs and anti-viral drugs should they contract Covid. It was not until 30 May 2022 that the first recommendations for those conditions were published [KM/99 **INQ000499068/2].** .

26. It is the DPO's concern that the delay in identifying these conditions meant that GPs and hospitals were not aware which patients could and should be offered therapeutics. We invite the Inquiry to analyse these issues further and consider whether they have led to life-saving treatment not being offered to those who on medical grounds either did not receive the Covid vaccine or for whom the vaccine was ineffective.

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 *CEO Disability Rights UK*

Dated: 19/11/2024