Witness Name: Vivienne Wilkes
No. :1
Exhibits: 0
Dated: 26th June 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF VIVIENNE WILKES

I, Vivienne Wilkes, will say as follows: -

1. I make this statement to provide information to the Inquiry about my experience of accessing healthcare as a disabled person during the Covid 19 pandemic. I am providing this statement following a Request for Evidence under Rule 9 of the Inquiry Rules 2006, dated 21 May 2024, in relation to Module 3 of the Inquiry. The facts and matters contained within this statement are within my own knowledge unless otherwise stated, and I believe them to be true.

2. I am aged 42 and live with my husband and my adult daughter. I am registered blind and have been since 2011 but I have experienced sight loss since 2007. This was due to a stroke. I have limited vision which impacts on my ability to access information and to get around independently in unfamiliar environments. To get around I use a white cane as a mobility aid. As well as my sight loss I have a number of other long term health conditions, including a compromised immune system and a condition which requires me to have precisely timed monthly injections.

3. Despite my sight loss and other health conditions, I consider that I live a full and active life. I work as a Circuit Safeguarding Officer and I am a regular volunteer for the Royal National Institute of Blind People (RNIB)

My experience of the Government's 'shielding programme' and accessing communications in an accessible format

4. My required format in order to access information independently is email or audio. When the NHS Accessible Information Standard came into force in 2016, the RNIB provided me with a template letter which I completed and sent to my GP asking them to record details of my required format in their computer systems. I was really keen to ensure that all my health information was accessible as I find it very upsetting to have to rely on other people in order to manage my own health.

5. At the start of the pandemic, I received a print letter in standard format indicating that I was required to shield. I had not been expecting this letter. It was sent in print despite, as described above, my having taken steps to ensure that all health related information was provided to me in an accessible format. I therefore had to ask my husband to read the letter to me. This was frustrating as I was unable to independently access the letter and study its contents along with the information that came with it. I was particularly worried about making sure that I followed the instructions in the letter but did not want to ask my husband to read it to me multiple times.

6. It is very frustrating to have to ask someone to read your personal medical information to you, even if they are a close relative like my husband. I have found that there is also a natural tendency for people, especially if they are in a hurry, to read you only what it is they think you need to know whereas if I was able to access information myself I could study it and decide for myself what was relevant.

7. There was a telephone number on the letter which you could ring to get an accessible copy. Obviously this is not ideal as you need to be able to read the letter to get the number but, in any event, when I tried this number it did not work. I also phoned RNIB but they did not have a copy of the letter either.

8. During the pandemic I was involved in a research project overseen by the UK Coronavirus and Immunology Consortium (UK-CIC). I was part of the lived experience panel. Through them I received quite a lot of information about the pandemic which enabled me to understand much better what was going on. For example, I discovered that a lot of the material the Government were sending out including the shielding letters were available online and so I was able to access subsequent versions of the letter via this route but it did take me quite a long time to find them online initially whereas if I had been able to read the original letter I would

have had the information straight away. I should also say that UK-CIC have been exemplary in sending me information in the right format, pretty much from the beginning as soon as I let them know what I required.

9. During the pandemic, whenever I had reason to contact a medical professional to update them on my situation and mentioned the inaccessibility of the information that I was receiving, the standard response that I got was that I should ask a neighbour to read it despite the fact that I was supposed to be shielding and not supposed to have close contact with others. These professionals also did not seem to appreciate that I had the right to access the information independently, it was just not part of their thought processes. They just seemed to be annoyed and irritated when I asked because they had more important things to deal with. I think there was a lack of any real understanding about the impact that receiving things inaccessibly has. It can make you feel as if your health is not really important. The pandemic was obviously a very stressful time. I was concerned about my health and the impact of catching Covid. Knowing that the information I was sent was not going to be accessible, only made things more stressful for me.

My ability to access healthcare services

10. During the second lock down in early Autumn 2021 I also had to visit the hospital for a routine follow up appointment. This appointment, which had originally come through just before the pandemic struck, had initially been cancelled because of lockdown. It didn't particularly matter that it was delayed, and in hindsight, given what happened at the appointment I would have preferred that it hadn't happened at all as I found the whole situation really difficult. On visits to hospital prior to the pandemic, someone would have guided me physically to the consultation rooms by me holding their elbow, but in the pandemic this support ceased and all the layouts changed. On the day of my appointment I had to go in on my own as I was told that I could not bring anyone with me. I managed to make my way to the check in desk on the first floor. From there I was told to sit on one of the chairs in the waiting room but each chair was in a Perspex booth so it was difficult for me to find the chair and sit in one without bumping into everything. I then had to go to the observation area which was down a long dark corridor and I really struggled with the fluorescent lighting in this area. Previously a nurse would have taken me to the observation area and would be chatting away and I could just walk by their side and but now they had to

ensure they were 2m apart and they would just stride off. There was no chatting because everyone was so stressed about the situation. The member of staff who took me to the observation area suggested I hold up my white cane so I could be led from the other end which made me feel like "a dog on a lead'. When I sat down in the observation area someone came over with, what I discovered was, anti-bacterial gel. They didn't tell me this was what they were doing so I didn't hold out my hand and so I ended up getting it squirted in my lap.

11. When I was seated I was lucky enough to be in the seat right by the consultation room (I don't think this was by design) so when the consultant came out and shouted, I could proceed straight into his room. If I had been sat in one of the other chairs, some distance away, I would have found it really difficult. The appointment was swift and the doctor seemed concerned that I should not be in the room too long. Once the appointment was finished I was just left to navigate my own way out. Luckily a member of the public came to my assistance.

12. My experience at GP appointments was also similar. There was no-one to guide you
to the seats which had been rearranged in the waiting room. Also there were notices
on seats telling you to not sit there but obviously I could not see those. My GP
13. practice also created a one way system with different doors in and out so that I had
to navigate a new pathway and couldn't rely on previous walking knowledge. Again
people would get annoyed when I went the wrong way or sat in the wrong chair as if
I was doing it deliberately and it did make the whole thing much more stressful. One
good thing though was that my GP practice did start to use text messages to
communicate with patients so this was helpful to me.

14. Another issue that would arise during attendance at appointments during the pandemic, and at both the GP and hospital, was wanting me to digitally 'sign in'. Staff did not seem to understand that some people were not able to use the digital 'sign in' facilities for accessibility reasons. When I explained that I couldn't use them it was as if I was doing it deliberately to subvert the system. I have found that since Covid the use of these 'sign in' facilities has become more common but they are still not accessible.

15. I also found it difficult to get GP appointments. My practice introduced new processes to get an appointment where the only way to get an appointment was to

ring at 8am. Before you had been allowed to prebook up to 2 weeks in advance or you could turn up in person. This had worked well for me as I needed precisely timed appointments to get my injections but having to rely on 'on the day' appointments became very stressful. The appointments were also often short and impersonal with the majority on the telephone with requests from GP to send pictures of ailments, not easy if you have sight loss, and in the end we ended up using a private GP. It was easier to get appointments and if you needed medication you could have it delivered straight to your door. Since the pandemic ended these arrangements for booking appointments are now business as usual.

16. During the pandemic, I also encountered problems when I had to pick up items from the pharmacy. They had a "one in one out" policy but this relied on you being able to see that there was someone in the pharmacy or notice someone come out and I frequently had people shouting at me because I had tried to go in when someone was there. I think people's ability to be compassionate was reduced because everyone was so stressed.

17. Another issue which proved very stressful during the pandemic was getting access to medicines. A lot of the medication that I need comes from abroad and there were shortages. However, even one of the main medications that I take, which is only made up the road, was difficult to get hold of. Apparently because they export it to other countries. In order to obtain medicines, patients were expected to ring around different pharmacies and take responsibility for researching alternatives if necessary, and for travelling to obtain them. This created an additional strain as the NHS didn't seem to have any way to assist me in getting hold of what I needed. I would sit in all day ringing round pharmacies to try and find some. I was lucky that my husband had to spend time working in Doncaster and Leeds and so he was able to find pharmacies in these areas that had the medication which he then collected. Otherwise I do not know what I would have done. Without my husband I would have been unable to access pharmacies in my local area, as I don't drive as a result of my sight loss, never mind the ones further afield. I also tried online pharmacies but their availability was even worse. It was all very frightening.

My experience of attending hospital during the pandemic

18. In early 2021, I had to have an operation to remove an early stage cancer. The hospital was adamant that I had to attend on my own. Usually my husband would come to these appointments with me. He would drive me to the appointment, help me with any paperwork that I needed to sign and would guide me physically while in hospital. However, the hospital told me that the only way that he could be present was if I had a Power of Attorney in place. When I asked about getting help with the paperwork if he was not there they suggested that if I couldn't read the paperwork that I didn't have capacity. I asked about having things sent in advance but they said they couldn't do that. They said they would not read the paperwork to me as they were worried that this might be said to influence me. I told them that if they refused to let my husband be with me, then staff would need to take on all the tasks requiring physical contact but this did not seem to have an impact. Eventually I made a formal complaint. It was then resolved quite quickly by allowing my husband to attend, I think because the person who looked into the complaint had a family member with sight loss and common sense prevailed.

The long term impact of the pandemic on me

19. The pandemic was a very difficult time for everybody but I think my sight loss made things a lot harder. Not only because of the physical accessibility issues e.g. with reading correspondence or dealing with social distancing measures, but also because everybody just became less tolerant and accommodating. I think there is a total lack of education around sensory disabilities and why we need to be provided with alternative formats. If this need for education is not addressed, I don't think things will change and if there was another pandemic people with sight loss would still be in the same position.

20. My experience of the pandemic has also made me less trusting of the medical profession. I am much more conscious now of the fact that I can't rely on support being provided or things being accessible and this has made me more anxious about my health.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: Personal Data

Dated: 26th June 2024