

Witness Name: Dr Sarah Powell

Statement No.1

Exhibits: 0

Dated: 27 June 2024

## UK COVID-19 INQUIRY

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### WITNESS STATEMENT OF Dr Sarah Powell

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I, Dr Sarah Powell, will say as follows: -

1. I am a Highly Specialist Clinical Psychologist, working with deaf people. I have been deaf since birth, and my primary language is British Sign Language (BSL). I live with my husband, who is also deaf and a BSL user, and my teenage sons, who are hearing. My husband and I were among the first to catch COVID-19 in March 2020 and experienced difficult times during the lockdown as well as post-COVID. Prior to catching COVID, I was healthy and active, regularly participating in HIIT, 5k runs, and even completing a 10K, half marathon, and full marathon. My last 10k was done in mid-March 2020.
2. I am submitting this evidence to highlight our experience, which I believe reflects the challenges faced by others. The systemic barriers I encountered made me feel vulnerable, putting my health at risk, my husband's health due to his pre-existing condition, and my son in a position he should never have been in. If deaf people had equitable access to healthcare services, our experience might have been mitigated, providing us with easier access to diagnosis and treatments.

#### **My experience of contracting Covid-19 in April 2020 and the barriers I faced in obtaining advice and healthcare**

3. On I&S I lost my sense of smell and taste while making brownies for my mother's birthday. At that time, the main symptoms of COVID-19 were reported to be a high temperature and a cough, which I did not have. I continued as normal, walking and working from home as the lockdown had started by then

4. A few weeks later, I experienced a burning sensation on my tongue and contacted my GP. I had a remote consultation, and they prescribed a spray. This went on for several weeks, and after three rounds of antibiotics, it was agreed not to prescribe any more. Soon after, I started experiencing muscle aches and joint pain, initially linking them to my daily 35-minute walks. It was a puzzling time, and I contacted my GP again. An X-ray came back normal, but then fatigue hit me, along with brain fog and an inability to name daily items.
5. My health worsened, and I contacted my GP numerous times, either face-to-face or via Ask MyGP. I was informed that due to health and safety restrictions, I was unable to have BSL interpreters during face-to-face appointments. Some GPs wore masks, making communication extremely difficult, and I was also wearing a mask, which made it harder for the GP to understand me. Left with no alternative, all communication took place by writing; because BSL is my first language, I was not able to articulate my symptoms effectively, delaying diagnosis and treatment. The frustration of having to resort to writing, made worse by the masks, left me feeling anxious, helpless, and isolated.
6. During my appointments, I repeatedly asked if my symptoms were linked to COVID-19, but the GP said no, as I had not tested positive. I knew it was linked to COVID because my husband was hospitalised with it at the same time, and my health suddenly deteriorated with many bizarre symptoms. However, despite my requests, from April to September 2020, I had no access to interpreter provision. It was incredibly frustrating and disheartening to be certain that I had COVID yet be unable to explain why, as I had no interpreter present to articulate my concerns effectively. Prior to 2020, I would visit the GP perhaps twice a year. Since April 2020, I have attended the GP at least once a month and continue to visit about 6-10 times a year.
7. By September 2020, my condition had worsened, and I was experiencing pain in my lung. I was admitted to a ward to rule out a blood clot. While on the ward, the doctor initially wore a mask, but when I explained that I am deaf and communicate using lipreading and BSL, he removed it. I explained my symptoms, and he immediately understood and diagnosed me with long COVID. I was in tears as finally; someone knew what was going on with me. I felt validated. However, there was no cure at that time as it was all new; the doctor himself had long COVID too. He recommended that I test for COVID antibodies to prove I had a past infection. I tested positive and scored very highly, proving I had indeed been infected with COVID. He also strongly recommended I take time off work to recover, which I did.

8. There continued to be frequent visits to the GP, with lots of blood tests coming back normal, and gaslighting from medical professionals saying everything was okay. I was told to exercise more, which I did, but it made my symptoms worse..

#### **The long-term health impact upon me**

9. I mostly work from home, and on working days, I do not go out in the evenings as I do not have any energy left. I go out one day at the weekend, and if I go out on both days, I book Monday off as annual leave to recover. I still have moments when I need to take time off work due to crashing, but I am working on minimising this.
  
10. I may appear healthy, but my body is falling apart. I often use the metaphor of a car: it looks okay on the outside, but the dashboard is full of symbols indicating faults. This is what it is like for me. It has been very hard as many people are either sceptical, puzzled, or do not appreciate the severity of my condition. It is also an ever-changing condition.

#### **My experience obtaining a diagnosis and treatment for long Covid**

11. Despite being diagnosed with long COVID, I have often encountered medical professionals who dismiss my concerns. I frequently must present evidence, such as the fact that blood donors with long COVID are not accepted and that the NHS has set up clinics specifically for people with long COVID. It would be helpful if they simply accepted this instead of arguing with me.
  
12. When I was diagnosed with long COVID in September 2020, I was referred to a long COVID clinic. However, it was not until September 2021 that I was seen. The initial assessment was done via post using English-based questionnaires. From there, I was referred to five different clinics: one for fatigue, one for muscle pain, one for my eyes, one for nutrition, and one for exercise. From September 2021 to early 2022, there were room restrictions which meant I had to cancel appointments even when the interpreter arrived because the room wasn't big enough for me, the interpreter, and the doctor. They only allowed two people, and several times they tried to find a bigger room but couldn't. I am still under physiotherapy and have only recently been referred to rheumatology, as I have also developed an autoimmune disorder, most likely Sjögren's syndrome.

### **The impact on my physical health and methods used to avoid issues in the future**

13. It has been over four years now, and still, not much is known about the future. I continue to have issues with my eyes, my tongue remains burnt (I have since found out that sugar makes it worse, so I have eliminated most sugar from my diet), my muscles hurt daily, and I often experience fatigue. I am still unable to walk for more than 30 minutes without pain and certainly not on consecutive days. Slopes, hills, and stairs remain very painful for me, and I try to avoid them as much as possible. I now have a blue badge, which has helped to reduce the pain and crashing. Pacing myself has been the best advice, along with cutting down on sugar, to minimise crashing.

14. I cannot clean the house in one go, so I do one room (or even half a room) at a time. My children help with household chores such as bringing the washing upstairs and batch cooking for when I have low energy. I need to take a bath with magnesium salts every morning because I often wake up in pain. If, for some reason, I do not have a bath, the pain is worse, and I must take painkillers. I am a member of a Facebook group called Long COVID Support Group, which has been a godsend and remains so. It has been very difficult to get information about long COVID as so little is known, and there are so many different symptoms. One striking thing is that there has been no information about long COVID in British Sign Language, and this remains the case.

### **A summary of my husband's personal circumstances and experiences obtaining an ambulance**

15. My husband, who is deaf and primarily communicates in BSL, has pre-existing conditions with his kidneys. We faced significant difficulties in ensuring he received appropriate care and treatment when he contracted COVID-19.

16. My husband's symptoms started on 23rd March 2020 when he began complaining about my cooking. He was working late shifts, so I cooked in the morning for him to eat in the evening. The next day, he bought ready-made food but continued to complain about the poor taste. He also began feeling increasingly tired. This continued daily, and by Friday morning, he felt unable to work, so he booked annual leave and went to bed. He slept and woke up intermittently throughout the day, eating a little, but he was sleeping far more than usual.

17. On Saturday, his excessive sleeping continued, and alarm bells started to ring. Whenever I tried to wake him up to have some fluids, he would wake briefly and then go back to sleep. I feared it might be sepsis as the symptoms were similar, so I rang NHS

111 via BSL at 9am. After waiting for two hours, they agreed with my suspicion and arranged for an ambulance, but it didn't arrive until 5pm.

- 18.** The ambulance finally arrived in the evening, and all the paramedics were in masks and scrubs, making it impossible for me to lip-read. I was reluctant, but I had no choice but to rely on my teenage son, who was 15 at the time, to help with communication because it was important that we had access to information. My husband was unable to follow the conversation, drifting in and out of sleep.
- 19.** The paramedics concluded it was an infection, not sepsis, and advised us to call the GP on Monday. I continued to monitor him closely and suspected it might be COVID-19, so I decided to sleep on the floor in the same room to be available if he needed anything. He wasn't showing classic signs of COVID-19, just extreme tiredness, and loss of taste.
- 20.** The following day, Sunday, he continued to sleep a lot and wasn't eating at all. I kept waking him to ensure he was drinking, which irritated him. I felt increasingly uneasy, as it was becoming harder to wake him up for fluids, and I didn't see him go to the toilet all day. I rang NHS 111 BSL again in the late afternoon, and they said a doctor would call me back. I explained that I am deaf and needed to use BSL because, from past experience, I knew that my local out-of-hours doctor service, could not call via text relay due to their system not allowing the necessary prefix. I was already liaising with PALS about this issue. I kept my phone and laptop close by in case they used text relay. By 1 am, I had to go to sleep. There were two attempts to call me; each time, I ran to my son's bedroom to get him to answer the phone, he was understandably disoriented due to being abruptly woken up, and both times the calls were cut off before we could respond.
- 21.** Around 4-5 am, my husband woke me up abruptly, sweating profusely and stating that he could not breathe. I used 999 via text message to request an ambulance, explaining the situation in detail. About 30 minutes later, an ambulance arrived, accompanied by a car with a doctor. My husband continued to struggle with his breathing. Once again, the medical staff were in scrubs and masks, making it impossible to lip-read, and there wasn't enough time to write things down, leading to heightened stress and difficulty in communication for the both of us. I had to wake my son again to assist with communication. I felt terrible involving my son in this, as I had always been determined not to rely on him for communication due to him being hearing. It was heartbreaking to involve my teenage son in such a traumatic situation. As a 15-years-old, he should not have to witness his parent in a vulnerable state, let alone bear the responsibility of

interpreting in a medical emergency. I wanted him to enjoy his life without being burdened by these responsibilities. At that moment, I felt like a failure.

### **My husband's experience in hospital**

- 22.** The doctor checked my husband's oxygen levels, which had dropped to 75 (it was 95 the previous day). They decided he needed to go to the hospital. I packed a bag with water, a portable charger, and a cable so he could communicate with me due to the COVID-19 restrictions preventing me from accompanying him. Neither my son nor I could sleep afterward; he was upset by what he had witnessed. He didn't talk about the conversation he had to have, but I felt upset and angry that I had to involve him. I had always wanted him to enjoy his childhood without the burden of communication responsibilities, and because of inequitable healthcare provisions for deaf people, this experience shattered that intention.
- 23.** While my husband was in hospital, I had very little contact from the staff. They did not call me, and I had to phone for updates because they could not reach me using text relay. There was a complete lack of BSL information or support provided. I often wonder if I was treated differently as a deaf person and if they contacted the loved ones of hearing patients more frequently, leaving me feeling isolated and excluded during a critical time.
- 24.** I had limited communication with my husband during his hospitalisation due to him being unwell. He would send me picture messages of machines, oxygen tubes, and readings, expressing his fear and uncertainty about what was happening. During that time, he communicated with the staff via pen and paper, asking many questions with brief responses.
- 25.** The significant differences in communication approaches highlights the lack of BSL interpretation or support within the hospital setting. I understand that the staff on the wards were overwhelmed, but while my husband struggled to communicate his issues and receive full updates, couldn't help but wonder if hearing patients were given more specific information and support. While he was there, he tested positive for COVID, and the lack of communication support added to the challenges we faced as a deaf couple navigating a hearing-centric healthcare system.

- 26.** On the third or fourth day, my husband sent me a text message saying that the hospital doctor had written to him, but he didn't understand it and asked me to translate. In the past, if he didn't understand, I would create a video message translating it into BSL for him. The note stated that he wasn't improving and that they were considering ventilating him, asking for his agreement. As his wife, I was upset about the severity of the situation. As a deaf person, I was angered by the disregard of his communication needs. This was critical information about his condition, in writing, leaving him unable to understand the seriousness of the situation; denying him the opportunity to fully understand and be involved in decisions about his healthcare. I had to stop work for the day and inform my manager of the upsetting situation. Once I had composed myself after crying, I responded to the text message in plain English. I had no idea his condition had deteriorated to the point of needing ventilation. I couldn't send him a video message due to being upset, so I explained the situation and advised him to ask the doctor for further explanation. Fortunately, his health improved later that day, and ventilation was not necessary.
- 27.** A few days later, I was surprised, pleased, but also concerned when he texted me saying he could come home. I received no communication from the hospital, and when I picked him up, he was in a wheelchair, very weak, and went straight to bed upon arriving home. It was clear that he was still in a vulnerable state and not fully recovered but had been discharged prematurely due to it being a high-risk environment and they needed more beds. He was in tears, describing the experience in A&E and the covid ward as awful and refusing to talk about it (he still does not want to discuss it). The discharge letter stated he had COVID pneumonia, a partially collapsed lung, and AKI level 2. None of this critical information had been communicated to him during his discharge.
- 28.** A few days later, his symptoms worsened, leading to more calls to the GP and NHS 111, who were initially reluctant to see him. Eventually, they agreed for him to attend a COVID centre, and I accompanied him. The staff were concerned and arranged for him to go to the hospital. Due to his previous experience with no interpreter, we arranged for one of our interpreters (whom we paid) to be present via video call, which reassured him. I had to drop him off at the hospital due to visitor restrictions, but he reported a much better experience, understanding what was happening and feeling reassured by the care he received. He was given additional antibiotics for a chest infection.

**Long term impact on my husband**

29. He was off work for several months and has long COVID, with symptoms such as fatigue, muscle pain, altered smell and taste, and a recent blood clot. He agreed to psychological therapy and is now on the waiting list, as the experience continues to affect him. He is also attending several hospital clinics for breathing, fatigue, pain, and physio. He wishes to remain anonymous as he does not want his friends and family to know the extent of the impact on him.

**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:** 27-06-2024