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Sherwood
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF ONDINE SHERWOOD ON BEHALF OF LONG COVID SOS

Introduction

1. My name is Ondine Sherwood. I am a founding member of Long Covid SOS (Charity No: 1199120 Registered address: 11A Westland Road Farringdon Oxfordshire SN7 7EX). I make this statement for the purposes of Module 2 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 will refer to the source. I am happy to give oral evidence to the Inquiry in Module 2 to expand upon the matters set out in this statement or address any other issues arising.

2. I have provided this statement in accordance with the Inquiry's request dated 18 August 2023. This statement expands upon the matters set out in the Long Covid SOS Rule 9 response. This statement is structured as follows:
 - (1) Who we are and what we do
 - (2) What Long Covid is and the impact it has on people with Long Covid
 - (3) Long Covid SOS engagement with and representations made to Government
 - (4) The impact of Government decision making on people with Long Covid
 - (5) Case studies of Long Covid sufferers' experiences

I. Long Covid SOS

3. Long Covid SOS was established in June 2020 as a volunteer-run patient advocacy and campaign group. Long Covid SOS advocates for recognition, research and rehabilitation for people impacted by Long Covid. Long Covid SOS has 25,400 Twitter followers; 11,500 Instagram followers and 6,468 individuals have signed up to the website. Long Covid SOS became a registered charity in May 2022.
4. Our organisation was formed to advocate for the many individuals who developed Long Covid in the absence of any public information about it. We initially reached out to find support and acknowledgement from fellow sufferers. The founders met in a support group for people who had not recovered from Covid-19 (Body Politic Covid-19 Support Group). It was clear from the posts in this group that there were large numbers of people worldwide, previously healthy, who were suffering ongoing symptoms after a Covid-19 infection and getting very little help. The founders of Long Covid SOS felt strongly that something needed to be done to draw attention to the many thousands in the UK and worldwide who were impacted and unable to get care.
5. Unfortunately, it took a very long time, and only after persistent advocacy, for the Government to accept that people could have lingering symptoms of Covid-19 or develop and suffer from consequences afterwards.
6. From our first-hand experience and the experience of our members, those who were suffering from Long Covid struggled for recognition; they struggled to access appropriate care, diagnosis, and treatment during this period.
7. Our organisation was established to advocate on behalf of Long Covid sufferers for appropriate recognition by the government and decision makers. We did so by documenting the long-term harm and disability that people infected from Covid-19 continued to suffer and shared this information with decision-makers.
8. Through our advocacy and work, as well as our own personal experiences, we have identified a number of issues in relation to the impact of government decision making on those with Long Covid. One of the issues we have faced since we formed is widely held misunderstanding of what Long Covid is. We therefore suggest that we should first

define Long Covid before explaining the chronology of our engagement with and representations to the Government on Long Covid.

II. What is Long Covid

9. Long Covid is a patient derived term; it was patient advocacy that was instrumental to the formal recognition of Long Covid as a clinical illness¹ as we explain further below. For this reason, we annex with this statement at [OS/1:INQ000272230] a chronology detailing all the advocacy to the government and relevant decision makers by our organisations as well as engagement with the media; but some of our key submissions are also included throughout this statement. Our engagement with the media and publications that we have authored or contributed to can be found at [INQ000099720].

10. We use “Long Covid” as an umbrella term to encapsulate long-term illness caused by infection from Covid-19. ‘Post Covid-19 Syndrome’ has been used by bodies such as NICE and the NHS to refer to the condition of Long Covid. We are aware that the WHO use the term post-Covid condition, which we accept.

11. We prefer to use the patient-derived name Long Covid for several reasons. The word ‘post’ implies that the Covid-19 illness is over, creating an artificial fracture between infection and what follows. Our experience of Long Covid is that for many people there is no clear delineation of symptoms between the acute phase and the period that follows; the initial illness has not resolved and Long Covid is not merely an after-effect of acute Covid-19. There is a growing body of evidence to suggest that in some people, symptoms may be caused by persistent virus suggesting they have not cleared the acute infection. Similarly, use of the word ‘syndrome’ is suggestive of an illness of an uncertain aetiology rather than one rooted in infectious disease. We perceive that this term could be used to stigmatise and minimise this condition. We urge that the patient-derived term Long Covid is used instead.

12. Overall, while we prefer Long Covid, the name is not as important as how patients are treated and how the condition is considered.

¹ Perego and Callard (2020)How and why patients made Long Covid, Social Science & Medicine Journal.

Definition

13. Long Covid was formally defined by the National Institute for Health and Care Excellence (NICE) in December 2020 as “*signs and symptoms that develop during or after an infection consistent with Covid-19, ... and are not explained by alternative diagnosis. It usually presents with clusters of symptoms, often overlapping which can fluctuate and change over time and can affect any system in the body*”.² Long Covid “*includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post -COVID-19 syndrome (12 weeks or more)*.”³
14. The World Health Organisation (WHO) developed an international clinical case definition for Long Covid (termed ‘Post Covid-19 Condition’) in Adults via Delphi methodology in October 2021. This definition is generally consistent with the definition established by NICE.

Symptoms and prevalence

15. Common symptoms include fatigue, shortness of breath and cognitive dysfunction but these are by no means the only symptoms of Long Covid. More than 200 known symptoms have been identified with Long Covid, affecting every part of the body and notably the following systems: ear, nose and throat, skin and hair, musculoskeletal, respiratory, neurocognitive, gastrointestinal, cardiovascular, reproductive and mental health and wellbeing.^{4 5} Organ damage (heart, liver, kidney, pancreas, lungs, spleen) has been found in 59% of Long Covid patients 12 months after initial diagnosis.⁶ Other studies have identified neurological damage.⁷
16. Long Covid symptoms are often debilitating enough to leave patients unable to work and are similar to those of Myalgic Encephalomyelitis/ chronic fatigue syndrome, and

² NICE, Covid-19 rapid guideline: managing the long-term effects of Covid-19, published on 18 December 2020

³ Ibid.

⁴ Greenhalgh, Sivan, Delaney, Evans, Milne, *Long Covid – an update for primary care* BMJ 2022 (published 22 September 2022) *BMJ* 2022;378:e072117

⁵ Davis, H.E., McCorkell, L., Vogel, J.M. et al. Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023)

⁶ Multi-organ impairment and long COVID – a 1 year prospective longitudinal cohort study, *Journal of the Royal Society of Medicine*, 14 February 2023 Volume 116, Issue 3

⁷ Douaud, G., Lee, S., Alfaro-Almagro, F. et al. SARS-CoV-2 is associated with changes in brain structure in UK Biobank. *Nature* 604, 697–707 (2022)

those triggered after infections with poliovirus, and borrelia (Lyme Disease) which fall under the well-known concept of post-acute infection syndrome.^{8 9 10}

17. We have advocated for the recognition of the multiple and varying symptoms suffered by those with Long Covid for example by sharing a poster of these symptoms created by Bruno Foret [OS/2 INQ000272232]

18. Long Covid is an often-debilitating illness that has been found to occur in at least 10% of Covid-19 infections.¹¹ A precise count of the population with Long Covid is difficult to obtain and estimates of prevalence vary. I rely here on recent estimates from the ONS and academic journals. It is estimated by ONS that 1.9 million people living in private households in the UK (2.9% of the population) were experiencing Long Covid as of 5 March 2023¹² This is a substantial number of people whose lives have been, and continue to be, directly harmed by Covid-19. Many previously fit and healthy individuals have suffered profound changes to their lives as they experience the continuing effects of the disease.

Recovery

19. As with the range of reported symptoms, recovery rates for Long Covid sufferers vary widely. Symptoms tend to be relapsing and remitting.. The British Medical Journal (BMJ) reports that while some Long Covid sufferers may improve, many patients plateau in their recovery and their illness fluctuates with exacerbations triggered by physical, cognitive, emotional and mental stress.¹³ It is therefore not possible to predict which patients will recover within weeks, and which will develop a long-term, or even life-long condition.¹⁴

⁸ Walker S, Goodfellow H, Pookarnjanamorakot P, et al. 'Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study'. *BMJ Open* 2023;13:e069217.

⁹ The Lancet Regional Health – Europe (November 2022) 'Long COVID: An opportunity to focus on post-acute infection syndromes'. Volume 22, 100540

¹⁰ Thomas C, Faghy MA, Owen R, et al Lived experience of patients with Long COVID: a qualitative study in the UK *BMJ Open* 2023;13:e068481

¹¹ Davis, H.E., McCorkell, L., Vogel, J.M. et al. (2023) Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146.

¹² Office for National Statistics (ONS), released 30 March 2023, ONS website, statistical bulletin, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 30 March 2023

¹³ Greenhalgh, Sivan, Delaney, Evans, Milne, Long Covid – an update for primary care *BMJ* 2022 (published 22 September 2022) *BMJ* 2022;378:e072117

¹⁴ Ibid.

20. There is evidence that a Covid-19 infection can cause other serious health issues, including cardiovascular and neurological events.¹⁵ I note that there have been studies published showing that the increased risk of heart problems one year after Covid-19 is substantial¹⁶ and that people who get Covid-19 have a greater risk of developing diabetes up to a year later, even after a mild SARS-CoV-2 infection¹⁷. It is clear that the long-term ramifications of Covid-19 remain yet to be fully understood.

21. We also know that being reinfected with Covid-19 can worsen the symptoms of Long Covid and can even reverse recovery. Research shows that reinfections also contribute cumulatively to the risks of post-infection sequelae including the risk of death.¹⁸ A survey by Long Covid Kids and Long Covid Support [OS/3:INQ000272233] found that, of those who still had Long Covid at the time of reinfection, 80% had a worsening of symptom severity. Of those who were in recovery or remission, reinfection caused a recurrence of Long Covid in 60%.

III. Our engagement with and representations to the Government and Key Decision Makers

22. Many of our members contracted Covid-19 early on in the pandemic. We understood from public health messaging at the time that Covid-19 was a short and mild illness for those who were not clinically vulnerable or elderly. We therefore could not understand why we were not recovering after experiencing Covid-19 infections. After we came to realise that we were not alone and were all suffering from the long term effects of Covid-19 infections, we formed an advocacy group to campaign for government decision makers to formally recognise the needs of those with Long Covid. We also sought to raise awareness among the general public of the condition in the absence of any public health messaging on Long Covid.

23. While our advocacy initially focused on the need for formal recognition for and treatment of Long Covid, we soon discovered that we also had to work hard to put pressure on

¹⁵ Knight R, Walker V, Ip S, Cooper JA, Bolton T, Keene S, Denholm R, Akbari A, Abbasizanjani H, Torabi F, Omigie E, Hollings S, North TL, Toms R, Jiang X, Angelantonio ED, Denaxas S, Thygesen JH, Tomlinson C, Bray B, Smith CJ, Barber M, Khunti K, Davey Smith G, Chaturvedi N, Sudlow C, Whiteley WN, Wood AM, Sterne JAC; CVD-COVID-UK/COVID-IMPACT Consortium and the Longitudinal Health and Wellbeing COVID-19 National Core Study. Association of COVID-19 With Major Arterial and Venous Thrombotic Diseases: A Population-Wide Cohort Study of 48 Million Adults in England and Wales. *Circulation*. 2022 Sep 20;146(12):892-906.

¹⁶ Xie, Y., Xu, E., Bowe, B. et al. Long-term cardiovascular outcomes of COVID-19. *Nat Med* 28, 583–590 (2022)

¹⁷ Xie, Y. & Al-Aly, Z. *Lancet Diabetes Endocrinol.* [https://doi.org/10.1016/S2213-8587\(22\)00044-4](https://doi.org/10.1016/S2213-8587(22)00044-4) (2022)

¹⁸ Bowe, B., Xie, Y. & Al-Aly, Z. Acute and postacute sequelae associated with SARS-CoV-2 reinfection. *Nat Med* 28, 2398–2405 (2022)

key decision makers so that important issues such as counting cases of Long Covid were addressed. The impact of decisions around easing restrictions and the distribution of vaccines on the prevalence of Long Covid is something we had to repeatedly bring to the attention of policymakers.

24. In this section, we have set out our advocacy grouped into the following broad issues:
- a. Campaign for formal recognition of Long Covid
 - b. Advocacy for the incorporation of Long Covid in Government decision making
 - c. Counting Long Covid
 - d. Advocacy for improved treatment for Long Covid
 - e. Other advocacy related to Long Covid

Campaign for Formal Recognition of Long Covid

25. As set out above, when many of us were first infected with Long Covid we expected to experience a mild, short illness. This was not in fact the case for many of our members, who as well as not recovering after the much publicised two weeks, would under normal circumstances probably have been admitted to hospital such were the severity of their symptoms during the acute phase. We slowly began to learn through online support networks that others were also suffering from the long-term effects from Covid-19 but their experience was not reflected in the public messages they were receiving from the Government.

26. We wrote to and met with key members of Government to raise awareness of our lived experiences. We annex with this statement at [OS/1 [INQ000272230](#)] a chronology detailing all our engagement with Government and decision makers and draw out some of our key submissions here.

27. On 3 July 2020, Long Covid SOS sent a letter to then Prime Minister Boris Johnson, copied to all sitting members of Parliament and Chief Medical Officer Professor Chris Whitty, UK Government Chief Scientific Advisor Patrick Vallance, Medical Director of NHS England Stephen Powis and the leaders of the devolved health administrations. [[INQ000238582](#)] In the letter we asked for government to attend to the plight of those with Long Covid and warned of the risk of the numbers of people with Long Covid increasing significantly if there were to be a second wave. We made specific requests on how the Government could address the needs of those with Long Covid. We did not receive any response from the UK Government but we did receive letters of support

from Labour MPs and from the Scottish and Welsh Government (which we set out below).

28. On 8 July 2020, Long Covid SOS shared a film we created called *“Message in a Bottle”* [OS/4: INQ000272234; OS/5: INQ000272235] highlighting the stories of more than 100 people, most of whom had been unwell for around 3 months. These stories were captured on placards held up by individuals with Long Covid and illustrated by a voiceover. Examples include:

- a. *“Was fit and healthy, now fatigue, no taste and smell, shortness of breath, sore throat”.*
- b. *“Day 131 and counting, alive but not ‘living”.*
- c. *“Day 146 and counting, debilitating fatigue, shortness of breath, bitter taste, chills, ear pain”.*
- d. *“104 days, can’t think, can’t breathe, can’t walk”.*
- e. *“Each of us has our own journey, but lots of us are feeling abandoned, dismissed, brushed off, ignored and given conflicting advice”.*
- f. *“It’s confusing and scary”.*
- g. *“Our numbers are growing, and we need to be taken seriously”.*

29. The film was created as part of a campaign for the Government and healthcare providers to recognise the needs of those with Long Covid and to raise awareness among the general public. The film was broadcast on CNN, ITV and BBC Radio 4 featured the soundtrack. It has since been viewed over 100,000 times on various platforms.

30. The first public acknowledgment of long-term effects of Covid-19 came on 16 July 2020 when the Rt Hon. Matt Hancock MP in a statement before the House of Commons referred to post viral fatigue as a significant problem for “a minority of people who have had coronavirus.”¹⁹ While it was positive that there was some public acknowledgement of post-viral fatigue, there was no recognition of the other physiological health impacts and no other mention of our concerns in public health announcements about the pandemic. There was still no formal recognition of Long Covid and we remained concerned that the number of people affected by Long Covid was still unknown. Rt Hon

¹⁹ INQ000086680

Matt Hancock MP did not respond directly to our letter of 3 July 2020 nor did any of the other ministerial recipients to the letter.

31. We did receive letters from the Scottish and Welsh Governments and from NHS England [OS/6 [INQ000272236]

- a. A letter from Professor Chris Jones at the Welsh Government dated 16 July 2020
- b. A Letter from the Scottish Government on 4 August 2020
- c. A letter from Public Health England (telling us to write to DHSC) dated 21 July 2020
- d. A letter from Sir Stephen Powis on behalf of the NHS dated 3 August 2020

32. Over the same period of time, the WHO reached out to us and took our concerns seriously. Long Covid SOS was contacted in July 2020 by Maria Van Kerkhove (Covid-19 Technical Lead at the WHO) [INQ000238544] and invited to convene a meeting about Long Covid.

33. The meeting took place on 21 August 2020 and was attended by WHO members including Director General Tedros Adhanom Ghebreyesus. Long Covid SOS members chaired the meeting and two of the co-founders, Frances Simpson and Lyth Hishmeh discussed their experiences of suffering from Long Covid and that of being a parent to children with Long Covid. WHO Director General Dr Tedros Adhanom Ghebreyesus told the audience that he had received our SOS and “heard loud and clear that Long Covid needs recognition, guidelines, research and ongoing patient input and narratives, to shape the WHO response from here on”.

34. Subsequently, several meetings took place between Long Covid SOS and WHO. An ongoing dialogue was established between Long Covid SOS and WHO to support WHO’s development of the clinical guidelines for Long Covid.

35. Over the summer of 2020, members of Long Covid SOS featured in news articles, television, and radio [INQ000099720]. Our goal was to ensure that the public were alert to the possibility of long-term disabling ill-health caused by infection from Covid-19. We sought to increase public awareness and fill a gap in government public messaging.

36. In the summer of 2020 members of Long Covid SOS met with UCL Partners to discuss provision for Long Covid in London. UCL Partners work with patients contributed to plans for COVID-19 rehabilitation needs and London wide commissioning guidance, including development of an app [OS/7 [INQ000272237](#)]
37. In August, we met with David Murphy who was developing the Your Covid Recovery website. This led to a meeting with Sally Singh of NHSE.
38. In September 2020 Long Covid SOS met with Sally Singh to discuss raising awareness of Long Covid. At that stage she was head of the Your Covid Recovery website project however we did not become formally involved until I was appointed PPV for 2021-2022.
39. On 7 September 2020, Public Health England (PHE) published the first official government guidance on the long-term health effects of Covid-19. [OS/8 [INQ000272238](#)]
There was research published on the Parliament website on the same day on the “*Short and Long term health effects of Covid-19.*”
40. On 10 September 2020, Matt Hancock acknowledged Long Covid and the need for treatment for people with Long Covid when giving evidence to the Health and Social Care Committee. Matt Hancock’s evidence caused some excitement and hope amongst people with Long Covid and was celebrated as a milestone. We published a blog about the statement. [OS/9 [INQ000272239](#)]
41. On 11 September 2020, we met with Professor Sir Stephen Powis, Director of NHS England and his team [OS/10 [INQ000272220](#)]. It was a critically important meeting for us because up until that point there had been little public acknowledgement from the NHS about Long Covid. (We have set out further detail about the meeting below).
42. In October 2020, Rt Hon Matt Hancock MP published a statement about the risk of the long-term effects of Covid-19 on a gov.uk website. He said “*The Health Secretary urges people to follow the guidelines to protect themselves and others from the potentially debilitating long-term impact of COVID-19*” [OS/11 [INQ000272221](#)]. He also issued a video at the time.

43. Despite this, Long Covid was not, as far as we are aware, subject to any subsequent public health campaigns. Long Covid was very rarely mentioned at the Prime Minister's briefings or other public health announcements. It was therefore left entirely to advocacy groups such as ours to raise awareness, via social media, the press and broadcast media, to seek recognition by policy makers and amongst the general public.
44. On 23 February 2021, Long Covid SOS directly appealed to the Secretary of State for Health and Social Care Matt Hancock to provide funding for research into treatments [INQ00060080]. This was followed up on 25 February 2021 by a letter to Matt Hancock [INQ000238601] in which we highlighted that within the support group we were part of individuals had been self-medicating due to the absence of medical care and were making decisions without clinical guidance. This risky behaviour had in my view directly arisen from the absence of government advice and medical guidance in response to Long Covid. He responded on 29th March 2021 stating that he hoped "*we can start to make progress in identifying appropriate treatment options for patients with Long Covid.*" [INQ000238602]
45. At this time as far as I'm aware there was still little if any public health messaging about the risk of developing long term damage to health or otherwise from Long Covid.
46. We are still unclear why there was so little public messaging to highlight the risk that infection with SARS-CoV-2 could cause long-term illness when it was known before the Covid-19 pandemic that coronaviruses can cause long-term effects. This lack of information persisted, after multiple cases of Long Covid were reported, and after NICE guidelines for managing the "*long term effects of COVID-19*" were published in December 2020 [OS/12 – [INQ000272222]]

Advocacy for the incorporation of Long Covid in Government decision making

47. We were concerned by the Government's failure to include consideration of Long Covid in its decision making and undertook a great deal of advocacy to try to ensure Long Covid was incorporated. In October 2020, the DHSC invited Long Covid SOS to attend Ministerial Roundtables on Long Covid. We raised matters of concern to people with Long Covid during these roundtables. We also continued to write to key decision makers asking them to factor in Long Covid when making decisions in response to the pandemic. We felt that the creation of this Roundtable was a positive development, as it seemed that at last Long Covid was being taken seriously and that something may

actually be done to address it. These roundtable meetings, and the NHSE taskforce, was seen by us in the early days as a response to the demand in our original open letter for “The establishment of a working group to investigate long-term Covid-19, headed up by a designated medical professional who will be responsible for implementing the following strategies”. It was validating to be able to discuss Long Covid with senior DHSC officials, who seemed to be taking the issue seriously and listened carefully to what we were saying.

48. The Roundtables provided a useful forum, as the patient representatives were usually given time to make comments or presentations. However, as time went on, the meetings seemed to lack a clear purpose and, despite the presence of government ministers, our pleas for policy change on various matters (including mitigation measures in schools; clearer public health messaging including an accurate list of symptoms; timely referrals for secondary care, provisions for long-term sick leave and benefits, and for all Long Covid services to be multidisciplinary), whilst being met with sympathy and understanding, unfortunately did not lead to meaningful action.
49. On 13 October 2020, I was asked to present on behalf of Long Covid SOS at the first roundtable we attended, and I raised concerns about the lack of funding for research into Long Covid and the need to record data on the prevalence of Long Covid. The following are extracts from my speech [INQ000238600]:

“In order to examine the evolution of Long Covid it is imperative that funding is provided for research on community patients and that longitudinal studies are carried out.”

“Demographic research is also urgently needed: we must now establish how many people have Long Covid in the UK and what proportion suffer for weeks, months or longer - something that we assume the ONS could provide. If we have hundreds rather than tens of thousands of sufferers then the potential impact on service provision is huge and the £10M investment will be inadequate.”

“A cohort this size of previously active contributors to the economy cannot be ignored. An unpublished survey of 1570 long haulers across a wide age band found that only 7% have been able to return to full time work without compromising their recovery. A third cannot work at all. Given recent infection

rates we risk continued disruption to the workforce with a significant economic impact. Provisions need to be made for long-term sick leave and benefits: we have heard from people who have lost their jobs or are being forced back into work and risking further ill health."

50. On 12 January 2021, Long Covid SOS wrote with concern to the Prime Minister Boris Johnson, copied to Rt Hon Matt Hancock, Rt Hon Jeremy Hunt, Professor Chris Whitty, and Lord Bethell of Romford [INQ000238583]. The letter was published in the British Medical Journal (BMJ) and was titled "*The risk of Long Covid must be a primary consideration in policy decisions.*" This followed Prime Minister Boris Johnson's announcement on 4 January 2021 regarding the vaccination programme and lifting of restrictions. One of our main concerns was that the impact of Long Covid was not being factored into decision making around the easing of restrictions.

51. Long Covid SOS said that: "*if all or most restrictions are eliminated during this period, we run the risk of the virus circulating freely among younger people. We will then likely see a huge rise in the number of those going on to develop long covid. [...] The potential for covid-19 to cause significant morbidity is now recognised, and both NICE and NHS England are making provision for assessing, diagnosing, and treating those affected.*" [INQ000238583]. I received a reply to this on 4 March 2021 from the DHSC, Ministerial Correspondence and Public Enquiries Team [INQ000238622]. The response did not address the issues we had raised about consideration of the risk of Long Covid when easing restrictions. The letter only referred to funding for research.

52. In June 2021, I presented at the Ministerial roundtable on the results of the survey we had carried out into the impact of Covid vaccines on Long Covid symptoms. [INQ000061094] I was subsequently contacted by the Head of Policy and Engagement at the DHSC Therapeutics Taskforce, who wanted to seek our thoughts and reflections on Long Covid – its possible causes, the classes of therapeutics for the condition, and the relationships between disease severity and the likelihood / intensity of developing long COVID.

53. On 6 July 2021, Long Covid SOS wrote an open letter to Rt Hon Sajid Javid MP copied to Lord Bethell of Romford, Rt Hon Jeremy Hunt MP and Professor Sir Chris Whitty. The letter was published in the British Medical Journal (BMJ) and was titled "*We must take Long Covid into account when easing covid restrictions*". This letter was also sent

to Mr Javid by email [INQ000238584]. The letter was prompted by the Prime Minister speech on 5 July 2021 setting out the Government's plans to ease Covid restrictions on 19 July 2021. We stated:

“Long Covid has been described as our ‘next national health disaster’... Unfortunately, continuing to allow Sars-CoV2 to infect huge numbers of people – 27,334 on 05/07/21 with forecasts that daily rates could reach more than 100,000 – will have serious implications for the health service despite the lower levels of hospitalisation during acute infection. Thousands of predominantly young, active people are being condemned to prolonged ill-health and disability every day... Long Covid has not only been ignored in policy making decisions, and barely mentioned in the roadmap out of lockdown - it has been almost completely absent from the government’s public messaging. The population are now being asked to take responsibility for their own safety and ‘exercise good judgement’, but due to this communications failure many do not realise the extent of the risk they are taking when exposing themselves to this virus. We note with concern that your fellow cabinet member Rishi Sunak has announced his intention to stop wearing a mask as soon as possible, despite the strong recommendation from the WHO that even those double vaccinated should continue to wear masks to protect themselves and, importantly, others from the Delta variant.”

54. Long Covid SOS did not receive a response or acknowledgement to this letter.

55. On 7 December 2021, Long Covid SOS attended the Ministerial Roundtable on Long Covid chaired by Maria Caulfield MP, Minister for Patient Safety and Primary Care [INQ000067606]. At this meeting I planned to ask:

“It’s really troubling that the risk of long-term morbidity due to Covid-19 has never been part of health policy planning... It’s likely that at least half a million people infected since that date will be already suffering or will go on to experience Long covid. Because morbidity isn’t considered, the UK didn’t put in place any mitigations to bring infections down to the very low levels until quite recently seen in other countries in Europe.”; “have highly infectious variant which we are told will predominate in the UK within weeks causing a high-level breakthrough infection which know can result in Long Covid... How can we tolerate this burden of ill health and disability? When will considerations around morbidity inform health policy?

How will the NHS cope with this and is anyone researching the cost to society and the economy?". I retained my note of my comments that I prepared for the meeting [INQ000238600]

56. I cannot recall if I made these comments at the meeting but it was my intention to do so and it reflects concerns that I had throughout the pandemic.

57. In response to the announcement in February 2022 that remaining restrictions would be phased out, Long Covid SOS issued a statement to the press on 10 February 2022 [INQ000238611] which urgently communicated that easing restrictions would increase the prevalence of Long Covid:

"If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically active people to a debilitating long-term illness for which there are currently no effective treatments. This policy decision also fails to take into account those many clinically vulnerable people who will not be able to safely participate in society."

58. In response to a further announcement later on that month, on 21 February 2022, that all measures to control the spread of Covid-19 would be scrapped, Long Covid SOS issued a further statement jointly with Long Covid Kids [INQ000238612]:

"Long Covid has never formed part of policy making decisions during this pandemic, despite repeated requests on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable."

59. On 10 March 2022, at a Ministerial Roundtable on Long Covid chaired by Ed Scully, Director of Primary and Community Health, DHSC, Long Covid SOS raised recent publications which together demonstrate the disease burden of Long Covid [INQ000238600]. These included ONS findings on large increases in disability, and the impact this then has on workforce attendance and job loss. Long Covid SOS

emphasised the need for research and policies to prevent uncontrolled transmission of COVID-19, and attention to morbidity in public health messaging.

60. On 21 September 2022, Long Covid SOS wrote a further open letter to Therese Coffey, Secretary of State for Health and Social Care which was published in the BMJ asking her to prioritise the needs of people with Long Covid when making decisions during the pandemic. [INQ000238585] Long Covid SOS received no response to this letter.

61. I can see no evidence from my interactions with the Government that they gave any real consideration to the excess numbers of people who would suffer Long Covid as a consequence of decisions to remove restrictions. There was simply no focus on excess morbidity, or the human, health and socio-economic toll it has inflicted.

62. Further, and perhaps most shamefully, this risk was exacerbated by the absence of public messaging. The public were not provided with information on the risks of Long Covid in order to make their own informed risk assessment. I believe the government's decisions on easing restrictions and on failing to issue public health messaging on the risk of Long Covid has increased the incidence of those suffering from Long Covid.

Counting Long Covid

63. The recognition of the impact of longer-term sequelae or Long Covid, requires an understanding of its prevalence, yet it took patient advocacy to ensure that the Government was monitoring the prevalence of Long Covid.

64. On 16 October 2020, following the Long Covid Ministerial Roundtable of 13 October 2020, Long Covid SOS contacted the ONS directly about the urgent need to count Long Covid and its absence from the national Covid-19 statistics as a measure of the impact of the pandemic [OS/13:INQ000272223] Ben Humberstone, ONS, was at the roundtable and had sent a message on the chat offering to help after I asked for something to be done about finding out how many people were suffering from Long Covid. We then contacted the ONS in response to that offer.

65. As set out above, we were concerned that the number of people with Long Covid needed to be counted in order for decision makers to understand and respond to its prevalence so we contacted them directly to catalyse action. We recognised that it was vitally important to count Long Covid because without statistics, it would be very difficult

to plan services. We also believed, and were correct, that the true number of people affected with Long Covid was considerably higher than estimated at that time.

66. This led to further productive meetings with the ONS on 29 October 2020, 12 February 2021 and 17 September 2021. The meetings were helpful, the ONS were always very open to learning more from us and we felt that they were focussing on the data and did not have any other agenda. In February 2021, we discussed counting the economic cost of Long Covid, after having presented to Ben Humberstone in January 2021 a rough calculation that one of our members had done to work out the cost to the economy in terms of lost tax revenues and benefits claims. He told us at the meeting that they had asked one of the economists at No.10 to carry out a similar exercise and they had reached a similar figure.

67. Ben Humberstone left the ONS in April 2021 and we continued the relationship with Dan Ayoubkhani. Dan Ayoubkhani helped put us in touch with Mina Mahmoudzadeh at DHSC who was working on a paper for SAGE on Quality Adjusted Life Years (QALY) loss due to Long Covid. This led to a useful meeting with her. He also introduced us to Logan Graham, who at the time was a Special Advisor at No. 10 focussing on modelling. He told us that the Government weren't taking Long Covid seriously because they felt it was hard to pin down, the numbers were uncertain, there could be no certainty whether the symptoms were caused by SARS-CoV-2 and so on. The meeting we had with Dan Ayoubkhani on 17 September 2021 was at our request because I wanted to discuss some 'experimental' data the ONS had published, which had been widely misinterpreted and used as ammunition by Long Covid deniers. The ONS subsequently wrote a blog post to explain more about the dataset but the damage had been done.

68. The ONS published its very first bulletin on Long Covid on 1 April 2021 [OS/14 – INQ000272224] following the publication of an initial set of early experimental results on 16 December 2020 [OS/15: INQ000272225]. In the April 2021 release, it was estimated that 1.1 million people were experiencing Long Covid. It is extremely disappointing that it required repeated patient advocacy and initiative on the part of ONS staff members in order to set up monitoring of the prevalence of something that had caused such widespread harm to the population.

Advocacy for improved treatment for people with Long Covid

69. Our organisation has observed that a direct consequence of the delay in recognising Long Covid is the subsequent delay in the development of adequate treatments and clinical pathways for Long Covid.
70. Members of the Long Covid SOS team were, and continue to be, part of the NHS England Long Covid Taskforce, NIHR Expert Group on Long Covid and the organisation is a stakeholder for NICE. They represent the organisation's views in these forums. We have set out further detail about our engagement in these forums in our statement for Module 3 and outline key parts here as they are relevant to Module 2's scope of investigation.
71. The first NHSE taskforce meeting was held on 29 October 2020 [INQ000238600]. In addition to the main taskforce there were four sub-groups: research; education and information; assessment services and online rehabilitation.
72. Two members of Long Covid SOS were recruited as PPV4 members sitting on the Long Covid Taskforce and we also had representatives in each of the sub-groups. Three current and former members of Long Covid SOS were Patient and Public Voice (PPV) partners for NHS England between June 2021 and June 2022. The members of the Taskforce were generally receptive to our comments although we were occasionally reminded that Government policy was not something that could be discussed or impacted by the taskforce. We ensured that the experience of our members was regularly transmitted to the NHSE national Long Covid team, and we worked on projects such as improving the Your Covid Recovery website, highlighting issues people were having with clinics, and encouraging improvements to data collection to better inform decision making around access to diagnosis and treatments for Long Covid sufferers.
73. It is for this reason that we have retained a connection with as many decision makers as possible. Long Covid SOS has maintained an ongoing dialogue with NHS England since first meeting with Professor Sir Stephen Powis, National Medical Director of NHS England, in September 2020. We continue to regularly meet with the Head of Clinical Policy of NHS England, Sarah Duncan, and their team. During these meetings Long Covid SOS feeds back the experiences and views expressed by people with Long Covid who are trying to get care, interacting with their GPs, being referred to and attending the Long Covid Clinics. Potential treatments are also discussed as well as issues with the Your Covid Recovery website and problems with diagnostics and the lack of available treatments. In general, NHSE are very keen to receive this feedback

and have taken up issues we have raised with individual clinics, although they can only issue guidance.

Other Advocacy relevant to Long Covid

Evidence submitted to Select Committee Inquiries

74. Members of Long Covid SOS provided written [INQ000238630] and oral evidence [INQ000238620] to the Health and Social Care Committee Inquiry into Clearing the NHS Backlog. On 21 September 2021, I gave oral evidence to the Select Committee. I said that:

“The aspect of not being believed is highly typical, certainly in the early days. Despite the fact that we knew from the first SARS epidemic that there were many people who did not recover in months or years, the whole system seemed to be completely unprepared for that possibility. Therefore, when people were not getting better, there was absolutely nothing. There were no resources for them. There was no information. I think that each individual felt alone. Certainly, that was my experience. I did not realise that there were other people in the same situation. I thought, “There’s something wrong with me. I can’t shake this off.” Everybody was unprepared. When they tried to speak to medical professionals, the medical professionals knew nothing. A lot of people said that they would go to A&E and be met with shrugs, because people did not know what to do for them.”

75. The evidence Long Covid SOS provided formed the basis for the section on Long Covid in the Committee’s subsequent report, which in turn informed the NHS England Long Covid Plan for 2022.

Advocacy to Business Owners

76. In May 2022, Long Covid SOS joined with others including Covid-19 Bereaved Families for Justice, Unison, Unite, UCU, ASLEF, the BMA and Independent Sage to launch the Covid Safety Pledge to encourage businesses to take measures to protect their workers, service users and customers from Covid-19.

IV. The impact of government decision making on those with Long Covid

77. Long Covid is serious, devastating and life changing in multiple ways, from daily struggles to significant physical harm to loss of employment. Government decision making which led to the increased transmission of Covid-19 naturally resulted in more people suffering from Long Covid. In our view, the absence of public health messaging on the risk of Long Covid and on the full range of symptoms also negatively impacted people suffering from Long Covid who did not know why they were still suffering from what they were told would be a short, mild illness. The failure to factor in Long Covid to the lifting of restrictions has also resulted in the spread of Covid-19 unchecked without any consideration of the potential impact on people who could go on to suffer from Long Covid. This has vastly exacerbated the harm caused by Long Covid.

78. Those we represent have suffered harm as a direct consequence of pandemic planning failures including poor public health support, treatment, and messaging. There were few measures in place to provide care for people who were developing a chronic illness as a result of Covid-19 infection. They felt ignored and abandoned by the government and health system. Our experience as an organisation was that there was no regard to and little willingness to accept disability caused by Covid-19.

Inadequate planning for chronic illness and disability

79. We believe the wholesale failure to plan for chronic illness and disability led to avoidable suffering. Pandemic planning was entirely focused on deaths alongside hospital and critical care capacity, rather than considering the potential for the fluctuating and disabling nature of post viral conditions. This delayed recognition of Long Covid, which in turn caused protracted suffering.

80. A fundamental aspect of preparedness and planning is whether lessons were learned from previous SARS outbreak and other viruses in regard to the likelihood of chronic illness. There was a body of evidence that survivors of previous coronavirus infections, including the SARS epidemic of 2003 and the Middle East respiratory syndrome (MERS) outbreak of 2012, suffered from a constellation of persistent symptoms similar to Long Covid. Both epidemics *“left survivors with fatigue, persistent shortness of breath, reduced quality of life and a significant burden of mental health problems.”*²⁰

²⁰ Long-term sequelae following previous coronavirus epidemics, COVID 19 Rapid Report, Clinical Medicine 2021 Vol 21 No 1: e68-70

81. The apparent failure to recognise and plan for this left us struggling without recognition or adequate healthcare treatment and detrimentally impacted (i) the recognition of Long Covid (ii) access to diagnosis and care for Long Covid (iii) public awareness of the risk of Long Covid as well as (iv) resulting in skewed public policy responses for the rest of the pandemic.

Delay in formal recognition of long-term sequelae/ Long Covid

82. We don't understand why there was no communication of the risk of long-term effects or planning to monitor for the emergence of those long-term effects when responding to the pandemic. We felt that it was left to us to raise awareness about the existence of Long Covid and to advocate for its recognition.

83. Advocacy from our organisation began in June 2020, but it was not until 7 September 2020 that the first official government guidance was published by Public Health England: "COVID-19: long-term health effects" [OS/8 INQ000272238]. This guidance was delayed and brief, including a list of the persistent issues being reported, links to research including the PHOSP-COVID study (focusing on hospitalised patients) and advice for sufferers to consult with their GP. The final paragraph of the guidance stated the following: "The NHS has produced guidance for primary care and community health services to meet the immediate and longer-term care needs of patients discharged following an acute episode of COVID-19". This guidance incorrectly suggested that Long Covid only occurs in individuals who have been hospitalised with severe Covid-19. Even after delayed public acknowledgement of Long Covid, Governmental focus failed to adequately consider the prevalence and impact of Long Covid in the community.

84. It cannot be overstated how profoundly not being believed has contributed to the overall trauma suffered by those with Long Covid. As a result of an apparent failure to learn lessons from previous pandemics that there would be mass chronic illness, people with considerable morbidity were forced to advocate for themselves and had to fight to be believed and to get care.

85. For many people, the Government's approach to dealing with Long Covid has been and continues to be traumatic and exhausting. Many describe this as one of the worst aspects of their illness experience. This was even more problematic for children; they

and their families continue to face particularly difficult challenges when trying to obtain a diagnosis and care.

Lack of testing

86. The Government's decision to restrict access to community testing for Covid-19 on 12 March 2020²¹ until summer 2020 meant that for a large number of people who developed Long Covid in the first wave, doctors were not able to definitively attribute their symptoms to infection from Covid-19. Without a positive test result on their records, several individuals found that their illness would often not be considered Covid-related. The lack of access to community testing created obstacles and delay for people seeking a diagnosis and care for their prolonged symptoms.

Public health messaging

87. Government decisions to communicate risk is a key pandemic tool to minimising harm caused by infection. We believe the prevalence of Long Covid could have and should have been lower had there been any public messaging on its risk.

88. Throughout the Covid-19 pandemic Government administrative policy and decision making has overlooked the risk of long-term illness caused by Covid-19. The general public have been assured by government and public health sources that most 'mild' or 'moderate' cases, that don't require hospital admission, resolve within two weeks. Despite emerging evidence from July 2020 that a significant number of people were not recovering, there were no changes to public messaging.

89. For example, the Covid-19 dashboard continued to refer only to hospitalisations and deaths, even after the ONS started regularly publishing statistics on Long Covid from April 2021, and the regular government TV briefings rarely mentioned Long Covid.

90. There was only one public health film featuring Matt Hancock in October 2020 which identified the risk of Long Covid to younger people [INQ000071192, INQ000071195].

²¹ Iacobucci G. Covid-19: Lack of capacity led to halting of community testing in March, admits deputy chief medical officer BMJ 2020; 369 :m1845

91. This left the general public uninformed about the risks of developing Long Covid. The burden of awareness raising about Long Covid has rested wholly on organisations like ours, run by volunteers who are themselves impacted by the condition.

92. I find it extraordinary and unethical given the profound debilitating harm and adverse effect on health and life that the Government did not warn the public after October 2020 about the risk of Long Covid as soon as they were alerted to it. Because information has not been transmitted by the Government, an individual cannot properly make an assessment of the risk that a Covid-19 infection poses to one's health as they are unaware that it may lead to long-term and often disabling health consequences. In my opinion, the frequent use by members of Government of terms such as 'Freedom day' and 'back to normal' serve to instil in people's minds the idea that Covid-19 is no longer anything to worry about and therefore they are at little risk from being infected. This is far from the case.

93. It is our experience that the public remains in the dark about Long Covid. In our experience unless you have it, or have a family member or close friend or colleague affected, the knowledge and awareness about it is very limited.

Morbidity as a measure of the pandemic

94. There was a failure to acknowledge morbidity as a measure of impact of the pandemic. Decision makers placed disproportionate reliance on the twin metrics of deaths and hospitalisations throughout the pandemic and used these to form the basis for public health and government messaging despite morbidity being a recognised direct measure of harm in public health terms.²²

95. The over-reliance on death and hospitalisation rates incorrectly gave the impression that all others recovered without any ongoing health issues and left health bodies unsupported to deal with the long-term health consequences of Long Covid. This also left the general public in ignorance of the risk of Long Covid. As a result, most of the

²² It is now known that by July 2020, the long-term health consequences of Covid-19 were formally recognised as a Category A direct health impact and in December 2020, the UK Government departments specifically recognised Long Covid as a Category A direct health impact, noting: "There are likely to be health impacts for those surviving COVID-19, particularly for those who are admitted to hospital and spend time in critical care. This may include cognitive, mental, and physical health impairments". Direct and Indirect Impacts of COVID-19 on Excess Deaths and Morbidity: November 2020 Update from Department of Health and Social care, Office for National Statistics, Government Actuary's Department and Home Office, published on 17 December 2020.

population, unless personally affected, would not have been aware that a Covid-19 infection could lead to long-term illness.

Delay in monitoring prevalence of Long Covid

96. The failure to recognise Long Covid caused an inevitable delay in monitoring its prevalence. It was not until 16 December 2020 that ONS published its first dataset on the prevalence of Long Covid symptoms and COVID-19 complications thanks to continuous advocacy by the Long Covid Groups [OS/15 INQ000272225]. It is not possible to understand and communicate the extent of the impact of Long Covid without monitoring the number of reported cases.

97. ONS published its last Long Covid dataset in March 2023. At the time, an estimated 1.9 million people experiencing Long Covid as of March 2023.²³ There do not appear to be any plans to reinstate the Covid Infection Survey and associated data on Long covid, despite its ongoing prevalence. This lack of surveillance will continue to have profound impact on the extent to which the public is able to know about long-term illness following a Covid-19 infection.

98. Our experience demonstrates that there should be foresight and preparation for the longer-term consequences of an infection. Adequate surveillance mechanisms should be in place to capture the epidemiology of the condition accurately, so that these risks can be communicated to the public.

Recognition of symptoms caused by Covid-19

99. Government decision makers were slow to raise awareness of the extended symptoms caused by Covid-19. It was not until the summer of 2020 that general awareness extended beyond Covid-19 presenting as mild with flu-like symptoms. Indeed, the list of symptoms associated with Covid-19 was not updated until April 2022²⁴ despite developing evidence that the official guidance was out of date.²⁵

²³ Office for National Statistics (ONS), released 30 March 2023, ONS website, statistical bulletin, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 30 March 2023

²⁴ Iacobucci G. Covid-19: UK adds sore throat, headache, fatigue, and six other symptoms to official list BMJ 2022; 377 :o892

²⁵ Mahase E. Covid-19: GPs urge government to clear up confusion over symptoms BMJ 2021; 373 :n1654

100. The failure to recognise the wide range of symptoms caused by Covid-19 adversely affected some people accessing care for Long Covid as they may not have been believed to have Covid-19 if they did not have one of the three officially recognised symptoms listed in the NICE guidance published on 3 November 2020 [INQ000205655] and widely circulated to the public from the start of the pandemic (minus the loss or change in taste or smell in the earliest days): fever, persistent cough, and a loss or change in taste or smell. Our members were often disbelieved and told they were exaggerating their symptoms. Symptomatic surveillance and early public recognition of the manifold symptoms associated with Covid 19 would have prevented the delays in recognising and treating Long Covid and, therefore, increased awareness of it and possibly reduced its prevalence.

Easing restrictions

101. Without Covid-19 infections there is no Long Covid. Despite this, in all of our interactions with the Government we cannot see that there was any adequate consideration of the impact of increasing prevalence of Covid-19 infections on the incidence of Long Covid. To my mind there is a real question as to whether 2 million people with Long Covid was avoidable through better management of the virus, data and public health warnings.

102. When designing strategies for easing restrictions, there was little or no discussion about how the obvious consequence of removing restrictions without mitigations in place would be to allow the virus to reach high levels within the community and lead to more people developing Long Covid. After the lifting of restrictions, government sponsored material on avoiding Covid-19 has focussed on vaccination as the sole preventative measure with very little guidance on avoiding infection through better ventilation or the wearing of masks in crowded indoor places. Although vaccination reduces the incidence of Long Covid it is by between 15-50% (depending on the research)²⁶. A 50% reduction, if correct, is significant however the numbers of people who have been infected in the Omicron waves is far higher than in previous variants.²⁷

²⁶ UKHSA (2022) UKHSA review shows vaccinated less likely to have long COVID than unvaccinated. Available here: <https://www.gov.uk/government/news/ukhsa-review-shows-vaccinated-less-likely-to-have-long-covid-than-unvaccinated>.

²⁷ WHO (2022) One year since the emergence of COVID-19 virus variant Omicron. Available here: <https://www.who.int/news-room/feature-stories/detail/one-year-since-the-emergence-of-omicron#:~:text=Omicron%20was%20quickly%20identified%20as,Delta%20as%20the%20dominant%20variant>.

103. The 'roadmap out of lockdown' published 22 February 2021 contained a single descriptive paragraph which referred to 'prolonged symptoms' [INQ000185087]:

"While for many people COVID-19 is a mild illness, for some, regardless of age, the effects can linger into the long-term. The NHS and partner organisations are already implementing initiatives to support people with prolonged symptoms following COVID-19 infection. In addition, the National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) have announced funding for a number of ambitious studies that will help the Government learn more about the long-term effects of the virus, including among people who have not been hospitalised".

104. Any reference to Long Covid was solely in relation to research and treatment. There was no recognition of the risk of increasing numbers of people suffering from Long Covid which results in otherwise healthy individuals suffering profound changes to their health. It is our concern that the potential for many people to develop Long Covid may not have been seriously or adequately considered when preparing the 'roadmap' and forming policy around easing restrictions

V. The experiences of those with Long Covid

My personal experience of Long Covid

105. My personal story was that I was infected in March 2020. Like many other 'first wavers' I did not understand why I had not recovered from the virus when all the public health messaging at the time was that it was a short illness for those that were not vulnerable. I suffered a relapsing and remitting illness for over two years and still have lingering symptoms. It has had a profound impact upon me, even though I was not as severely impacted as many of my colleagues. I suspect that many of the 582,000 others who still suffer with Long Covid after an infection during the first wave will still be experiencing a continuing, severe disruption to their lives.

Case Studies

106. We exhibit to this witness statement anonymised case studies of people suffering from Long Covid at [OS/16: INQ000272226]. These are case studies from our members and are provided to illustrate the range of problems people with Long Covid experience, the

impact Long Covid had on them and whether they were aware of public messaging regarding Long Covid. Below are examples extracted from the exhibited case studies:

- a. O, 59 years old, states: *"I was a Covid frontline Nurse in the first wave and at the point I went down with covid, 'Long Covid' had not been mooted as a thing. As a result, my ongoing symptoms were often met with scepticism and a degree of 'gaslighting'. By about September 2020 I was classified as a 'long hauler' but there was still no real awareness then of Long Covid and what the trajectory was" [...]* *"I no longer have a home. I struggle to maintain a sense of strength around my children and worry that they perceive me as 'weak' and feel somehow responsible for me on some way rather than the other way around. "*

- b. G, 53 years old, states the following when asked what impact Long Covid has had on his life: *"There are not enough words in the English language to answer this question. It has had a significant impact on my everyday life. I lay in bed, a three year old giving me a cuddle, as I was his Dad, and he became along with my wife and family my carer. Taken to the toilet, as I couldn't walk the 3 to 5 metres on my own. Even getting out of bed, putting my feet on the was like fighting lungs full of sand that wouldn't inflate. Fed, because I couldn't feed myself. Woken up as I slept so long my family thought I had died in my sleep. Woken up coughing in a pool of sweat. Finger tips gently rubbing the duvet cover that was places on me. Trapped in a body that I didn't recognise, covid was infecting every part of my body and fighting every organ. It has placed significant impact on my family, friends and my loved ones. My Wife has a husband, of sorts. My children lost their Dad. I am still me, but not me. Having medical professionals cry in early 2021 as they couldn't do anything for me. But, tell me to rest. This as I left A&E. Long Covid has bled I to every aspect of my day and night. Impact, different for us all. Impact... every second of my life is calculated. Before long covid. I was free, spontaneous. Now I have to say no. No to a 6 year old child who has seen his Dad, medicate his way through the day. Impact, there are not enough words. Lived experience is a horror story. Not a gift of knowledge. Impact = Everything. Investigations for over 2.5yrs. No cure, no answers, no treatment. That's the impact of Long covid."*

- c. H, 53 years old, states: *"Having Long Covid has affected every part of my life. It's unrecognisable from my life pre Covid. My life has altered beyond all*

recognition. I've lost my independence, my livelihood and rely on my husband and family for everything."

- d. S, 54 years old, states: *"I knew very little about Long Covid, but as I already had asthma and fibromyalgia, a clinical friend had told me that Long Covid could make my existing conditions worse. That was all I knew."*[...] *"I had seen no public messaging before I contracted Covid in Jan 2021, I have seen none since in my geographical area."* When asked whether they were aware of the Long Covid video published by the Department of Health and Social Care in October 2020, S responded *"No...?! Where was it published?"*
- e. K, 41 years old, states the following when asked what public messaging they heard about Long Covid: *"I had no idea, I thought it was just going to be a cold because I was 37, went to the gym several times a week and all the messaging was that Covid was nothing to worry about if you were young. It was before the first lockdown so everyone was carefully washing their hands and not wanting to touch anything"*. When asked about the impact Long Covid had on their home and family life, K states *"I live on my own and it's so hard to keep up with washing and cooking, I have to have a cleaner visit because I just can't manage that. I struggle to keep up with the garden too, and I have pets and it's hard to explain to the vets that I can't always easily go out and pick up a prescription. I worry that if I deteriorate further I won't be able to look after them. I don't see my family often anymore, I can't drive far enough to visit them and they feel it's too far to collect me for a visit and then bring me home – either a 4 or 6 hour round trip twice. It's also really hard to talk to them about Long Covid, they find it hard to accept that I'm disabled and keep telling me I should 'try and get better' for something they want to do, not accepting that if it was just a case of trying I'd be better by now. It's hugely isolating and dispiriting to hear that, or for them to blank me when I try to talk about the impact Long Covid is having on my quality of life. After more than 3 and a half years it's still my responsibility to try and manage their emotions about my disability as well as my own, and it's another challenge on top of the physical symptoms. I feel very alone and am incredibly grateful that I know other people with Long Covid through an online forum as well as on a research study PPI group, as I at least can talk about the challenges to people who are going through similar challenges."*

107. A summary of further case studies highlighting the range of problems people with Long Covid experience can be found below:
- a. An adult states: *“The impact of Long COVID on my life is quite literally that it has destroyed my life. With no exaggeration, I have almost no life left, and before I contracted COVID I was completely healthy and happy with no underlying health conditions, and I was under 30. I am no longer able to work more than a few hours a week due to fatigue, PEM [post exertional malaise] and cognitive dysfunction. I am no longer able to leave the house without someone pushing me in a wheelchair, and even then, only for very short amounts of time, due to the same symptoms.”*
 - b. An adult states: *“March 26th 2020, I thought I had taken my last breath collapsed on the bed. Short of breath and chest pains, Paramedics called next morning who confirmed suspected Covid-19. I was not taken to hospital [...] I am no longer the same person pre-covid [...] I have to pace very carefully, some days still bedbound, exhausted short of breath and chest pains I have medical oxygen. I cannot cope very well in crowds as I struggle to talk loud.”*
 - c. An adult states: *“I was unable to walk more than fifteen meters, unable to empty a dishwasher or shower without intense chest pains, breathlessness, and dizziness. The slightest effort wore me out. Improvement was painfully slow.”*
 - d. An adult states: *“The autumn and winter of 2020, my energy levels stayed extremely low, and I slept 12 hours a day, and I was unable to do basic domestic activities. I also experienced extreme crashes in my mood, corresponding with the physical relapses. I started experiencing persistent pain and discomfort in my legs. Two years later has not recovered.”* This adult has been required to step down from their job, having been on part time furlough due to symptoms.

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.

Signe: Personal Data

Dated: 25/09/2023