

Witness Name: Natalie Rogers

Statement No.: 1

Exhibits: NR/1 – NR/27

Dated: 25 September 2023

## UK COVID-19 INQUIRY – MODULE 2

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### WITNESS STATEMENT OF NATALIE ROGERS ON BEHALF OF LONG COVID SUPPORT

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#### Introduction

1. My name is Natalie Rogers. I am a founding member of Long Covid Support (Charity No: 1198938. Registered Address: 87 Standen Road, London, SW18 5TR). 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 Support's Rule 9 response dated 15 December 2022.<sup>1</sup>
3. This statement is structured as follows:
  - I. Who we are and what we do
  - II. What Long Covid is and the impact it has on people with Long Covid
  - III. Long Covid Support's engagement with and representations made to Government
  - IV. The impact of Government decision making on people with Long Covid
  - V. Case studies of Long Covid sufferers' experiences

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<sup>1</sup> INQ000099721

## **I. Long Covid Support**

4. The Long Covid Support Facebook group was established to provide a space for patients who went online seeking support and information about their ongoing health issues during the early days of the pandemic. On 18 May 2020, two founding members of Long Covid Support started a placard campaign on Twitter listing symptoms and the number of days of being ill. The concept was later used in films made by patients in France (June 8th), Spain (June 15th), and the UK (July 8th). Since May 2020, Long Covid Support has been instrumental in providing lived-experience expertise to the Long Covid response.
5. At the time there was a void in policy and medical information about the chronic illness resulting from Covid-19 infections. Individuals began to work together to form a coalition of volunteers under the umbrella of Long Covid Support. Members of this coalition connected with other individual advocates and patient groups that came together internationally. Some individuals from the Long Covid Support Facebook Group went on to form separate groups that focused on specific issues such as Long Covid Kids and Long Covid Physio. Others formed groups that advocated on the specific government and health policy of the devolved nations - Long Covid Wales and Long Covid Scotland, international members of the group went on to set up organisations in their own countries.
6. Long Covid Support went on to register as a charity in England and Wales in May 2022. The organisation hosts an active programme of online social and wellbeing activities including our Long Covid Choir, weekly zoom chats, chair yoga, opera breathing, and other areas of potential help or interest to our members. Together with others, Long Covid Support was instrumental in establishing the term Long Covid and bringing the condition to the attention of the medical profession, policy makers and the wider public.
7. Long Covid Support facilitates a peer support group via Facebook offering international support. Strictly for people with Long Covid or their direct carers, this online group is one of the largest of its type in the world, with members in over 100 countries and territories. It presently has over 61,000 members, 39% of whom are from the UK. The group has grown continuously since its creation and continues to grow, membership having increased by 20% over the past year.
8. Long Covid Support advocates for UK policy changes regarding non-pharmaceutical interventions (NPIs), NHS England healthcare provision, employment, welfare, and

research funding. Long Covid Support has a dedicated team focused on employment and benefits, comprising people with professional as well as lived experience.

9. The Long Covid Support Employment Group comprises a multidisciplinary team of associate vocational rehabilitation professionals whose work is focused on supporting workers and employers with return to work. We have co-developed materials with bodies including the UK's Society of Occupational Medicine (SOM) and Chartered Institute of Personnel and Development (CIPD). The group have also worked extensively with Unions and have collaborated with the TUC to run surveys into the impact of the condition on employment status and quality of life. Members of the Long Covid Support employment group also set up the Long Covid Work website.
10. Long Covid Support has been instrumental in facilitating patient involvement in research in the UK. The charity runs the Covid-19 Research Involvement Group, a thriving forum of 5700 members in which researchers, investigators and academics interact with each other and patients. We work extensively with researchers, including as co-investigators, members of advisory groups and co-authors of numerous papers published in respected journals. We have provided training in Patient and Public Involvement in Research to members of the Long Covid community in the UK. We worked closely with the NIHR to recruit people with Long Covid to be trained as lay reviewers for the Community Long Covid commissioned calls for research in Autumn 2020 and Spring 2021.
11. Long Covid Support is a member of Long Covid Europe, which has partnered with the World Health Organization Europe and seeks to influence European Union (EU) wide policy on Long Covid to ensure that there is an agreed definition for Long Covid and shared learning with regards to research, innovation and healthcare policy around the condition.
12. Internationally, Long Covid Support has worked with the World Health Organization (WHO), the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC) and The Global Research Collaboration for Infectious Disease Preparedness (GloPID-R). Together, we organised the Long Covid Forum in December 2020, the first international research conference on the condition, which was opened by the WHO Director General. In February 2021, the WHO held the first of three webinars on Post-Covid Condition at which Long Covid Support presented.
13. Our aim as a charity is to improve the futures of people with Long Covid by ensuring equitable access to high quality healthcare, employment rights and welfare services.

## II. What is Long Covid

14. I have seen the statement of Ondine Sherwood of Long Covid SOS and statement of Sammie McFarland of Long Covid Kids and endorse their summaries of what Long Covid is. I will add some further information specifically in relation to the National Institute of Health Research (NIHR) reviews as this is of particular importance when considering the development in understanding of Long Covid.
15. In October 2020, the first NIHR review which was led by Dr.Elaine Maxwell<sup>2</sup> highlighted that Covid-19 could affect not only the respiratory system but also the heart and cardiovascular system and the brain directly and indirectly kidneys and gut and that post-Covid sequelae were both multi system and fluctuating.<sup>3</sup> The review noted that “*evidence from previous coronavirus outbreaks indicates the risk of ongoing virus-related effects.*” Our members participated in the evidence gathering from June 2020. Based on the evidence collated, the NIHR made various recommendations for services needed. The review was guided by an expert advisory group, with a wide range of experts. It was a comprehensive review of the international evidence of serious long term health problems caused by Covid-19, including for people who had never been admitted to hospital.
16. NIHR invited one of the Long Covid Support members (Dr Jo House) to join the advisory group for the second review. Long Covid Support members helped to design the survey that informed the second review, including details of access to healthcare service and impact on work, social and family life.
17. The second review was published in March 2021 and again showed that Long Covid was a significant problem that had to be taken seriously [INQ000248872]. It found that there are more than 200 known symptoms 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.<sup>4 5</sup>

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<sup>2</sup> For clarity I should explain that Elaine Maxwell became part of Long Covid Support for a period of time.

<sup>3</sup> INQ000058418

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

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

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

18. In summary, Long Covid Support advocated on behalf of people living with Long Covid in the UK by:

- 18.1. Writing to the Prime Minister and relevant Government Ministers
- 18.2. Meeting with Government Ministers
- 18.3. Participating in relevant Task Forces and expert panels relevant to Long Covid
- 18.4. Submitting evidence to All Party Parliamentary Group (APPG) and Select Committee Inquiries
- 18.5. Collaborating with other relevant partners
- 18.6. Contributing to UK and international research
- 18.7. Conducting surveys into patient experience, co-creating and publishing original research
- 18.8. Undertaking wider advocacy

19. This statement focuses on representations we made to core political and administrative decision-makers to influence decision making in response to the pandemic. We annex with this statement a chronology detailing all our engagement with Government at **[NR/1 – INQ000272250]** Our engagement with the media and publications that we have authored or contributed to can be found at **[INQ000099721]**. In this section, we have set out our advocacy grouped into the following broad issues:

- 19.1. Campaign for formal recognition of Long Covid
- 19.2. Advocacy for incorporating Long Covid in Government Decision making
- 19.3. Counting Long Covid
- 19.4. Advocacy for improved treatment for Long Covid
- 19.5. Other advocacy related to Long Covid

#### *Campaign for Formal Recognition of Long Covid*

20. Long Covid Support has advocated at the highest level of government from the very early days of the pandemic, for morbidity and specifically the risk of Long Covid, to be a primary concern for decision makers.

21. As mentioned above, on 18 May 2020, two founding members of Long Covid Support started a placard campaign on Twitter listing symptoms and the number of days of they had been ill with the aim of raising awareness of the diverse and persisting symptoms following Covid-19.
22. On 16 and 17 June 2020, UK parliamentarians, Natalie Bennett, Baroness of Manor Castle, and Steve McCabe MP for Birmingham, Selly Oak, tabled written questions about Long Covid in the UK House of Commons, the latter in response to a letter written to Steve McCabe MP by Claire Hastie, a founding member of Long Covid Support, who was his constituent [INQ000248889, INQ000249035].
23. On 5 August 2020, members of Long Covid Support gave evidence to MPs and members of the House of Lords at the second hearing of the UK's newly formed All Party Parliamentary Group on Coronavirus, which was covered in all major media outlets, including on the front page of The Telegraph and on Channel 4 News. Members of Long Covid Support went on to give further evidence to several APPG hearings on Long Covid (extracts of the testimonials our members provided are set out below).
24. The APPG published an interim report in December 2020 that concluded: "*The UK government is not counting the number of individuals who are left with long-lasting effects of COVID-19 as a measure of the severity and impact of the pandemic; As a medical condition, Long Covid has not yet received full recognition, sufficient research funding or adequate rehabilitation support. There are very few guidelines for employers or for GPs on recognising and managing Long Covid.*" [INQ000249062]
25. On 28 August 2020, Long Covid Support and partners sent a letter to Jeremy Hunt, Chair of the Health & Social Care Committee, to ask for the UK Government to assemble a multi-disciplinary Long Covid Taskforce to address the urgent needs of people living with persistent on-going symptoms of COVID-19 [INQ000248911]. We said:

*"We are grateful to the Health and Social Care committee for shining a light on the failures in the UK's response to COVID-19 and pressing for better responses by our government. Many of us bear witness to those failures having become ill because the right action was not taken at the right time; we were poorly informed and poorly supported. A large number of us served on the front line of the response to COVID-19, many of us in the earliest days of the pandemic. Our persistent, ongoing health challenges are distressing not only because they were avoidable, but also because far*

*too many of our peers in the health and social care sectors are failing to respond with the care and support that we desperately need, because they do not have the information they need to provide the right responses now. Sadly, too many of our UK members are reporting experiences of extremely poor, uninformed and dismissive responses from professionals in health and care sectors when we turn to them for help. This is not the fault of individuals, rather that the systems are failing us - when we try to access health care, social care, and benefits - often because there is inadequate awareness about the thousands of us who have not received a positive test result or been hospitalised.”*

26. I should explain here that many of our members who contracted Covid-19 in the first wave of the pandemic were unable to demonstrate that they had Covid-19 during their acute phase of illness due to the decision to stop community testing in March 2020. This meant that the first step was getting a healthcare professional to believe that you had Covid-19, which was very difficult when the advice was to stay home and there were limited in-person assessments. This in turn led to an unnecessary delay in identifying that long-term health impacts were being caused by Covid 19, and led to pervasive disbelief of the symptoms that patients were presenting with. In our view the decision to stop community testing fed into a widespread narrative of disbelief around Long Covid which was inappropriate and wholly unhelpful.

27. In our letter to Jeremy Hunt, we explained that we wanted the Department of Health and Social Care (DHSC) to:

- 27.1. Develop and disseminate information on treatment, management of symptoms and rehabilitation
- 27.2. Fund more and better research
- 27.3. Provide quality psychosocial and mental health services
- 27.4. Implement better public health programmes, including improved public health messaging
- 27.5. Help NHS and social care workers to return to work safely (many had been infected on the frontline of the pandemic response)
- 27.6. Provide funding for patient-led support groups.

28. As explained in Long Covid SOS's statement, on 7 September 2020, Public Health England (PHE) published the first official government guidance on the long-term health effects of Covid-19. The UK Parliament had published a "Rapid Response" on the Short

and Long Term health effects of Covid-19 on 7 September 2020 [NR/2 INQ000272259] The advocacy work of Long Covid Support is referenced in this report. The report states: “*There is emerging evidence that COVID-19 affects many systems of the body, with patients reporting a wide range of symptoms. ‘Long-haulers’ are patients who experience ongoing COVID-19 symptoms for several months after infection.*” It is noted that “*As described on the NHS website, the main symptoms of SARS-CoV-2 infection are: 1) a high temperature, 2) a new, continuous cough, and 3) a loss or change of smell or taste. However, there is emerging evidence supporting a more complex range of clinical features of SARS-CoV-2 infection.*” It then goes on to note that there is a much broader range of symptoms listed in Guidance from Public Health England. Despite our repeated requests for the NHS symptom list to be updated this did not happen until 1st April 2022. This directly impacted on test eligibility, public awareness that their symptoms were due to COVID-19 and hence transmission of SARS-CoV-2 and ability to seek help for ongoing symptoms of Long Covid.

29. Matt Hancock MP gave evidence to the Health and Social Care Committee on 10 September 2020. He acknowledged the existence of long-term symptoms of Covid-19 and that the impact of Long Covid can be debilitating for a long period of time. At the end of the hearing, Jeremy Hunt, the Chair of the Health and Social Care Committee asked Matt Hancock MP to reply to our letter of 28 August 2023 [INQ000248911] and the points raised in it. Matt Hancock confirmed he had seen the letter the night before and would reply to it, which he did on 14 September 2020 though I have not seen that letter. On 12 October 2020 Jeremy Hunt wrote to Matt Hancock responding [INQ000249042] the response raised concerns that our main points had not been addressed including that awareness of the “*risks of acquiring the complex long-term condition known as Long Covid.*”

30. Then in October 2020, Matt Hancock MP published a statement about the risk of long-term effects of Covid-19 on gov.uk website. After months of seeking to raise awareness and lobbying for rehab, research, and recognition, it was gratifying to see official recognition of Long Covid, although the urgent need for research, treatment and public health messaging remained.

#### *Advocacy for incorporating Long Covid in Government Decision making*

31. In October 2020, members of Long Covid Support were invited to attend the Long Covid Roundtables, initially chaired by Lord Bethell of Romford. We had understood that the first Ministerial Roundtable was held on 13 October 2020 at which Claire Hastie, a founding member of Long Covid Support, was invited to speak [INQ000058536]. However, from



reviewing disclosure to the Inquiry, we are now aware that there were two Ministerial meetings before on 31 July 2020 and then on 10 September 2020 attended by Matt Hancock MP, Lord Bethell, and other representatives of DHSC [INQ000070625].

32. The first one we as patient advocates attended with Long Covid SOS was on 13 October 2020. At that meeting our member Claire Hastie emphasised the need for support, that there was a need for research and data on non-hospitalised Long Covid sufferers and Long Covid sufferers generally. The meeting covered the need to address Black, Asian and minority ethnic (BAME) and women sufferers of Long Covid particularly as there was a risk that these communities would be taken less seriously by GPs.
33. On 11 November 2020, at the next Ministerial Roundtable on Long Covid we repeatedly raised concerns related to the recognition of Long Covid [INQ000058981]. Our concerns were that the government's published symptoms list was too limited, that awareness of Long Covid needed to extend to community cases, that symptoms and prevalence data (including geographical data) collection on Long Covid and research was urgently needed, and that the impact of Long Covid on schools, healthcare systems and staff and employees more generally needed to be factored into decision making. It was our position that there was a need to avoid widespread prevalence of Covid-19 because of the risk to health it presented. We discussed raising public awareness on Long Covid and to reach under-represented communities.
34. On 16 December 2020, there was a further Ministerial Round table on Long Covid and the topic of the roundtable was on diversity. We re-iterated our concerns that ethnicity data was not collected by GPs [INQ000112676].
35. On the same day, 16 December 2020, the Office for National Statistics (ONS) released an initial data set on prevalence of Long Covid. [NR/3 – INQ000272260]
36. On 9 and 10 December 2020, Long Covid Support members spoke at the Long Covid Joint Research Forum initiated by Long Covid Support and co-produced with ISARIC and GloPID-R. Long Covid Support gathered video testimonies from people around the world to be played in the breaks of the Long Covid Forum. On 17 December 2020, Long Covid Support wrote to Dr Tedros Ghebreyesus, Director General of WHO, to thank him for opening the Long Covid Forum [NR/4 [INQ000272261]] On 21 December 2020 Dr Tedros Ghebreyesus replied to our letter and in his letter, he stated "*I agree wholeheartedly that greater action is needed to provide for people living with the complications caused by*

*COVID-19 ...we are committed to working side by side with you to ensure that the needs of people suffering from the lasting impacts of COVID- 19 are understood clearly..." [NR/5*

**INQ000272262**

37. In February 2021, Long Covid Support member, Richard Roels spoke at the press briefing of the WHO Europe publication "In the Wake of the Pandemic: Preparing for Long COVID" at which he made the following points:

- 37.1. People have extremely varied symptoms.
- 37.2. We should focus more on the impact on people's lives, rather than the symptoms.
- 37.3. Living with Long Covid, everything becomes a burden.
- 37.4. It was a trauma at the beginning as no one knew what it meant when Covid symptoms returned - you had to confront and navigate this illness alone.
- 37.5. Long Covid is now on the radar of health professionals (in the UK) but Long Covid denial is still widespread among the public.
- 37.6. We are still "at sea" regarding diagnosis.

38. Long Covid Support was invited to participate in the consultation process for the National Institute for Health and Care Excellence's (NICE) COVID-19 Rapid Guidelines: "managing the long-term effects of Covid-19," which were published on 18 December 2020. Long Covid Support welcomed the NICE guidelines approach but were disappointed that several concerns raised during the consultation process were not addressed. By putting too little emphasis on the physical characteristics and the relapsing remitting nature of the condition, we feel that the guideline minimises patient experience and potentially puts patients at risk. Some of our concerns include:

- 38.1. Insufficient guidance on the range of physical symptoms leading to problems of diagnosis, coding, referral, and treatment.
- 38.2. The rather arbitrary three phases, risking barriers to investigations and care, as evidenced in the NHS guidance for clinics, which at that time specified that referral to services could take place from 12 weeks post-infection rather than 4 weeks outlined in the NICE/SIGN/RCGP clinical guideline.
- 38.3. The guideline seeks to rename the well-established Long Covid term without any sound basis for the proposed replacement name. Renaming should only occur when there is clear evidence driving the new name and when a clear definition can be given; neither is offered in this document. This also leads to problems with applying codes (post-acute Covid rather than Long Covid in EMIS (one of the NHS healthcare records systems))

39. On 18 December 2020, members of Long Covid Support wrote an article for the Lancet, in which they raised concerns about the shortcomings of the NICE guidelines [INQ000249005]. Notably that:

- 39.1. It did not cover the full range and severity of symptoms as noted by patients.
- 39.2. It did not acknowledge the relapsing remitting nature of the disease, which may lead to premature dismissal of patients.
- 39.3. There was an over-focus on self-management, psychological support, and rehabilitation, resulting in the potential for "watered-down" versions of NHS Long Covid clinics that did not provide thorough physical assessments of patients.
- 39.4. There was no mention of the three proposed mechanistic theories - persistent virus in immune-privileged sites, aberrant immune response, or autoimmunity.
- 39.5. The use of arbitrary phases (ongoing symptomatic Covid-19 from 4 to 12 weeks and post-COVID-19 syndrome - 12 weeks or more) with the risk of damaging patient care by creating barriers to services and investigations.<sup>6</sup>

40. On 9 January 2021, Long Covid Support founding member Claire Hastie sent a letter by email to all MPs urging them to participate in the Commons debate on Long Covid scheduled for 14 January 2023, as well as the APPG on Coronavirus oral hearing about Long Covid among health professionals on 12 January 2023 [INQ000248900].

41. The letter raised the following key points:

- 41.1. Long Covid affects vast numbers of people and has a significant impact on people's lives and ability to work. It stated that almost 70% of people with Long Covid who fell ill prior to June 2020 were not working or were working reduced hours [NR/6 [INQ000272263]]
- 41.2. More needed to be done to prevent more people getting Long Covid including preventative public health measures to raise awareness and early treatment interventions for those infected by Covid-19
- 41.3. More needed to be done to support people affected by Long Covid including better and more consistent access to Long Covid services, greater investment in research and support with returning to work.

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<sup>6</sup> In our view the rather arbitrary three phases, risking barriers to investigations and care, as evidenced in the NHS guidance for clinics, which at that time specified that referral to services could take place from 12 weeks post-infection rather than 4 weeks outlined in the NICE/SIGN/RCGP clinical guideline. Our view was that there was insufficient guidance on the range of physical symptoms which led to problems with people suffering Long Covid being diagnosed, as well as coding, referrals and ongoing treatment. When the NICE Long Covid guideline was published it was stated that it would be regularly reviewed but to date it has not been updated

41.4. For support groups to be funded to continue the valuable work that they do.

42. Importantly, we raised our early concerns about public health messaging and awareness.

We stated that more could be done to prevent Long Covid, and this would include:

42.1. *“Make Long Covid part of the narrative”*

42.2. *“Bring Long Covid into the public consciousness via platforms such as the Covid briefings and news reports to encourage compliance with public health measures. When reporting the numbers of cases, we suggest including a phrase such as ‘...an estimated 10% of which are likely to experience the debilitating symptoms of Long Covid for 3 months or more”*

42.3. *“Communicate the diversity of symptoms: Symptoms are so diverse and poorly communicated that many are unaware that they have Covid or Long Covid, with obvious risks to public health. We urgently need to make people aware that many people do not experience the three symptoms recognised by the NHS of fever, cough and loss of smell and taste. Instead, people should be encouraged to seek tests if they experience any unusual symptoms.”*

42.4. *“Evaluate the merits of early intervention (for example with antiviral medications) ahead of vaccine rollout: Research from Hong Kong indicates that early intervention with antivirals may prevent Long Covid, a route that perhaps ought to be explored while the vaccine is rolled out”<sup>7</sup>*

43. On 29 January 2021 another Ministerial Roundtable was held which Long Covid Support attended [INQ00059730]. This meeting discussed that if infection rates remained high that it was likely that Long Covid would become widespread particularly among younger people. At this meeting the ONS discussed the Covid Infection Survey from November 2020 which found that 10% of people were still symptomatic at 12 weeks. Many of our members had been unwell since the first wave and so had been experiencing debilitating symptoms for nearly a year at this time. ONS stated that a new question on Long Covid would be included in the survey to directly report on the impact of and prevalence of Long Covid [NR/3 INQ000272260]

44. We also discussed the impact of Long Covid on employment during the course of this meeting. Long Covid Support along with the other patient advocates from Long Covid SOS consistently raised concerns about the prevalence of Covid-19 and the risk this

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<sup>7</sup> Day One: Long Covid Forum 9- 10 December 2020 available at: <https://www.youtube.com/watch?v=LmjJ2yuhT-o> at 1.29 minutes.

presented in terms of widespread Long Covid. I note at the meeting on 29 January 2021 Long Covid SOS's letter to the Prime Minister about the risk of Long Covid being a primary consideration in policy decisions was raised [Exhibit].

45. On 23 February 2021, Long Covid Support attended a further Ministerial Roundtable chaired by the then Secretary of State for Health and Social Care, Matt Hancock, with Lord Bethell and Jennie Harries [INQ000060080]. At this meeting the ONS representative Daniel Ayoubkhani, reported that the ONS would publish data updates monthly. At the meeting Long Covid Support explained that there were barriers to people with Long Covid tracking symptoms through the Zoe App because they may be too unwell to engage. From the minutes, Matt Hancock concluded the meeting by noting that there was "*lots left to do*" and that there was a need for dynamic and collaborative decision making.
46. I am now aware from disclosure received from the Inquiry that Matt Hancock wrote to the Prime Minister on 14 February 2021 raising concerns about lifting restrictions before the virus was under control warning that this would result in a significant number of deaths, serious illness, Long Covid and hospitalisation rates [INQ000153728]. We were not aware at the time that he had warned of the need to bring cases down as much as possible alongside the vaccination programme.
47. After the meeting on 24 February 2021, Members of Long Covid Support wrote to Emma Spencelayh, Head of Long Covid at the DHSC, and sent her the Long Covid Support Patient Survey as well as our communications with ONS [INQ000249048]. We said that:

*"Our calls for research fall into two main categories, both equally urgent: how to prevent new cases, and how to help the vast numbers who have Long Covid: What can we do to prevent Long Covid, as well as severe acute cases and transmission? Can we identify an early intervention to be taken soon after symptom onset to stop viral replication? (community, orally administered, low side effects, low cost, linked to Test & Trace)?"*
48. On 16 June 2021, Long Covid Support presented at the Ministerial Roundtable the findings of their survey into patient experiences of Long Covid assessment services and their concerns regarding the NHS England 5-point plan. [INQ000061094, INQ000249050] Our representative highlighted that the survey had shown that 37% of respondents could not get a referral to a Long Covid service and that there was a lack of awareness at GP level about local services, and also that some people were not being believed, although this

was improving. This highlights one of the major concerns that the Long Covid Groups have around public awareness and communication by the Government about the risk of Long Covid, and the warnings to the public about the long-term health consequences of Covid-19.

49. On 8 July 2021, Long Covid Support wrote to Rt Hon Sajid Javid MP, the new Secretary of State for Health and Social Care urging that, when evaluating policy, he takes account of the devastating and prolonged impact that Long Covid can have on people of all ages [INQ000248931].

50. We urged him to:

50.1. ***“Expand service provision to enable inclusive and equitable access to assessment, treatment and rehabilitation at the earliest opportunity to maximise chances of recovery and resuming work, education and/or caring responsibilities. Currently Long Covid clinics are not available in the devolved nations, and our most recent survey indicates that only half of patients in England seeking referral are successful.”***

50.2. ***“Count Long Covid to better plan health and social care support: Many doctors are not applying the SNOMED code for Long Covid, and coding is not applied retrospectively. Digital health records are often incomplete, not joined up, or not associated with Long Covid. We call for the establishment of a patient registry that would also serve to follow up any potential longer-term consequences of Covid-19. Despite the ONS estimating 741,000 people in England up to 2 May were experiencing symptoms of at least 12 weeks’ duration, the NHS England 10-point plan estimated only 342,000 would need NHS support.”***

50.3. ***“Support NHS staff with returning to work: Many caught Covid-19 and have gone on to develop Long Covid. A significant number are either unable to work at all or to their previous capacity, or are working, unsustainably, while still ill, reducing the health of an already stretched workforce. More and more of our members report losing their jobs with NHS Trusts due to Long Covid. Yet there are skills shortages; 35,000 unfilled nursing roles within NHS England alone. We assert that it is not only possible, but essential, to retain and rehabilitate staff, through appropriate occupational intervention, workplace adaptations and flexibility within the NHS. Greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce. The government has devoted***

*large amounts of money to keeping businesses afloat and to preserving viable jobs. Preserving the health of the workforce is of equal importance in limiting longer-term costs and contributing to economic growth.”*

50.4. **“Prevent further people being affected by Long Covid [...] In your own words you stated that Covid cases could soon rise to above 100,000 per day, which would suggest at least 30,000 new cases of Long Covid per day. It is likely that children and young working age people will be disproportionately affected, as will frontline workers. Long Covid already disproportionately impacts those of lower socio-economic status and inequality gaps are likely to widen. We are pleased that vaccines have currently weakened the link between hospitalisations and deaths, but they do not necessarily protect against Long Covid; Tim Spector of the Zoe Covid Symptom study, states that double vaccination reduces the chances of developing Long Covid by only 30%. Vaccinations may protect you from having severe acute disease but they do not necessarily prevent you from having Long Covid.”**

51. As far as we were aware at the time there was no adequate consideration given to the excessive numbers of people that would go on to suffer Long Covid following the removal of all restrictions on “Freedom Day” on 19 July 2021.

52. On 2 September 2021, we received an email response from the DHSC to our letter of 8 July 2021 which did not respond to the substance of the letter [INQ000249052]. The response referred to research and support for Long Covid. It did not refer to any consideration given by the Government to the prevalence of Long Covid caused by its decisions to facilitate high infections levels and end restrictions or our concerns about inconsistencies in the provision of services.

53. On 29 November 2021, Long Covid Support met with Jeremy Hunt, Chair of the Health Select Committee [INQ000249053]. At the meeting we raised concerns about many of our members being unable to continue work, education or caring responsibilities since acquiring Long Covid and that a significant number were NHS workers who risked losing their jobs due to Long Covid. We shared our concern that Long Covid disproportionality impacts those of lower socio-economic status and inequality gaps were likely to widen. We also shared our concern that children and young people were at risk of developing Long Covid. We asked him to:

- 53.1. *“Support NHS staff returning to work. Providing greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support, which would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce.”*
- 53.2. *“Require the use of appropriate PPE for all health and care staff working with patients with confirmed or suspected Covid-19. Surgical masks provide inadequate protection.”*
- 53.3. *“Reinstate the advice for face coverings to be worn in schools, given the rapid increase in infection rates of the Delta variant and the disproportionate rise in cases among school-aged children.”*
- 53.4. *“Offer vaccination to children, with the aim of reducing individual risk, as well as that of communities and wider society, and educational disruption.”*
- 53.5. *“Provide grants for equipment to improve ventilation and air quality in schools, healthcare settings, public transport, workplaces, and arts/leisure venues.”*
- 53.6. *“Expand service provision to enable inclusive and equitable access to assessment, treatment and rehabilitation at the earliest opportunity to maximise chances of recovery and resuming work, education and/or caring responsibilities.”*
- 53.7. *“Count Long Covid to better plan health and social care support by establishing a patient registry that would also serve to follow up any potential longer-term consequences of Covid-19.”*
- 53.8. *“Communicate an updated list of acute symptoms of Covid-19 in both adults and children to allow people to apply for PCR tests and to prevent unwitting spread, including taking account of the differing presentations of the Delta and new variants.” [INQ000249053]*

54. In December 2021, at the first Ministerial roundtable chaired by Maria Caulfield MP, Long Covid Support questioned Graham Bums (Long Covid Speciality Advisor) on his repeated assertion that Long Covid could be attributed to anxiety at the thought of never recovering and associated insomnia [INQ000067606]. He first stated these views at the Westminster Health Forum in Spring 2021 when Long Covid Support had written to raise concerns about his dismissive approach to Long Covid [NR/7 [INQ000272260]. When we challenged him at the roundtable in December 2021, he admitted that Long Covid is a serious physical condition.



### *Counting Long Covid*

55. On 7 February 2021, Long Covid Support emailed the ONS to express concerns that the ONS survey questions on Long Covid were too limited to capture the potentially high numbers of people unaware that their symptoms may be due to Long Covid. **[INQ000249020]**
56. On 12 February 2021, Long Covid Support member Claire Hastie sent an email to the DHSC, NHS England and the ONS raising concerns that NHS Budget modelling significantly underestimated the burden of disease; that the NHS England list of 3 symptoms for acute illness was resulting in many not realising that they had COVID-19; that community cases of Long Covid were significantly greater in number than those who were hospitalised, and that community cases were taking significantly longer to recover than hospitalised cases, likely due to lack of treatment **[INQ000248996]**. Our concerns highlighted the importance of gathering accurate information about the prevalence of Long Covid.
57. On 16 February 2021, members of Long Covid Support met with the ONS to discuss the Long Covid questions. Long Covid Support emphasized that people who had been asymptomatic or had a 'mild' disease at the acute stage of infection could go on to develop Long Covid and that survey questions needed to take account of the relapsing remitting nature of the disease.
58. On 22 February 2021, Long Covid Support emailed the ONS with a summary list of concerns about the existing survey questions and suggestions to improve **[INQ000249021]**.
59. As set out above, we remained concerned about the need to count Long Covid and advocated Government decision makers to ensure there was better recording of cases of Long Covid on 8 July 2021 in a letter to Sajid Javid **[INQ000248931]** and on 29 November 2021 at a meeting with Jeremy Hunt **[INQ000249053]**.

### *Advocacy for improved treatment for Long Covid*

60. Long Covid Support has also been heavily involved in advocating for improved treatment for people with Long Covid. Further detail of our involvement with NHS England is set out

in our Module 3 statement where we have explained our concerns about access to treatment and support for people living with Long Covid.

61. On 8 August 2020, Claire Hastie, one of the founding members of Long Covid Support, and Professor Nisreen Alwan spoke with Professor Sally Singh (Head of Pulmonary and Cardiac Rehabilitation at University Hospitals of Leicester NHS Trust and the University of Leicester) about plans for the Your Covid Recovery website, initially targeted at post-hospitalised patients. It was emphasised that it should include short videos for people with cognitive difficulties, making clear that exercise and other exertion can lead to post-exertional malaise/ post-exertional symptom exacerbation (PEM/PESE), and that vast numbers of people who had not been hospitalised were experiencing debilitating symptoms.

62. Long Covid Support were members of the NHS England Task Force on Long Covid since the first meeting on 29 October 2020. At this time, Long Covid Support had a representative on the main Task Force and on each of the 8 subgroups. NHS England announced a restructuring of the Taskforce in Feb 2021, at which point our members were informed that we would have to reapply. None of our members were reappointed to the new Long Covid Task Force which began meetings in July 2021. Several of our members continued to attend meetings of a separate patient advisory group. As it was unclear at the time how this fed into the main taskforce meetings, we successfully lobbied to have a representative of the charity attend the main Taskforce meetings<sup>8</sup>.

63. From February 2022, NHS England began working collaboratively with lived experience partners on the NHS plan for improving Long Covid services in 2022. Through this partnership, Long Covid Support raised concerns with NHS England that budget modelling significantly underestimated the burden of Long Covid.

#### *Employment, Disability and Occupational Health*

64. A key concern for our members has been loss of employment and / or access to benefits arising from their loss of health from Long Covid. Long Covid has had a massive impact on our members' employment status, family, financial circumstances, well-being, and lives.

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<sup>8</sup> I should note that when we initially joined the Taskforce in October 2020 we were a grass roots patient group, as it was prior to our incorporation and thereafter registration as a charity.

65. Long Covid Support has advocated for recognition of the economic impact of Long Covid. The Long Covid Support Employment Group has provided evidence to relevant bodies and committees including the following:

- 65.1. In March 2021, the Long Covid Support Employment Group provided evidence to the Health and Safety Executive leading to their Report on Return to work after Long COVID. [INQ000249009]
- 65.2. In 2021, we also collaborated with the Society of Occupational Medicine to produce guidance for Employers and Employees on Returning to Work with Long Covid [INQ000249029, INQ000249030]
- 65.3. In June 2021, the Long Covid Support Employment Group submitted written evidence to the Work and Pensions Committee DES008 regarding employment support. [INQ000249010]
- 65.4. In October 2021, the Long Covid Support Employment Group submitted written evidence to the Work and Pensions Committee HAO126 - Health assessments for benefits (published May 2022)
- 65.5. On 11 October 2021, the Long Covid Support Employment Group submitted a response to the Department for Work and Pensions, Shaping Future Support: The Health and Disability Green Paper consultation. Much of our evidence focused on DWP support and possible solutions for people with Long Covid who receive benefits (ESA/ UC) [INQ000249013]
- 65.6. On 1 December 2021, the Long Covid Support Employment Group submitted a response to the Department for Business Energy and Industrial Strategy consultation on Flexible working [INQ000249014]
- 65.7. In February 2022, the Long Covid Support Employment Group submitted evidence to the Parliamentary Inquiry on Health Benefits [INQ000249011].

66. Our main concerns and reasons for advocating government on these issues were:

- 66.1. To support people with Long Covid to stay in, return to or leave work well.
- 66.2. To ensure that people with Long Covid are facilitated to stay in or return to work through the use of appropriate sickness management procedures, phased returns, and flexible working arrangements.
- 66.3. To ensure that people with Long Covid, who have been rendered unable to work are recognised by the DWP and able to access appropriate support.
- 66.4. To provide guidance to employers on supporting people with Long Covid in the workplace thus enabling inclusion, improving productivity and retaining skills.
- 66.5. For appropriate health and safety measures to be put in place to protect employees from contracting C19 in the workplace.

66.6. For Long Covid to be recognised as an occupational disease - particularly in the case of frontline healthcare workers - enabling those too disabled to work to access long-term sickness benefit.

66.7. To enable economic recovery through sustainable, healthy workplace practices and culture.

#### **IV. The Impact of government decision making on those with Long Covid**

67. Government decision making at every stage has had an impact on people with Long Covid.

68. The risk of post-acute sequelae was well-known but was not communicated to the public in the early stages of the pandemic nor was it apparently factored into the response to the pandemic. This meant that many people who developed Long Covid did not know of the risk and did not understand what was happening to them. It also led to their experiences being minimised and dismissed as not real.

#### *Mischaracterisation of Covid-19 as mild*

69. Covid-19 was mischaracterised as 'mild' and short-term. There was little public acknowledgment of the risk of Long Covid. The limited announcements in place were only introduced after concerted efforts by Long Covid Groups for recognition. Covid-19 can be a serious disease with profound and serious consequences. The mischaracterisation of Long Covid resulted in people with Long Covid being overlooked and their concerns dismissed; they have struggled to access healthcare and experienced significant denial and stigma.

70. It has been an ongoing battle for patient advocates to explain that Long Covid is not a psychological response to the pandemic but is a physiological illness caused by Covid-19 infection. Whilst of course many people may suffer overlapping symptoms, particularly anxiety and fatigue, this does not mean that Long Covid is psychological (this is separate from acknowledging that being severely ill can additionally affect your mental health). We have sought to challenge these claims which minimise our experiences and impede our ability to access medical care.

71. The physiological harm due to Covid-19 infections are not caused by lockdowns, and to us, claims that it was indicates a mindset which seeks to minimise the harm that we have suffered. We find ourselves having to constantly remind others of the physical evidence of

Long Covid. For example, there are numerous studies that show that people with a diagnosis of Long Covid have biomarkers (for example the PHOSP Study). One study in August 2022 found that there were 113 biomarkers which were significantly associated with Long Covid. Compared with healthy control or recovered patients without Long Covid symptoms, 79 biomarkers were increased, 29 were decreased, and 5 required further determination in the Long Covid patients.<sup>9</sup> Several of our members have suffered organ damage arising from persistent inflammation such as myocarditis. Further we know from our members that there are really obvious indicators like “covid toes” or blue limbs where one’s extremities turn blue.

72. In our view, this arose from the Government’s mischaracterisation of Covid-19 from the outset. The Government mischaracterised Covid-19 as “flu like” even though the severity of the disease was far more serious, and the message the public received was that most people (who were not ‘clinically vulnerable’) would suffer a short, mild illness.

73. Long Covid Groups had to advocate for formal and public recognition of Long Covid and it was a struggle to be recognised. It is essential that relevant bodies listen to and act on the lived experience of patients. Early acknowledgement would have significantly improved the experience of healthcare of people with Long Covid.

#### *Public health messaging*

74. The risk of developing Long Covid from Covid-19 infection was not adequately included in public health messaging. It was consistently absent from public health messaging save for a DHSC video produced in October 2020. This, along with poor communication about the breadth of Long Covid symptoms, may have led to behaviours where people assumed the risk of a short infection with recovery but instead are now suffering from long term illness. Many people are now suffering episodic or full-time disability as a consequence of infection.

75. We continue to have members joining our Facebook Group and Support Groups who were simply unaware of the risks of developing Long Covid. Whilst there has been growing awareness due to our campaigns and networks, the reality is that unless and until you or

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<sup>9</sup> Lai Y-J, Liu S-H, Manachevakul S, Lee T-A, Kuo C-T and Bello D (2023) Biomarkers in long COVID-19: A systematic review. *Front. Med.* 10

a close family member or friend is affected, people are unaware. This is further true for the poor minority of children unlucky enough to develop Long Covid.

76. In Germany there was a public health campaign on Long Covid, and recently in Lancaster I saw posters warning about developing Long Covid from Covid-19 (this was my personal observation and there may have been posters before in this area that I have not seen). I also have confirmation of sightings in Manchester, Salford and Warrington. It is entirely unclear to us why the Government chose not to consistently warn the public that Covid-19 could lead to Long Covid much earlier in the pandemic. As part of our involvement with the NHS England Taskforce, we were invited to give feedback on a proposed NHS England patient information leaflet in April 2021 [NR/8: INQ000272265]. At the time, Long Covid Support were already working on our own leaflet, which we made NHS England aware of and encouraged them to incorporate some suggested amendments to their draft. By October 2021, despite several meetings, we were still unclear as to when the NHS England leaflet would be finalised and decided that we would publish our own leaflet on the website [NR/9: INQ000272266].

77. In our view, as they were not informed of the risks of developing long-term illness, there has been a mass disabling of previously fit and healthy people. Clear messaging from the Government regarding the impact of Long Covid on quality of life, ability to earn a living and care for others would have enabled people to make more informed choices about their personal risk.

### *Counting Long Covid*

78. The failure to introduce early mechanisms to count Long Covid meant the true impact of Long Covid was not appreciated by decision makers. Throughout the Covid-19 pandemic, mortality was the main measure of the pandemic. The so-called twin metrics of deaths and hospitalisations used throughout the pandemic formed the very myopic basis for public health policies and government messaging.

79. The questions the Government should have been thinking as metrics of harm of a pandemic were hospitalisations, deaths and morbidity. Long-term illness can be profoundly harmful, disabling, and detrimental to individuals and society. As highlighted by Davis et al, "*on the basis of more than 2 years of research on long COVID and decades*

*of research on conditions such as ME/CFS, a significant proportion of individuals with long COVID may have lifelong disabilities”<sup>10</sup>*

80. From our experience of the pandemic, we believe that the UK should have ensured that decision-makers prioritised the early collection of syndromic surveillance data of longer-term sequelae. The failure to do so has caused avoidable harm for Long Covid sufferers. This must extend to include ongoing monitoring of prevalence data on longer-term sequelae so that healthcare systems can prepare for a unified approach to the clinical definition, diagnosis, care, and treatment of longer-term illness.

#### *NPI decision making*

81. As noted by Chris Whitty, the Chief Medical Officer for England, the way to avoid Long Covid is to avoid Covid-19 infections [INQ000073417]. Despite this self-evident fact, Government decision makers did not adequately consider Long Covid in decisions relating to NPIs. The Government ought to have known, or been advised, of the likelihood of chronic illness/disability due to corona viruses, but certainly by May 2020 there was an extensive body of evidence of people not recovering and continuing to experience worrying and debilitating symptoms. As an organisation, we are concerned that the Government did not give sufficient consideration to morbidity in its pandemic planning; that this continued not to be given sufficient weight throughout the Government's ongoing response and that this problem persists into the present.

82. In addition, Government decisions during the pandemic meant that there were high-levels of community transmission. Plans to respond to the pandemic from Summer 2020 failed to plan for a cohort of the population suffering prolonged illness as a result of infections of Covid-19.

83. From our engagements with Government representatives, it is not clear that the Government took into account the reality of huge numbers of people suffering from Long Covid. It did not take steps to prevent Long Covid either by raising public awareness, adequately warning the public (beyond one film in October 2020) or making sensible mitigation decisions to limit numbers of community cases.

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<sup>10</sup> Davis et al (March 2023) 'Long Covid: Major findings, mechanism and recommendations, Nature Reviews Microbiology Vol 21 133-146.

84. We repeatedly raised with the Government, ministers, NHS England and others the need to take long-term health consequences into account in relation to NPI decision making. It is essential when considering the health impacts of any infectious disease that resulting morbidity is given sufficient weight in decision-making from the earliest possible point in time. This was not the case during the ongoing Covid-19 pandemic.

85. In our opinion, the long-term disabling impact of Long Covid should have been factored into decisions about a public health approach that allowed high levels of community infection.

#### *Inequality related issues*

86. I would add that many of our members are from BAME communities, and that barriers to health inequalities are something that we as an organisation have been raising with the Government throughout the pandemic. We are conscious as an organisation of the impact of intersectionality on people with Long Covid being overlooked and also of patients' experiences of being gaslit when reporting their symptoms. This is a common experience of people with Long Covid and is in common with the BAME community's experiences in relation to Long Covid and other non-Covid conditions. We therefore have tried to raise concerns about intersectional discrimination in our advocacy.

#### *Ventilation*

87. There was a delay in communicating the extent to which Covid-19 was transmitted through aerosols. This had an impact on increased transmission and the resulting number of people suffering from Long Covid. Many healthcare settings had poor ventilation in place which increased the risk of transmission to staff who were on the frontline of the pandemic. There was also insufficient or poor PPE available to staff.

88. From our experience, the use of ventilation, clean indoor air measures and PPE measures should have been at the forefront of planning during this pandemic. HEPA filters and CO2 monitors in public buildings are sensible and proportionate measures to mitigate risks.

89. It is extraordinary to us that mask mandates in hospitals have now been removed where there is a constant cycle of reinfection from Covid-19, the long-term harms of which are showing. It is commonplace not to be exposed to HIV and tuberculosis in the workplace but there seems to be a complacency with regard to preventing exposure to Covid-19 in the workplace.



*Employment, Disability and Occupational Health*

90. As explained above, we have advocated on behalf of our members in relation to the economic impacts of Long Covid.

91. Long Covid Support collaborated with the Trades Union Congress (TUC) and we support their campaign to have Long Covid recognised as a disability. Long Covid Support and the TUC conducted research into Workers' Experience of Long Covid. This report found evidence of shockingly high levels of poor treatment by employers [NR/10 INQ000272240]. One in seven respondents (14 per cent) had lost their job because of reasons connected to Long Covid. Given the high numbers of people experiencing Long Covid, this finding is extremely concerning and many people losing their jobs could be in key sector roles. Two thirds of respondents (66 per cent) said they had experienced one or more types of unfair treatment at work. This includes one in six (16 per cent) who had been subject to bullying and/or harassment at work, one in 13 (8 per cent) told us they had been threatened with disciplinary action and almost a quarter of respondents (23 per cent) said their employer has questioned whether they have Long Covid and/or the impact of their symptoms. Around half of respondents (49 per cent) said they had reason to believe they had contracted Covid-19 at work highlighting that many people are being continually failed by their employer, from a lack of health and safety measures, including ventilation, to poor treatment in response to Long Covid.

92. ONS data shows that serious economic inactivity is associated with Long Covid. In July 2022, 23.3% of people aged 16 to 64 years with self-reported Long Covid infection that could not be explained by something else were economically inactive, compared with 21.4% of those without self-reported Long Covid. Between July 2021 and July 2022, the inactivity rate among working-age people with self-reported Long Covid grew by 3.8 percentage points, compared with 0.4 percentage points among working-age people without self-reported Long Covid [NR/11 INQ000272241]. ONS statistics released in August 2023 indicate that the working age population who were inactive due to long term sickness was at a record high. The ONS has stated that Long Covid was a relevant factor along with NHS waiting times and an aging population [NR/12 INQ000272242].

93. In our view, the policies pursued by the Government in allowing widespread prevalence of Covid-19 without either adequate mitigation measures or sufficient warnings to the public about the risk of developing Long Covid is a catastrophic failure that has had significant impact on economic activity.

94. Long Covid Support has advocated for the recognition of the economic impact of Long Covid during the pandemic and increased support for people suffering from Long Covid.
95. The number of people not working in the UK due to long term sickness has risen to a new record, with nearly two and a half million not working due to health problems according to the ONS; Darren Morgan director of economic statistics at the ONS noted an increase in category including 'post-viral fatigue', with "perhaps Long Covid having an impact".<sup>11</sup> A survey conducted by the TUC and Long Covid Support, published in March 2022 shows that 14% of respondents said they lost their job because of reasons connected to Long Covid – nearly triple the percentage (5%) of people who said that in a 2021 survey [NR/13 INQ000272243]
96. The Netherlands is among the countries that have introduced a statutory scheme for compensation to healthcare workers who suffer from Long Covid. We support Long Covid being recognised as an occupational disease providing access to long term sick pay or other compensation for those who need it. The special provisions for Covid-19 have ended and now healthcare workers can only claim statutory sick pay. This is inadequate and fails to recognise that several people with Long Covid continue to suffer from long-term chronic illness and disability which prevents their ability to work.
97. There should be a duty on employers to make reasonable adjustments for people with Long Covid, taking into account that recovery from Long Covid is neither certain nor linear. These reasonable adjustments have to account for the unique nature of Long Covid being a fluctuating, episodic and multi-dimensional disability. That is, the symptoms often present in clusters, come and go in episodes and present differently and change over time. There is no one size fits all approach to reasonable adjustments that would work for an illness like Long Covid, and employers need to be mindful to accommodate the diverse needs of their employees.
98. The lack of support and failure to recognize Long Covid as a disability affected people suffering from Long Covid during the pandemic. Future modelling and policy decisions need to recognize that this is an ongoing problem.

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<sup>11</sup> Edser, N & King, B (2023) Record numbers not working due to ill health. BBC News. Available here: <https://www.bbc.co.uk/news/business-65596283>.

### *Research and Treatment*

99. We have provided further information on research and treatment for Long Covid in our statement for Module 3. We do note here that there needed to be early research into and treatment for people with Long Covid. From our experience, symptom, and prevalence research into Long Covid was not prioritised and this led to the overall delay in recognising and responding to Long Covid.

100. Patients should be at the heart of planning provision and service development. The voices and lived experience of patients should be heard and actively engaged with by decision makers. Patient and patient group participation in policy decisions, research prioritization and service planning should be mandatory.

### **V. The experiences of those with Long Covid**

101. The Long Covid Support Facebook group continues to grow. We have 61,300 members. New members joining now raise the same issues that many of us have been experiencing for three years. We provide guidance on the site so that people can search for symptoms and understand what other people have found helpful in symptom management and access to healthcare services. It is an incredibly useful and powerful resource for people who suffer with Long Covid, and it continues to be to this day. It is also validating to have other people confirm their experiences, get recognition for the myriad of symptoms and the devastating reality of some symptoms like, post-exertional malaise, POTS and cognitive deficits get support with how to communicate and seek support from family members, friends, and employers. Having Long Covid can be lonely. It is isolating to be facing daily health battles that may not be seen to an outsider, may not show up in standard diagnostic tests, and may not be recognized by your healthcare professional. The community and validity of having recognition from peers is invaluable.

### *My personal experience of Long Covid*

102. I am a deputy headteacher. I contracted Covid-19 in March 2020. The respiratory physiotherapist that began working with me in September 2020 suggested that it is most likely that I was hypercapnic during my acute illness. Like many others who heeded the advice to shelter in place, I would have been treated in hospital under non pandemic protocols.

103. I was mostly bedbound for the first 6 months of my illness, as walking to the bathroom would leave me breathless and exhausted. I also experienced dizziness and vertigo due to extreme tachycardia. It took a further 6 months of working with a respiratory physiotherapist and occupational therapist to be able to walk the few houses to the end of my street. I also experienced significant cognitive dysfunction, more akin to a traumatic brain injury than 'brain fog'. Suffering from receptive and expressive dysphasia, I have been working with a speech and language therapist since Summer 2021. They also supported me with dietary advice as my ability to swallow had been affected. Also suffering with profound headaches, I was referred to a neurologist, who prescribed medication to reduce inflammation, which I continue to take.
104. Since becoming unwell, I have been determined to do everything I can to rehabilitate myself. I have been fortunate to have the support of many talented allied health professionals, but I had to advocate ruthlessly to do so. Over three years later, I have still not recovered to my pre-pandemic health status. Nor did the gains that I have made come quickly enough for me to be able to retain my previous job. The loss of my independence in terms of my self-care and of a career that I have worked my whole life to climb was devastating for me and had a detrimental impact on my family.
105. Fortunately, I have now secured a new role with an employer that understands my condition. Knowing that many people are unable to self-advocate in the same way and face greater barriers to healthcare and employment, is what drives me and others like me to run Long Covid Support. However, it should not be left to sick people to do this on a voluntary basis.

#### *Case Studies*

106. We exhibit to this witness statement anonymized case studies of people suffering from Long Covid at [NR/14 INQ000272244]. 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.
107. Below are examples extracted from the exhibited case studies:
- a. S, 31 years old, states: *“Long Covid had had an intolerable, devastating, and revolting effect on my employment and financial circumstances which haunts me most days. There are no words to truly describe what it is like to be unwell*

*whilst navigating employment which appears to have a structure that works against you, not with you.”*

- b. *F, 35 years old, states: “I am no longer independent and have to rely on others to do everyday tasks and to go outside. This is tough to experience and to see how I have become a burden for my loved ones. The impact on my partner’s life has been significant as he suddenly had to switch to a 24/7 carer role, having to constantly adjust expectations for our future and put his own needs aside. It’s hard for my partner and my family to deal with the ups and downs of my illness, there are months in the year when I am still bedridden, and other months when I am able to do a bit more physically but suffer cognitively from the fog. I was able to carry on working from home during these years though I have had to reduce my working hours significantly and stick to a working pattern with rest periods that do not make my fatigue crash. The “brain fog” is the worst, I find it hard to think, write and read and to absorb new information - things that are necessary to my job. Unfortunately, work is coming to an end, and I will soon be without a job not knowing whether I will be able to find employment again in my condition. This is terrifying as being able to carry on working was an important anchor from my pre-covid life. My mental health has been impacted by this sudden loss of my wellbeing and independence, I now struggle with anxiety and low mood on top of all the physical symptoms.”*
  
- c. *T, 22 years old, states: “Long Covid has changed my life in every way. I was a professional tennis player at the time of infection and now I rely on a wheelchair. I was bedbound for over a year. I am also unable to work or study and my hopes for a tennis career are long gone.”*
  
- d. *G, 46 years old, states: “The impact on my life was profound to say the least. Prior to Covid, I was healthy, working full time in a pressurized job and physically active. Having developed Long Covid, I was mostly bed bound for 6 months. I was on sick leave from work for 4-5 months. Without a positive Covid diagnosis, I had a lot of difficulty proving I was physically ill. Instead, the doctors diagnosed me with anxiety and depression. Relationships with my friends and family came under immense strain. This affected my mental health to the extent that I tried to take my own life.”*

- e. I, 53 years old, states: *"I didn't know much about Long Covid at all. All I knew was Covid lasted about 14 days and then I should expect to get better. Clearly at the start of the illness there was real worry due to the amount of people dying each day from the illness, but I don't recall any talk of Long Covid." [...] "I was a drama teacher when I got Covid. I had to leave that job as I wasn't able to function in it anymore - I couldn't manage my energy levels, and I couldn't process what was happening in the room fast enough. It absolutely flattened me. So, I had to leave employment."*

#### *Long Covid Support testimonials*

108. Set out below are the testimonials from Long Covid Support members who gave evidence to the AAPG on Coronavirus evidence session on Long Covid, on 5 August 2020

[NR/15 INQ000272245]

- a. *"[...] It best characterised as something that can attack any system in your body. For myself it started 17<sup>th</sup> march with a mild sore throat, barely noticeable. But I took the children out of school immediately and started isolating. By Mother's Day Sunday, I felt like I had been hit by a bus. My chest was tight, I could hardly breathe, I felt frozen to the core for several weeks. That was the opposite of the Government recognised symptoms of fever. I was experiencing heart pain and chest pain which progressed over weeks. For the last month I have been using a wheelchair. I had been bedridden for months, only able to shuffle to bathroom and kitchen once a day. I am a single parent of a 16 year old and 11-year-old twins who had to care for me. They went to stay with their father and I went to live with my mother as I got worse... My GP recognised my symptoms were real and it wasn't in my head, but said they don't know how to treat it. Many people I know find GPs saying "it is all just anxiety". It is not caused by anxiety but it can cause anxiety. We know more about this with our lived experience, and we are having to teach medical community about it. We get recommended exercise which is intolerable to many of us. I used to cycle 13 miles a day for work, now I can't walk 13 metres."*
- b. *"I was a doctor in good health prior to infection. I had been working on the ICU with Covid cases. It started as a sore throat and feeling tired, and by day ten I had a dry cough, shortness of breath and fevers. I now have ongoing chest*

*pain and palpitations. I have improved gradually over the last few months but I still describe myself as impaired by those symptoms. I have managed to care for myself and just about manage daily activities, but it is on the borderline. I can now walk for about 30 minutes before I experience shortness of breath and chest pains. That is very different from who I used to be. I used to do 12 hour shifts in ITU in a very stressful, high intensity and active environment. I used to go the gym 3 times a week, now a flight of stairs or food shop is all I can manage before I have to stop."*

- c. *"I have had Covid-19 symptoms since 3<sup>rd</sup> May. I developed shortness of breath, extreme exhaustion, persistent coughing, and am unable to get up and have been bedbound. I expected to get better in two weeks, I knew a lot about Covid due to my job, so I was very anxious when I didn't get better. I still have ongoing problems, I get palpitations and have difficulty walking. A ten-minute walk puts me in the house for a week. I am trying to work part-time but my energy levels are shot. I am self-employed, so lost a lot of work. I can work, but only under very intense focus. I get terrible brain fog which means something that used to take 20 minutes now takes 2 hours. When I am trying to work I cannot do anything else. I have developed reactive arthritis and walk with a limp, and I find that small injuries now recur. I am constantly on painkillers. I used to be a high energy person, flying internationally for work 3 times a week, now I can't leave the house."*

109. I have set out below some of the recorded testimonials from Long Covid Support members who attended the Long Covid Forum 9-10 December 2020 [INQ000248868, NR/16 INQ000272246]

- a. Jen states: *"I first acquired Covid-19 symptoms on 20<sup>th</sup> March 2020. I was 38 years old, working full-time in a senior management role and was fairly fit. I am now eight and a half months in to my Covid journey and am currently relapsing, I am four days into a lapse at present. My symptoms include diagnosed post-covid tachycardia, acute fatigue, tightness in my chest and breathlessness, low mood and anxiety, muscle aches and pains (especially in the evening), memory loss and insomnia."*

- b. Kate states: *"I live with husband and children (age 7 and 4), all have had Long Covid for 8 months since we were first infected in March. I am 41, I used to be fit and healthy. I was really ill at first and called an ambulance a few times, but didn't get admitted to hospital. My early symptoms were gasping for breath, chest pains, shaking and passing blood. I've experienced over 60 different symptoms, it has been very frustrating."*

110. As set out above, members of Long Covid Support raised awareness of their experiences and loss of health throughout 2020. We have continued to try to raise awareness to date, including by conducting research, spotlighting our members' stories, and collaborating with others.

#### *Patient Experience of Long Covid Assessment Services Survey*

111. Long Covid Support conducts regular surveys of patient experience of Long Covid assessment services. I refer and produce the Patient Experiences Survey between 5 January 2021 and 19 April 2021 [NR/17 INQ000272247] which showed that 75% of responses up to 2 February 2021 were refused an onward referral to the Long Covid Service by GPs, and that this changed to 48% by April 2021. Among 373 respondents, key issues mentioned were that GPs were not aware of a clinic or service or lacked information about referral pathways, first-wave patients were refused because they had not had Covid-19 recently enough or until they had been sick for 12 weeks or more. Extracts from the survey include:

- a. *"Next appt with Respiratory Team. After being taken by the paramedics to A&E in August 2020 the GP was advised by the hospital to organise a 24 hour heart monitor. Despite chasing this, it still hasn't happened and we are in January 2021. Symptoms worsened during this time and it was only after requesting this yet again, that there was an admission that they had dropped the ball. requested to be sent to Imperial and I finally got to have a 9 minute telephone appointment with a cardiologist. Still awaiting next tests!"*
- b. *"It has been 4 and half weeks now and so far I have had no contact. I understand that the NHS must treat those whose lives are at risk first but I was hoping for investigations into heart rate and breathing when exercising. I was hoping for investigation into the headaches other than don't do anything during the day"*



*because activity triggers them. I was hoping to be referred for scans of my heart, lungs and brain if the initial investigations warranted it.”*

- c. *“I requested referral to UCLH long covid clinic in October. I sent my then-GP’s practice the referral criteria. I had at that point, already had a chest X-ray taken 6 weeks after positive test result. It showed significant fibrosis and read of ground glass opacity. GP said this would “clear up”. My then-GP said I was not ill, despite fatigue, difficulty breathing, loss of feeling in fingers and toes etc. Rather, he said, I had anxiety and depression. I pressed for a referral to UCLH and asked for an appointment for a stand-sit test. My then-GP claimed no such examination existed and refused to help. I switched practices and am now going through referral process, 6 months after contracting covid. As a result of my initial experiences with old GP practice I am worried that I will not be believed, and do not deserve help because I am a “depressed and anxious” middle aged woman.”*
- d. *“I get the impression my GP doesn’t think my referral is important in the grand scheme of everything else going on. I am made to feel like a time waster for asking to see multiple specialists for my multi system issues, even though as a previously healthy 40 yr old I now faint every day, have chronic fatigue, breathing difficulties, and rashes all over my body. I am on the verge of giving up my career as a scientist because my symptoms seem to be getting worse not better 10 months on.”*
- e. *“I continue to have so called brain fog which is more like a cognitive impairment. This has only happened since I had the COVID symptoms in March 2020. I am unwilling to go back to the Doctor because I feel I will either be told “It’s in your head/ it’s anxiety/ it’s stress”, none of which is true, or I will be told as I was last time ‘Learn to live with it’.”*

#### *Reinfection survey*

112. We also know that being reinfected with Covid-19 can worsen the symptoms of Long Covid and can even reverse recovery. A survey by Long Covid Kids and Long Covid Support [NR/18:INQ000272248] published in August 2022 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%. The survey was open for 11 consecutive weeks, from Monday 4 April 2022 to 19 June 2022 and all responses were collected in that period. Responses were received from 484

adults and 112 children and young people (CYP) who had had at least two Covid-19 infections.

## **Conclusion**

113. In our view, the Government response to both the prevention of Long Covid and the care for those with Long Covid appears to have been inadequate and arose from the Government's ongoing failure to respond to the evidence and to factor in the risks of Long Covid throughout its pandemic management and decision making. Whilst it may be understandable for the decision makers' immediate focus to be on acute illness and ensuring services are not overwhelmed, chronic illness and disability should have been considered as an important part of pandemic preparedness and response.

114. Long-term ill-health such as Long Covid creates a burden on health and social care systems and dampens the wider economy for years to come. It is therefore worth monitoring and considering in relation to the prevalence and spread of a disease like Covid-19.

## **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: 25<sup>th</sup> September 2023